

Improving mental health support for refugee communities – an advocacy approach



For better
mental health

Mind's mission

The activities detailed in this report were part of Mind's Refugee and asylum-seeker advocacy project which was funded by the Department of Health and delivered by Mind's Diverse Minds unit.

Diverse Minds was set up in 1997 with support from the Department of Health in response to serious concerns raised by people from black and minority ethnic (BME) communities about their experiences of mental healthcare in this country.

Diverse Minds commissioned Daniel Sollé to map the mental health concerns and needs of refugee communities, deliver training to community advocates and to collate the findings of the research and the training into this report.

Almost 150 communities participated in the project, with backgrounds in Africa, Asia, Latin America and Eastern Europe.

All of the project's recommendations are drawn from engagements with the refugees and asylum-seekers consulted over the course of the two-year project.

Mind would like to thank everyone who has lent their time and support to this project, particularly to the refugees who spoke so honestly about their experiences.

Our vision is of a society that promotes and protects good mental health for all, and that treats people with experience of mental distress fairly, positively and with respect.

The needs and experiences of people with mental distress drive our work and we make sure their voice is heard by those who influence change.

Our independence gives us the freedom to stand up and speak out on the real issues that affect daily lives.

We provide information and support, campaign to improve policy and attitudes and, in partnership with independent local Mind associations, develop local services.

We do all this to make it possible for people who experience mental distress to live full lives, and play their full part in society.

We are working to:

Change society: Mind influences and changes public attitudes and government policy and practice towards people with mental distress.

Provide support: Mind helps people to take control over their mental health. We do this to make it possible for people who experience mental distress to live full lives, and play their full part in society.

Give people a voice: The needs and experiences of people with mental distress drive our work. We champion the right of people with direct experience of mental distress to have a voice and be heard.

Create mentally healthy communities: Mind works with the local Mind association network and other partners to improve the delivery of services for people experiencing mental distress.



All photos were taken by the author, Danny Sollé, apart from the images on pages 11 and 23 by Claudia Simoes.

Table of contents

Introduction	2
Who are refugees and asylum-seekers?	2
Refugees and asylum-seekers' entitlements to mental healthcare in the UK	2
Advocacy and refugee community organisations	3
Research methodology	5
Recommendations	6
Experiences of mental ill health	7
Principal causes of distress	7
Leave to remain	7
Isolation and dislocation	8
Relationship with home	10
Destitution	11
Family relationships	12
Perceptions of mental health in refugee communities	13
Accessing statutory mental health services	17
GP services	17
Engaging with primary care trusts	19
The diversity of refugee communities	19
Researching communities	20
Working in partnership	21
Hospital care	22
Developing mental health advocacy	24
The challenges of mental health advocacy	24
Mental health knowledge	24
Creating a dialogue with the community	24
The wellbeing of the advocate	26
Conclusion	27
Appendices	28
i. Mind's mental health advocacy training programme	28
ii. Statistics	34
iii. RCO activities	35
iv. Case studies	36
v. Delivering the training programme	38
vi. Contributors	40
vii. Accessing Mind, its networks and information	42
viii. Other useful contacts	43
References	45

Introduction

The Refugee and asylum-seeker mental health advocacy project was developed to build a better understanding of the mental health concerns of refugees and asylum-seekers in England and to use these data to improve their ability to find pathways to appropriate mental health support. The core approach was to work with advocates from refugee community organisations to develop a robust form of mental health advocacy. This form of advocacy includes not only focused support for individuals, but also advocacy for the community as a whole. In the community function the aim was to create a dialogue with the community on issues of mental health (including stigma) and to engage with primary care trusts and other provider agencies to develop community-focused services.

The project grew from previous work by Mind in 2005/06 which consulted with mental health service users in order to develop a user-focused advocacy model (Mind, 2006). Over the course of this it became clear that Mind's networks from which the core advisers were drawn lacked input from refugee communities. It also emerged that among those refugee groups subsequently consulted, effective mental health support in the community was minimal, with community advocates for the most part lacking the knowledge necessary to advocate effectively in a mental health context.

The aims of this project then, have been:

- to engage with refugee community organisations (RCOs) in England to ascertain their concerns over mental health and their ability to address these concerns
- to share key learning with PCTs in order to stimulate the development of effective relationships with RCOs and the commissioning of appropriate, accessible services
- to devise and deliver a training course for advocates within RCOs which will disseminate key mental health information, tackle stigma and prepare the participants to advocate in mental health contexts.

The report has been prepared for refugee community organisations that aim to develop mental health advocacy and engage more effectively with services, and for PCT commissioners and staff who wish to work more successfully with refugees and asylum-seekers.

Who are refugees and asylum-seekers?

The definition of a refugee as stated in the 1951 United Nations *Convention Relating to the Status of Refugees* is as follows:

“A person who owing to a well founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his nationality and is unable or, owing to such fear, is unwilling to avail himself of the protection of that country; or who, not having a nationality and being outside the country of his former habitual residence as a result of such events, is unable or, owing to such fear, is unwilling to return to it.”

An asylum-seeker is recognised in the UK as someone who has applied for refugee status in the United Kingdom and is still waiting for a decision on that application. Where the word refugee is used in this document it refers not only to refugees but also asylum-seekers, unless otherwise specified.

Refugees' and asylum-seekers' entitlements to mental healthcare

Currently, everyone awaiting a decision on their asylum claim is able to access primary and secondary care free of charge. Anyone who has been refused leave to remain can continue to receive primary care but will be refused most free secondary care (hospital) services. Treatment in an

accident and emergency department and treatment for serious infectious diseases is currently free to all. Unaccompanied minors and people who are being supported by the UK Border Agency in order to avoid destitution are also exempt from all charges.

These rules are often changed by successive governments and subject to change and challenge in the courts.

This report will show that the entitlements to mental healthcare for refugees in England do not necessarily ensure effective engagement or outcomes.

Advocacy and refugee community organisations

What is advocacy

Over the course of this project, the terms 'advocacy' and 'advocate' have always prompted discussion. Some of the communities consulted over the course of this project had never heard the words, while others recognised them only in a purely legal context. The majority, however, recognised the words as referring to someone who helps someone else to achieve their goals. Some individuals had described themselves as advice workers, but in most cases when they elaborated the functions of their role, they revealed an empathetic, culturally focused and supportive role more akin to advocacy.

The majority of respondents revealed that their advocacy role in their community encompasses a number of functions including providing information, engaging with service providers, supporting community members in accessing information and support, and the facilitation of social events. More detail of the breadth of this work can be found in the 'What Are RCOs?' section that follows.

For the purposes of this project, we shall use the following definition, which encapsulates the role carried out by the participants in our training course:

"An advocate is someone who supports another person or community to express their views and concerns, access information and services, defend and promote their rights, feel secure and explore choices and options."

In the mental health context adopted for this project, this definition is not limited to clinical interventions, but rather a holistic approach that draws on the multiple needs and approaches of the community.

The advocates that were consulted with for this project all identify themselves as belonging to refugee community organisations (RCOs).

What are RCOs?

Refugee community organisations are groups set up by an individual or a group of refugees to support their communities as they arrive and try to build lives in the UK. Broadly, they do this through signposting, advice, social activities and advocacy. They usually begin their activities while unfunded, unincorporated and without premises. In many cases they grow to attain charity status, apply for funds and become recognised experts in certain fields of work. However, our research has also made clear that many RCOs remain essentially a one-man or one-woman operation, with that individual being someone well known and well connected in the community who has been in the UK longer than most other people from the community that they serve. Whether working alone or in a group, we refer to this person as the 'advocate'.

While some RCOs only last as long as their founder is in a position to facilitate it, others have been in existence for as long as 30 years. Many Iranian RCOs were set up after the Islamic revolution in 1979 and continue to provide services for their community. Some RCOs grow to support other communities or shift their focus as global events change patterns of migration. During our research we found, for example, a Zambian group that had become settled and safe and so had devoted its resources to supporting first Bosnian and later Somali refugees.

Other RCOs work with individuals from a number of different countries because of cultural, language and religious links. For example, there are many Arabic-speaking groups that work with individuals from across North Africa and the Middle East, and many African groups that focus on the Great Lakes region of East Africa, while others work with francophone people in West and Central Africa.

A number of RCOs, particularly in metropolitan areas with large refugee populations, specialise in

helping particular elements of their communities. Mind has engaged with a large number of RCOs that are run by and for women, and others that primarily support the elderly, children and young adults, the disabled, and lesbian, gay, bisexual and transgender refugees.

Particular challenges are faced by communities that are dispersed across the country, with few obvious nuclei to bring them together. Our research revealed that this dynamic mostly applied to the Vietnamese, Chinese and Burundian communities.

The principal activities of RCOs

Our engagement with RCOs revealed the range of activities being carried out across England, some funded, many not. There are few obvious projects aimed at dealing with issues around mental health. However, after a period of engagement with the RCOs, mental health was in most cases either alluded to or addressed directly. RCOs' engagement on the issue of mental health will be discussed in detail later in this report, but it is important in all cases to look beyond the surface function of RCO activities and to recognise the impact that the various services and activities have on the mental wellbeing of the community.

The principal RCO activities that our research identified are:¹

■ Assistance with asylum applications and appeals

The lengthy procedures involved in claiming asylum (complicated by shifting government initiatives and language difficulties) were considered the highest priority by the RCOs consulted.

■ Housing

Many refugees are housed in poor or inappropriate housing and seek help in being rehoused. Extended families are often housed separately and seek to be rehoused together. In other cases parents of young daughters have anxieties about being housed in accommodation with men from outside the family.

■ Health

Negotiating the health service in England presents significant challenges for many refugees. Problems can be linguistic, cultural (some cultures

have difficulties talking to different-sex professionals about medical issues) or systemic (specific appointment times are uncommon in many countries). RCO advocates therefore support their users to access GPs, opticians, dentists, pharmacists and accident and emergency services. At the outset of this project, very few RCOs had the confidence or knowledge to advocate on mental health issues.

■ Education

Many parents worry about their children's education. Education systems and teaching styles often differ considerably from those in their home countries, and this combined with language difficulties can disadvantage refugee children. Refugee children can often be victims of bullying at school or become involved in anti-social behaviour. Approaches to discipline in the school system can differ significantly to those of refugee parents. The RCO will support the parents to understand and engage with the system. Many adults also seek support for education, including English classes.

■ Interpreting and letter-writing services

RCOs will provide these services usually in relation to the above four issues, and also in legal matters.

■ Social events to bring together the community and combat isolation

As noted, RCOs usually spring up as a result of a need for cultural togetherness and to combat isolation. This function always remains central to their work. This plays a central role in supporting the mental wellbeing of many refugees. Many RCOs also use these events to engage with the other communities in their locality, particularly during national Refugee Week each June.

Many RCO activities equip the participants to engage further with the wider community and, in many cases, gain employment through the skills, experience and engagement that they have gained. Some refugees have gained the confidence to engage further in local affairs and politics, some progressing to paid positions within local authorities. Some of the projects even end up generating income for the RCO.

There is considerable evidence that these activities have positive impacts on self-esteem and wellbeing. In some cases they have re-engaged and rebuilt the mental health of individuals who were thought by members of the community to be

1. A more complete list of RCO activities can be found in Appendix II.

beyond help. The advocates consulted for this project recognise the value of social and creative activities in promoting mental wellbeing, and for many of the participants this dynamic was the springboard for addressing issues around mental health.

Research methodology

In recent years many mapping reports looking at refugees in the UK have been produced, building a comprehensive picture of refugee communities and their dispersal.² This is a particularly difficult proposition due to the transient nature of the refugee experience. In one year there may be a large number of arrivals from one region, but international events may mean that the following year more refugees come from a different part of the world. Some conflicts are resolved more quickly than others, meaning that some communities have higher rates of voluntary return.³ Government dispersal policies change and in turn alter the demographic of a particular area. Furthermore, census and other monitoring information does not always have categories that accurately reflect the make-up of a community.⁴

An additional challenge to this particular project was to engage with close to 150 communities in England⁵ through the RCOs that support them in order to analyse the community's experience of an issue which is highly stigmatised. Therefore, our

approach to the mapping was to build relationships and then build the trust necessary for refugees to open up about the mental health experiences of their communities.

The quality of recorded data is of course directly linked to the support that we were able to gain from partner organisations, principally refugee forums, a number of Basis Project⁶ workers, other umbrella agencies that work closely with and are trusted by refugees, and our project advisory group.

In the few cases where the engagement or confidence of a forum could not be sought, the success of engagement with RCOs was predictably much weaker. However, in all of those areas we were able to successfully engage at least three RCOs, often by searching the internet or by going to cafés, restaurants and shops frequented by particular communities and building our engagements from unfacilitated conversations.

Our work in the south-east of England met with early complications, but these were soon addressed. At the time of the project's conception there was evidence of a small but growing number of RCOs in North Kent, particularly in the Thanet area due to arrivals from Dover, Ramsgate and Folkestone. However, by the time that the project had begun we found that due to changes in asylum policy, this picture had changed dramatically. Our mapping exercise soon found the development of a series of small RCOs along the south coast, particularly in Southampton.

Our interview technique was to initially ask about what concerned people in the community, rather than immediately focusing on mental health issues, due to the high levels of stigma mentioned previously. The interviews were semi-structured so that the interviewee could explore key issues without constraints.

2. Many refugees are dispersed to locations around England. This policy was developed in order to reduce resource pressure on major metropolitan areas, but it has been a controversial policy as it has often separated refugees from their communities and placed them in areas where local services do not have the experience of addressing their needs.

3. One should not assume, however, that the cessation of a conflict means that it is safe to return.

4. For example, an increase in people in an area falling within the category of South Asian may suggest the growth of a settled Indian, Pakistani or Bangladeshi community and may overlook an increase of people fleeing the conflict in Afghanistan. Furthermore, the large Somali population in the UK often falls within the category of Black African, a category that many Somalis feel does not effectively differentiate their cultural experience and their needs from other Africans living in the same communities in the UK.

5. Due to the conditions of funding, this report focuses on England.

6. The Basis Project is a new, England-wide service giving one-to-one support to hundreds of refugee community organisations to help them manage, develop and sustain their work.

Recommendations

Improved engagement between PCTs and refugee community organisations (RCOs) in order to develop more accessible, culturally appropriate services.

Recognition by PCTs of the key role that mental health advocates play in supporting the refugee community and not inhibit the advocate's ability to do so.

Improved support from PCTs to provide fully funded mental health awareness events for refugee communities.

Long-term funding for refugee mental health projects by PCTs in recognition that short-term funding can often leave service users compromised and with worse problems when funding comes to an end.

The adoption of partnership approaches by PCTs when consulting with refugee communities. Remuneration, expenses and access to opportunities should be offered as appropriate, and communities should be kept informed of developments that arise from the research.

The development of an accredited mental health advocacy qualification for refugee communities.

The development of a robust, funded network for mental health advocates from refugee communities.

Support for mental health advocates from refugee communities to develop the skills to become Independent Mental Health Advocates (IMHAS).

Cultural competence training for statutory staff at all levels, including commissioners, managers, GPs and receptionists. It is recommended that refugee advisers be involved in developing and delivering this training.

Focused support from mental health and refugee umbrella bodies to tackle stigma around mental health in refugee communities.

The commissioning of an indepth study into mental health in all detention centres, and the development of appropriate support to meet need.



Experiences of mental ill health

Principal causes of distress

Refugees' lives are complicated and consequently the factors contributing to a lack of mental wellbeing should not be oversimplified. While our research demonstrates certain trends, one should not make the mistake of assuming that all of the factors listed below apply to all communities or to all individuals. It should always be borne in mind that it is not the refugees who are abnormal, but rather the circumstances in which they find themselves. These circumstances are forged by many factors, including traumatic situations in the country of origin and in transit to the UK, the effects of UK government legislation, cultural and language barriers and tensions within families. This section attempts to unravel some of the factors that can adversely affect the mental health of refugees in England, while recognising that in reality they are inextricably linked.

Leave to remain

Just as 'leave to remain' is the most significant issue being addressed by RCOs in England, the process of waiting for this status has the most significant impact on the mental health of refugee communities. While an asylum-seeker is awaiting their leave to remain, the process and the waiting are unavoidable obstacles over which they have no control. No plans can be made until a positive decision on an asylum-seeker's claim is given. He or she cannot find a home of their choosing, they cannot seek employment, cannot go to university, cannot make concrete plans for their or their children's future, and cannot begin to deal with the past. Currently, a single adult asylum-seeker has to survive on benefits of £35.15 a week compared with £64.30 for an adult claiming income support.

Our research has shown numerous examples of men, women and children who have lost their way because of the enormous strain of waiting for an asylum decision. As previously noted, the reality of leave to remain affects many aspects of an asylum-

seeker's life. The core effects of the process itself are explored below.

The interview process

The pressure of Home Office interviews places an enormous strain on individuals. For many the experience of being questioned in a confined space by an authority figure so soon after interrogation and even torture experienced in the country they fled inspires panic and in some cases emotional paralysis. One interviewee told us in no uncertain terms that "the pressure from the Home Office is just like the pressure back home".

A number of RCOs also told us about asylum-seekers who had been refused status because they had changed their stories over successive interviews, despite there being evidence from mental health practitioners that repeating questioning helps to clarify memory after trauma.⁷

Some RCOs point to the lack of education of some refugees as disadvantaging them through the interview process.

Similar confusions present themselves over age assessments. Anecdotal examples have been given of tall or well educated boys being treated as adults, and small, poorly educated young men over 18 being assessed as children. This can lead to children being treated as adults under the law and therefore not receiving the intensive level of support provided under the Children Act.⁸

Pressure of supporting role

The pressure of being the person identified in the community as having skills to advocate for a community can cause considerable stress, as the advocates have very little time to themselves and can absorb the stresses of the entire community.

7. Presentation by MAPP (Netherlands) at Mental Health Care for Asylum Seekers in the European Union conference, Austrian Red Cross, Vienna, 2009

8. Unaccompanied minors are supported under the provisions of Section 17 of the Children Act 1989.

Vouchers

Asylum-seekers' benefits are given in vouchers, not cash. This limits asylum-seekers' ability to organise their own lives as vouchers are only accepted in certain locations, and can only be claimed in one location. This adds additional complications to daily life and often affects self-esteem.

Reporting

Many asylum-seekers have to report regularly to asylum services or to police stations. As with the example of benefits cited above, this can be a difficult experience, not only because of the practical considerations (we heard many cases of Zimbabwean women walking long distances when either pregnant or with small children) but also because of the fear of detention having arrived at the place of reporting.

Fear of decision

All asylum-seekers know that ultimately the decision on their claim will arrive by post. Many people fear the sound of the letterbox because it may signal bad news. Crucial medical appointments have been missed because the asylum-seeker believed the windowed envelope was a decision letter and was too frightened to open it.

Detention

Many asylum-seekers and those who have failed in their claims are now confined to detention centres. The rationale from the authorities seems to be that those detained are likely to abscond and work illegally. However, many of the advocates interviewed for this study felt that the decision-making process was far more arbitrary. This detention includes families with children of school age and below.

"There are a lot of people in detention centres now. It seems that they are automatically put there and the community can't reach them."

Vietnamese advocate, London

Few of our respondents spoke in detail about detention because they found it difficult to support members of their community who were in detention. The principal reason for this is that the detention centres are in remote areas and for many there was a lack of clarity about visiting procedures. In some cases refugees who were placed in detention a

considerable distance from their community felt abandoned and struggled to re-engage with the community if they were later released.

"If people are visited 'too often' the authorities move them."

Zimbabwean advocate, London

The majority of cases of the detention that Mind is aware of involve the Zimbabwean community, and a number of advocates from Zimbabwean RCOs highlight a lack of healthcare support in detention centres. Many in the community have mobilised to protest against the practice of detention as they see the effects that it has on the wellbeing of their community.

"We received letters from some women who went on hunger strike to resist deportation. They were beaten up and when the doctors finally saw them all that they saw were the bruises, not the effect on their mental health. It is very difficult to get any kind of medical help in detention, but we have seen no support at all for mental health."

Zimbabwean advocate, London

The community

The question of leave to remain and the fear of deportation hovers over the community at all times. Even after an individual has been given refugee status he or she continues to meet friends and compatriots who are waiting for leave to remain or who know someone who is in detention, causing further anxieties. This is particularly acute for communities from long-term conflict areas such as Somalia or the Democratic Republic of Congo.

Isolation and dislocation

Most RCO advocates talked at length about the difficulty that their communities have in engaging successfully with people and systems in the UK. More established communities with robust RCOs are on the whole able to cope much better, but the shock for most individuals of being in a completely different environment with minimal resources has clear and often significant impacts on mental wellbeing.

"People lack self-confidence and the ability to engage with the wider community. They can struggle to express themselves"

and push for better opportunities. Most are well educated, but have low self-esteem in the UK."

Russian advocate, London

"Some people have been in the UK for 15 to 20 years and still haven't integrated."

Eritrean advocate, London

"Family and other support systems may have been left behind and without proper mechanisms to aid engagement people can become very isolated."

Iraqi advocate, London

Language

Inevitably many refugees cannot understand English. They need to rely on others to speak for them. For some, the struggle to express oneself causes considerable frustration.

"I suffocated in 2002 because I couldn't speak."

Congolese advocate, Nottingham

Some refugees who had come from some rural areas were considered to be more disadvantaged linguistically than those from urban environments. A number of Somali RCO advocates made this observation. Refugees from the cities and from the trading ports on the coast tended to have experience of speaking English, and many from the cities are well educated, with some having held positions in government. Somalis from rural areas tended to have none of these advantages and were therefore more likely to become linguistically isolated.

Many RCOs have responded to these linguistic challenges by helping their communities access English classes,⁹ but in some cases wider issues around isolation prevent some refugees from attending.

"The local college runs good English classes, but the women won't go and instead they go to the Tamil Centre where the facilities and standard of teaching are not as good but where they feel comfortable. We have to motivate them – to mentor them to move forward."

Tamil advocate, London



Systems

From the practice in London of paying for a bus ticket before boarding a bus (but only on some routes) to the size and complicated nature of public sector bureaucracies and their complex forms, many refugees struggle to adapt to the "way that things are done" in the UK. One Congolese advocate referred to the "technical" nature of life in the UK, identifying the numbers of forms that needed to be filled in and the various bureaucratic procedures as being completely different for a more relaxed, informal approach in DRC. Another Congolese advocate – in Nottingham – talked in detail about the impacts of the benefit system on self-esteem, leading at times to intense frustration and anger.

Dispersal, urban and rural life

Many Somali, Afghan and Kurdish advocates talked at length about the difficulties faced by rural-

9. Currently unavailable to asylum seekers in their first six months in the UK.

dwelling farmers and herders upon arrival in metropolitan areas, not only because of the linguistic and systemic challenges, but also because of the nature of the built environment. Many refugees from these environments are unused to heavy volumes of traffic and traffic signals and many people who have been housed in high-rise blocks with lifts had never previously encountered such environments.

Many advocates in rural and newer dispersal areas talked of the lack of a safe meeting place. For many communities, public houses are not considered appropriate.

When starting a new life in the UK food and other products from the home country have proved to be a significant factor in making people feel comfortable. In smaller communities and new dispersal areas these products are not always available, presenting further obstacles to wellbeing. A mental health advocate in an RCO supporting Arabic-speaking communities in London put it simply: "One man just needed couscous to help him open up". A Congolese advocate in London concurred, but added that this was just one part of a wider need for togetherness, stressing that, "Speaking Lingala helps to bind people together. Not only in terms of information, but also a sense of togetherness, of oneness".

All RCO advocates concurred with the sentiments expressed above, but there was a note of caution from one RCO representing Latin American communities in south London. They felt that, owing to the considerable size of the Latin American community in that area, there can be some disinclination to engage with the wider community and felt that the impact of this may be an altogether different – but equally damaging – isolation.

Racism

A number of RCOs reported considerable experience of racism. This was more common in new dispersal areas. One Kurdish community that had experienced racism expressed their particular distress, having come to England because of the aggressive racism that they had experienced in Turkey.

Housing

Many asylum-seekers are housed in poor and cramped housing, often alongside individuals or groups with very different cultural norms. Many respondents

spoke about the negative effects of these conditions on mental health. Many refugees continue to have difficulty finding appropriate accommodation after having been given leave to remain.

Relationship with home

Over the course of this research very few respondents talked about life in their home countries, and those that did made it clear that the memories were either too distressing to recall, or not appropriate to discuss with a stranger or someone who did not have a shared experience. Some of the participants in Mind's training course revealed some more details during discussions of trauma and post-traumatic stress disorder, but they were few and far between.

"There are a lot of bottled-up feelings and memories about the past."

Latin American advocate, London

"We have a lot of issues from the war zone – war takes away trust."

Sudanese advocate, London

"People talk about what happened back home, but quietly, and only with their compatriots."

Congolese advocate, London

Broken family networks

Many refugees are unable to contact their families once they have arrived in the UK. Not knowing what is happening back home, or even whether family members are still alive, places considerable strain on the refugee. This is often compounded by intense feelings of guilt for having left relatives behind.

Trauma / PTSD

Most respondents who did talk about the effects of trauma had some mental health training and were comfortable talking to a stranger about the issues in the abstract. Most said that the trauma is always there but that it is suppressed by the intense focus on leave to remain and the need to support family and to appear to be strong.

Many said that trauma tends to be suppressed during the process of waiting for leave to remain and is resurrected after a decision had been given, irrespective of whether the decision is negative or not. If the decision is negative the trauma is of course exacerbated by fear of return.

Fear of return

Despite the British Government's assurances, many refugees fear being sent home because they do not feel their homeland is in fact safe. In many cases it is clear that conflict has ended, but that the area to which the refugee would expect to return is still either under the control of, or at least partially populated by, the group that forced him or her to flee. A Sierra Leonean RCO worker from London put it thus: "Home is calling them, but they fear going back, despite the end of the war."

Many refugees fear not so much political opposition or militias but, simply, change. "How will I restart back home?" asked one refugee. He was worried that his home would not be as he remembered it, and that he would not be as his family and community remembered him. He feared that he would in fact be the "broken one" having lived in limbo for just short of seven years.

Finally, a number of advocates addressed the issue not only of their lives and those of family and friends, but of their country itself. An Iraqi advocate asked, "How will we rehabilitate ourselves as a nation?" These sentiments have been shared by advocates from Afghanistan, Zimbabwe and Somalia.

Visibility

Inevitably, when events from a refugee's home country are being reported at length in the British media, the anxiety in the community grows and in some cases makes it difficult for people to function effectively. During the acceleration of the conflict in Sri Lanka that took place during the delivery of this project, a Tamil advocate commented that "people in the English class were talking about what is happening back home... it was not useful".

The Tamil advocate went on to express the frustration of her community during the period of conflict. They wished to protest in order to show support for their people in Sri Lanka, but feared that to do so would make them visible to the police and may make them more liable to be detained or deported.

Destitution

Once an asylum claim is refused, the applicant no longer has access to public funds. He or she may be immediately removed from the UK or put in a

detention centre, but in many cases people whose claim (and appeal) has been refused will become destitute.

Many refugees who are well connected with their community will be supported with a place to stay, food and a bed, although these necessities may not be available on a long-term basis. Many failed asylum-seekers will stay with other asylum-seekers, but this is illegal and so presents considerable anxieties for the guest and the host.

"All we can do is gather around – use family ties and friendship."

Ugandan advocate, London

Churches and mosques also provide support for the destitute, as do charities of varying size and capacity, including notably, the British Red Cross. However, resources are not unlimited. Many people enter employment illegally and some engage in criminal enterprises, risking exploitation and imprisonment. The fear of arrest, particularly if using forged documents, contributes considerably to anxiety.

The sense of shame experienced by those destitute having to constantly be beholden contributes to worsening wellbeing, sometimes exacerbated by the further shame that some women and gay men experience when they slide into prostitution. A number of RCOs revealed that many of these women had been raped during warfare, and so work as a prostitute also re-awakened earlier trauma.

Some failed asylum-seekers inevitably end up sleeping rough, some are detained, some imprisoned. All of these factors lead to an increase in mental and emotional distress. As failed asylum-seekers for the most part do not have access to healthcare benefits¹⁰ the fear of being ill and being charged for healthcare increases anxiety still further. Owing to the fear of stigma and uncertainty about entitlements and services, for many refugees their first experience of engagement with a mental health service is as a result of being sectioned under the Mental Health Act. The evidence presented by the RCO advocates consulted for this report shows that this eventuality is more common among the destitute.

10. Entitlements change regularly and are often challenged in the courts.

Health and wellbeing

In addition to the difficulties of engaging with healthcare provision and the fear of being denied support, RCO advocates identified a number of health issues that create considerable anxiety within refugee communities.¹¹

- HIV-AIDS
- unwanted pregnancy
- post-natal depression
- tuberculosis
- drug use, including khat
- alcoholism
- high blood pressure
- cancer
- female genital mutilation
- headaches
- musculoskeletal aches
- domestic violence
- pregnancy where the male partner is absent.

Many of the symptoms discussed were considered by some to be psychosomatic – a product of compound anxieties.

Seeking employment

Asylum-seekers are not able to legally take paid employment in the UK, but once leave to remain has been granted, refugees often find difficulties in finding employment. A number of RCOs expressed frustration that their qualifications are not recognised in the UK. A Sudanese advocate explained: “Graduates from Sudan, their degrees are not recognised here, so even if they get leave to remain, they can often only get work as casual labourers.”

The compound anxiety of inability to successfully engage in an appropriate level of employment is succinctly summed up by an Algerian refugee in London: “It is impossible to get a wife if you don’t have a job.”

11. It is important to note that not all of these issues refer to all communities.

Family relationships

Men

From the very first engagements for this project it was clear that challenges to the status of men as provider and head of the household were a key issue when looking at refugees’ mental health. The prohibition against working while awaiting leave to remain clearly has a significant impact on many men, leading in many cases to chronic loss of self-esteem, and in some cases to relationship breakdown, domestic violence and reliance on alcohol and drugs.

A number of advocates said that men from some areas of the world fear Western liberal attitudes will lead to them losing control over their wives and daughters, thereby causing another threat to their self-esteem and status.

Our research shows that many men will seek out other men in the same situation and abandon their family (either on a daily or permanent basis). However, men who perceived themselves to have fallen in status below the benchmark of men in their community will not continue to engage with the community, often leading to further isolation and distress.

Women

In many communities, women remain far more isolated than men. The reasons for this tend to be cultural norms which prohibit women from engaging outside the family network, lack of appropriate childcare and, in many cases, poor English.¹²

The challenges of employment also appear to change the dynamic between men and women in many cases, leading to a perceived change in the balance of power in a relationship. In many of the groups surveyed, particularly Latin American and francophone African, women were more likely than their partners to gain employment as they are prepared to work in the service industry for lower pay than men.

In some cases, women’s financial advancement and their new integration with diverse groups of

12. Many men will have acquired English skills in their home country through business activities and through social links acquired in the street. This was less likely among women in the communities we consulted.

colleagues can create friction in relationships with husbands or boyfriends, as the man may not also be advancing as he wishes. Evidence from advocates suggested that a wife's new liberty presents a threat to a husband's masculinity, causing him distress and sometimes resulting in domestic violence.

A similar dynamic also appears to develop when refugees have children of school age. As the woman is more likely to accompany the children to the school gates, they are more likely to engage with parents of other cultures, thereby widening their cultural understanding to an extent not experienced by the man.

Elders and generational issues

Elders can have particular difficulties in adapting to a new life in a new country. The unfamiliar environment can affect their ability to provide advice and guidance to their families, thereby reducing their status. In their country of origin they had been sought out for their wisdom, but upon arrival in the UK, children are usually more likely to gain knowledge of the new country more quickly as they are legally obliged to attend school. This often results in a role-reversal, with older people relying on young people for information and interpretation which, while helpful, causes changes in the family dynamic. Some older men also express distress at young people's loss of connection with their culture.

Children

A large number of refugee children are bullied in school for being different, putting considerable stress on them and on their parents. They also struggle in school when language, culture and curriculum differ significantly from their previous experience.

Some of the children react by engaging in antisocial behaviour, and in some areas join gangs. Some children then become involved with the police because of their behaviour, and yet when their parents try to discipline them, some of the methods they use may mean that the parents themselves become under scrutiny by the police and social services.

“People are losing their children to social services.”

Somali advocate, London

As demonstrated earlier in this report, the supplementary schools and other activities provided by RCOs are a great support for refugee families, but the pull of other influences in mixed communities is great, particularly for the older children. In many instances the parents simply lack the cultural understanding to effectively tackle these issues at an early stage, and as their children grow older so the anxiety of many parents increases.

Perceptions of mental health in refugee communities

Mental health is understood differently by all communities, hence the rationale for working with RCO advocates to develop more effective mental health support. It is precisely their embedded position within communities that allows them to address these issues most dynamically. The advocates that Mind worked with in the training element of this project were able to demonstrate not only an understanding of taboos and cultural specificities within their communities, but also skills in building trust to ensure that a dialogue can be built with the community so that the issues can be addressed effectively. This level of understanding is rarely to be found outside the community.¹³

Yet, despite the trust and respect accorded to the RCO advocates within their communities, discussing mental health remains a significant challenge. In many communities the concept of mental health differs considerably from European approaches. Cultural and religious taboos and family dynamics can all make it hard for individuals in refugee communities to be open about mental health issues. Many of the services made available by the NHS therefore encounter barriers to engagement, and there are significant challenges for advocates trying to bridge the gap between service provider and community.

13. It is important to note that many individuals in refugee communities will seek out professionals outside their community in order to address issues that may have sensitivities within the community for fear that the community will know their business or ostracise them. Our evidence shows, however, that this does not preclude the involvement of a trusted individual to attend the consultation as in advocate, interpreter, or for moral support. Sometimes this may be a friend, sometimes a family member, but often is also a trusted community advocate as described above.

This section will look at how refugee communities view mental health and wellbeing and give perspective to the analysis of engagement with statutory services detailed in the following chapter.

Common perspectives on mental health

Many RCO advocates described a community perspective that does not look at mental health as a separate issue that needs focused attention. Rather, they described mental distress as being seen as wrapped up in all the other stresses of life. It is often felt that if all these issues could be dealt with, then the distressing feelings would disappear. The concept of addressing mental distress through any psychotherapeutic approach would not be considered – or in some cases immediately understood – by many of the communities.

Indeed, the only concept of ‘mental illness’ understood by many of the communities relates solely to incidents of extreme distress displayed by an individual within the community back home or someone who has a serious learning disability – someone who, to use negative English parlance, might be labelled as ‘mad’ or ‘mental’. The use of the word ‘mental’ then, has become highly problematic, in many cases preventing communities from addressing issues of mental distress and preventing individuals from receiving effective support.

The majority of descriptions of people who have found themselves under pressure describe feelings of failure and frustration and to use the words of an advocate in Birmingham: “dashed expectations”. Many felt that the promise of safety and the hope for a better life had not materialised, and that the asylum and benefit systems and a lack of real opportunities had robbed people of their ability to run their own lives or to “function properly”. This was clearly identified by many RCOs as leading to a change in the character of a great number of refugees, particularly those who had experienced a long wait for a decision on their asylum claim.

“There is this frustration of not being able to do things for oneself – we are not used to this benefit culture.”

Somali advocate, London

“It is nice to have a house, but it’s hard if it’s not through your own work. People are used to looking after their own business.”

Kurdish advocate, Plymouth

“People have lost their human dignity.”

Zimbabwean advocate, Bristol

Many RCOs summed up people’s experiences by the phrases “suffering in isolation”,¹⁴ feeling “so small that they become overwhelmed”,¹⁵ and becoming “isolated psychologically.”¹⁶ The words ‘worry’ and ‘withdrawal’ are used often, in some cases the former word being used to describe female behaviour, the latter, male. In many cases, examples were given of alcohol and drugs (particularly marijuana and khat) being used by men as coping mechanisms and exacerbating existing problems.

Some RCO advocates who had given a great deal of consideration to the mental health of their communities felt that most refugees wait too long before they receive help. Needless to say, lack of knowledge of mental illness, of UK systems and the fear of stigma have played a significant role in restricting access to appropriate support.

Among the communities there appears to be very little understanding of types of mental illness, with ‘stress’ and ‘depression’ being used the most commonly as catch-all terms, and ‘crazy’ and ‘madness’ being used when referring to someone who has been extremely distressed.

Cultural interpretation

Non-Western cultural approaches play a significant part in the recognition, understanding, and treatment of mental health problems within refugee communities. RCOs from the Congolese, Somali, Eritrean and Vietnamese communities gave the deepest insight into cultural approaches in their communities, as described below.

A number of Congolese RCOs spoke of a fear of the casting of spells, the influence of spirits and punishment from ancestors.

Many Somalis talked of ‘madness’ being defined in Somalia as the behaviour of someone who is extremely distressed or who has a learning difficulty. In such cases the people viewed as ‘mad’ may be tied or chained up and beaten or ostracised. The fear of refugees who are experiencing mental distress being identified in this way has led to

14. Somali RCO, London

15. Zimbabwean RCO, London

16. Sudanese RCO, London

people never leaving their houses because of the shame they feel might be visited upon their family. Many people feared that no one would marry a son or daughter if they were mentally unwell.¹⁷

An Eritrean woman who was described as having depression went back to Eritrea and spent time with her family and “bathed in the sacred waters”. In time she became well, and many in the community felt that her recovery was due to the sacred waters, while others felt it was due to the time spent in familiar surroundings with loved ones.

Traditionally, the approach of the Vietnamese community to mental health has been based on notions of organic impairments of the brain, the balance of hot and cold elements inside the body, spiritual and supernatural factors, a belief in destiny and the importance of self-control (VMHS, 2001). A psychiatric approach to mental health, when lacking medicinal interventions, would appear valueless, given the community’s associations of medicine with magic.

Of the advocates that mentioned cultural approaches, there was a concern that the culturally based view of the community may not always have all the tools to address the mental health problems faced by communities that have migrated. These advocates identified an urgent need to open a dialogue within their communities and with PCTs so that community and psychotherapeutic approaches can be reconciled and joined in order to provide the most effective support for the community.

Stigma

Stigma plays a considerable role in the way that mental health is addressed (or not addressed) in refugee communities. Stigma is addressed throughout this report, but is perhaps best illustrated by verbatim quotes from RCO advocates.

“Our children are our pension. If the community knows that our son has a mental problem no one will want to marry him.”

“People will not talk directly about mental health – we are very good at not talking about it.”

17. This concern over marriage was shared by an RCO supporting Roma refugees in London.



“A lot of people don’t seek support because of what the community thinks – yes, it is about stigma.”

“They don’t know the difference between mental health and mental illness. There is a fear of being labelled with being the type of mad person that people would throw stones at back home.”

“People say ‘be a man’ and ‘pull yourself together’ because it is not usual to seek psychiatric help.”

“People fear the person with a problem because they think they can catch it.”

It is important to mention the particular circumstances faced by some asylum-seekers and refugees who identify themselves as lesbian, gay, bisexual or transgender. In many cases they face

even greater stigma and isolation if they are from certain communities where they feel it is not safe to identify their sexual orientation or status. A lesbian asylum-seeker from Jamaica was told by a Jamaican solicitor in the UK that intense Bible study would “cure her problem” (he perceived her distress and sexuality as being one and the same). Other examples include one gay asylum-seeker from Iran and another from Uganda who were treated with contempt by professional counsellors from their respective communities in London.

Fear of mental health services

Many advocates have talked at length about their community’s fears of engaging with a system (including GPs) that they do not understand and promote the need to develop services that are more culturally competent.¹⁸ The process can present many difficulties for the client, not least the uncertainty about the process and fear of revealing information about themselves that they fear may leak into the community or be passed to the Home Office or another organisation that causes distress to them.

“Our community has been infiltrated by security services many times – people don’t feel safe to talk.”

Algerian advocate, London

“People need a reassurance of confidentiality.”

Iraqi advocate, London

“Our community isn’t used to talking to strangers about their problems.”

Vietnamese advocate, Bristol

Many advocates are able to support clients to access well known voluntary sector therapeutic services for refugees such as the Medical Foundation for the Care of Victims of Torture, the Refugee Therapy Centre and Solace¹⁹ which are commonly viewed as having greater cultural competence. There are still obstacles for some refugees, however, sometimes related to trust, but also in the form of waiting lists and travel to visit these specialist services.

“Some will ask for help to book an appointment with a specialist – but this is rare.”

Kurdish RCO, Southampton

18. The issue is addressed in the following chapter, and at length in *A civilised society: mental health service provision for refugees and asylum seekers in England and Wales*, Mind (2009).

19. Contact details for these and other services can be found in Appendix viii

Accessing statutory mental health services

As demonstrated in the previous chapter, refugees can face significant challenges to finding appropriate methods for addressing mental wellbeing. A key obstacle only briefly touched upon in the previous section is the difficulty that refugees face in engaging with services provided by primary care trusts. Inevitably, a lack of confident engagement with both primary and secondary services leads not only to a lack of effective support and treatment, but also overburdens voluntary sector and accident and emergency services.

Mind recognises that these issues can only be dealt with effectively by facilitating long-term, well-funded, reciprocal engagements between primary care trusts and refugee community organisations, with the RCO advocate playing a key role (alongside PCT community development workers) in facilitating the relationship.

This section will detail examples of various engagements between RCOs, PCTs, and the secondary services that they commission.

GP services

Community-based GPs should be, and in many cases are, a first step to getting appropriate help. However, there are still difficulties for refugees in engaging with these services. In their attempts to support their communities to access GPs, RCO advocates have identified a number of obstacles.

“People travel long distances, then wait for a long time, and then are not understood.”

Iraqi advocate, London

“All this waiting just leads to more and more stress.”

Congolese advocate, London

Language and interpreting

A great many refugees experience problems communicating with their GPs because of language difficulties.

Most GPs surgeries make attempts to provide interpreters, but this can still present difficulties. In rural areas and less developed dispersal sites it can be particularly difficult to access an appropriate interpreter. That said, this picture has improved with the recent increase in the use of telephone interpreting services. This approach is by no means failsafe, however, as the practice of speaking through a stranger on the other end of a telephone line often exacerbates the problem that many refugees have about revealing their problems to strangers and the three-way approach to conversation does not lend itself to confident, natural dialogue.

Another drawback with this type of interpreting is that the dialect of the interpreter may differ so much from that of the patient that effective communication is all but impossible.

“The LanguageLine²⁰ interpreters used by the NHS are usually from South Vietnam, but most of the asylum-seekers in Bristol are from North Vietnam. The accent is very different, so there are lots of misunderstandings.”

Vietnamese advocate, Bristol

Technical language can also be an obstacle in circumstances where complicated and specific medical terms are used. Many interpreters do not have the experience of working in the mental health field and so are unable to effectively interpret the detail of certain conversations.

Many refugees inevitably find themselves having to use a member of the family or someone from the community as an interpreter. Given the stigma around mental health in the communities that we have engaged with, this can present significant problems, including in some cases the interpreter altering the meaning of the patient’s words in order to not reflect badly on the community.

Needless to say, interpreting takes time, but many refugees have noted that the length of their

20. A telephone-based interpreting service used by many public sector agencies in the UK.

appointment has not been extended to accommodate the additional time needed.

A number of RCO advocates have suggested lengthening appointment times for patients who need to use an interpreter, and the development of specialist surgeries in areas of with significant refugee populations.

Access

Many examples have been given of refugees who have found the process of registering with a GP so difficult or distressing that they have abandoned the process, or have instead used accident and emergency services. This is often for linguistic reasons, but more often because the process seems complicated and too little time is given for the process. The process is inevitably sped up when an RCO advocate is available to support the patient, but some advocates said that they had been barred from assisting the patient with the paperwork.

In addition to the difficulties (and unfamiliarity) of the registration process, many refugees found other aspects of the relationship with GPs overly bureaucratic. One Congolese advocate talked of the complicated nature of referrals and the lack of flexibility for appointments for a community used to a one-stop-shop, first-come-first-served approach. As a result, many refugees have missed appointments and have had to rebook appointments, leading to further anxiety. In many cases women with children but without childcare could not afford another bus fare to the surgery.



Many RCOs also expressed concerns that receptionists were not always well equipped to support refugees in understanding these processes.

GP attitudes

Many refugees expressed concerns over GPs' manner. Some found them too formal, others too informal, some rude. Many GPs were felt to be lacking in cultural competence, for example discounting patients' wishes to see a doctor of their own sex. Some GPs were described as being irritated by having to work with patients who could not easily express themselves. It was felt that in some cases GPs would circumvent these complications by not consulting thoroughly and by prescribing medication rather than exploring other possible interventions.

“One person was very distressed and seeking asylum and was told by a GP that he was faking [mental distress]. The GP was expecting him to behave like someone who could read or write.”

Cameroonian advocate, Nottingham

Too many GPs seemed not to recognise the role played by stigma when addressing issues of mental health and many became impatient when their explanations could not be easily understood. Many advocates also felt that some GPs seemed not to consider the effects of trauma and migration on the demeanour and confidence of the patient.

Many refugees do not know that they can change their GP, and many feel uneasy about making complaints because of previous relationships with authority. In some cases, advocates have been able to support them through this process.

Medication

GPs and pharmacists are not always clear when explaining to refugees about how and when to take medication. Some patients expected immediate results and so would cease taking medication if seemed to have no effect within a day or two. Others did not know or could not understand the procedure for applying for repeat prescriptions.

“Some people don't take their prescriptions as they believe that it may cause harm. Sometimes there is a fear of addiction. They are not sure when to take the medicine, or how much.”

Somali advocate, London

Fear of the medical profession

Some refugees are afraid of doctors because they do not understand what they do, particularly, as noted above, in relation to medication. An advocate representing victims of torture from Chile also noted that many of those who were victims of torture in Chile were tortured by or with the participation of medical doctors, or using surgical equipment.

Engaging with primary care trusts

“People don’t understand the NHS, and the NHS doesn’t understand people.”

Iraqi advocate, London

The overwhelming majority of RCO advocates are familiar with the term ‘primary care trust’ and understand that PCTs commission health services for the community. Most do not know how their work relates to mental healthcare and if RCOs are aware of mental health trusts they are for the most part unsure of the division of functions. Few RCOs have the confidence, experience or resources to effectively engage with PCTs to ensure the right type of support for their communities. Many RCOs that have attempted to engage with PCTs felt that the PCT way of operating is neither sufficiently consultative nor flexible and have concerns that the services that the PCT commission are not always appropriate or sustainable.

The diversity of refugee communities

One of the dangers of using the phrase ‘refugee communities’ is that it can oversimplify a complicated and diverse picture. Many RCO advocates have expressed their frustration over the lack of cultural awareness and a tendency towards oversimplification on the part of some PCTs, and feel strongly that in adopting such an approach, different sectors of the community can be overlooked and excluded from service provision.

Monitoring approaches

A number of advocates felt that their communities’ identities are not reflected in the monitoring

approaches of PCTs, and felt this omission disadvantages them because tailored support then cannot easily be developed for them.

A number of Iranian groups gave examples of their communities seeking help, but being directed towards services for Pakistanis, Bangladeshis and Moroccans. They felt that this situation was purely because the PCTs identify Iranians purely on the basis of their Muslim faith, rather than looking into the specifics of their cultural experience.

Similarly, members of the significantly sized Somali community felt that its particular identity and needs are not reflected in the catch-all category “black African” used in monitoring information. Many Somali minority groups also felt that where PCTs did understand the majority culture of Somalia, they overlooked the cultural and linguistic nature of Somali minority groups.

Other African advocates felt that PCTs do not appreciate the diversity of Africa. A Congolese RCO in the Midlands felt that the PCT was working under the false assumption that services developed for the Caribbean community are appropriate for the Congolese community.

Roma groups had a similar experience of PCTs (and other agencies) not recognising that they come from different countries and different tribes, and use different languages and dialects.

Some communities from countries with no obvious connection to the UK, such as the Malian community, felt that they had little hope of effective support due to there being no tradition in the UK of working with their community and hence no specific monitoring focus.

Stereotyping of communities

A number of advocates from RCOs that had had some support from PCTs also felt that stereotyping was taking place in respect of the type of services that are made available. This was particularly remarked upon by a number of Congolese and Somali RCOs. Groups from both communities had made repeated attempts to engage their PCTs to gain support for mental health in the communities. In the case of the Congolese communities they reported that they could only attract support for HIV-AIDS, and in the Somali communities the same dynamic applied, though in relation to khat use, tuberculosis and (to a lesser degree) HIV-AIDS. All of these communities recognised the importance of

tackling communicable diseases, but felt that to ignore mental health was not only to ignore a considerable need in their communities, but also to overlook or avoid the level of support that the communities need to address this misunderstood and hugely stigmatised issue.

Inter-community distrust

A number of RCOs across England spoke of attempts by public sector bodies to persuade them to enter into partnership with other RCOs as a way to attract funds and co-ordinated support. When they asked groups with shared countries of origin to come together, PCTs and local authorities failed to realise that in many cases these groups were on opposing sides in conflicts that were still continuing in their home countries. In other cases, the lack of cultural competence of public sector agencies prevented recognition of cultural, religious and linguistic differences between communities which belied superficial impressions of commonality.

Translation of materials

Many refugees have difficulty accessing essential information in their own language. A number of RCOs pointed to the lack of translated healthcare information, particularly outside the major metropolitan areas. One advocate in London representing Swahili-speaking communities expressed concerns that when information is translated into Swahili, it is not done accurately, resulting in a very low awareness of public service provision within the community, and subsequent social exclusion. Other advocates felt that PCTs did not identify appropriate locations in which to display and disseminate sensitive information, one remarking that she could easily support the PCT to rectify this problem if only the PCT would engage with her.

Conversely, a number of Somali communities pointed to Somalia's oral tradition as an obstacle to their community engaging with the written information provided by statutory bodies in the metropolitan areas. Many Somalis cannot read or write in their own language, but that is not the sole issue – for most Somalis, the exchange of information always takes place orally. A number of advocates in London, Bristol and across the Midlands were surprised by what they saw as clumsy misunderstanding on the part of their PCTs and used this example as a key driver for the need to engage with their PCTs.

A further oversight affecting Somali communities is the assumption that all Somalis speak the Somali language. The Bajuni people from southern Somalia, for example, are linguistically more wedded to a Swahili tradition and many Bravanese people tend not to have fluency in Somali.

E-Engagement

In metropolitan areas across England there are many internet cafés run by refugees and frequented for the most part by their own communities. They are an invaluable method of cheaply engaging with friends and family and news from home. As a result of the increase in internet connectivity across England, many statutory providers and businesses are now switching their activities to web-based systems. However, for some communities dispersed outside the large cities, internet access is not quite so simple, however, and as noted by an Eritrean RCO in London, a large number of refugees (particularly old people and those from rural areas) are not computer literate. PCTs need to properly understand this reality before developing systems that will exclude elements of the communities that they seek to help.

Talking therapies

A number of RCO advocates felt that some PCTs made talking therapies available without truly understanding the cultural and stigma issues for the communities that they were intended to serve. Again, the advocates sought engagement with the PCT in order to more effectively engage their communities with the concept of talking therapies. Examples of effective engagement around talking therapies can be found in Appendix iv.

Researching communities

During the research for this report, a number of RCOs initially showed a lack of willingness to engage with the researcher. It soon became clear that this dynamic did not always reflect an anxiety around the subject matter, but rather previous experience that the RCOs had had with researchers. Refugee communities are regularly asked for their opinions by PCT and academic researchers, but many feel that despite giving up their time, there is often little given in return.

“Sometimes we fear committing to putting the effort into engaging, because we have so many bad experiences where there is not a good outcome for us.”

Sierra Leonean advocate, London

“The PCT did come to talk to us, but they never came back.”

Somali advocate, London

Many RCOs feel that while PCTs can spend considerable time researching the needs and dynamics of a community, in many cases the community never sees any of the fruits of that research. This affects the perception of the PCT and damages future possibilities for collaboration. Many RCOs recognised that not all of the research carried out by PCTs can be converted into practical projects, but were clear that the impact of not keeping the community informed could create false hope, and later, animosity. It is felt that this difficult dynamic could be improved considerably by recompensing refugees that have contributed to research or helped to facilitate engagement for – at the very least – their travel and subsistence expenses. An ex-RCO advocate from Southampton who is now working as a community development worker for a PCT suggested that PCTs would be more respected by refugee communities if they reciprocated by alerting communities to new opportunities (including employment) as a matter of policy.

Working in partnership

Many refugees choose to use mental health services provided by the voluntary sector. In some cases this is because these services specialise in working with survivors of torture and trauma, but in many cases the rationale is that they are either run or staffed by people from refugee communities. In some cases these services grow out of RCOs, providing further reassurance about the sensitivity of stigma and an understanding of cultural dimensions. Many are funded in part or in whole by PCTs to deliver specific services. It is precisely these types of services that many RCO advocates hope will be developed through robust engagement with PCTs.²¹

RCOs also value the role of PCTs in facilitating



mental health awareness sessions for their communities, and the strongest praise is reserved for those that involve the community throughout the process of development.

Most RCO advocates that recognise the role of community development workers (CDWs) provided by the Delivering Race Equality in Mental Health Care (Department of Health, 2005) initiative appreciate the value that their interventions have made in the last few years. A number of RCOs described how the CDW approach had completely altered their engagement with their PCT and gave examples of successful interventions. These examples revolved primarily around disseminating mental health information effectively and supporting voluntary sector agencies to work in partnership with the PCT to develop effective access to psychological therapies.

21. Examples of good practice in partnership can be found in Appendix iv.

It is clear, however, that the level of CDW support is not consistent across all PCTs, and where there is a lack there are inevitably gaps in the PCTs' ability to recognise the breadth of challenges that face refugee communities and the holistic approach needed to tackle mental health problems. A number of RCOs gave examples of PCTs wanting to provide mental health awareness sessions for communities, but not providing the RCO with funds for marketing or venue hire.

Some RCO advocates, however, felt that communities that share the same cultural identity as the CDW are more likely to receive effective support. One London-based advocate also expressed frustration that the local PCT had chosen a CDW with no experience of the borough that she was to serve, although there were local candidates who would have been more appropriate. A number of RCOs also felt that each area should have two CDWs – one male and one female, in order that the needs of both sexes are properly addressed.

These examples of where the CDW is not perceived to have the experience (or remit) to serve all communities were identified by many RCO advocates as an ideal opportunity for PCTs to recognise the value of the community advocate's role and to engage with them to better understand and serve the needs of the community. Indeed, it was recognised that a number of CDWs had in fact previously been RCO advocates, as have refugees who are now running therapeutic services for communities.

Dispersed communities

Additional challenges are also faced by the more dispersed communities. These communities may not have a large population in one area and so may be overlooked for support as their needs are not recognised by their local PCT. The challenge for the RCOs that support them is to engage with a number of PCTs, an approach which is very labour-intensive, and therefore not feasible for most RCOs. Examples include the South London Tamil Welfare group which supports its community across six London boroughs, and the Chinese National Healthy Living Centre, which currently works with 31 different PCTs.

Sustainability

While some communities have benefited from PCT funding, many RCOs have only been able to attract short-term funds, and are unable to address long-

term issues within communities. The cessation of some funded wellbeing and counselling projects had thrown a number of users into greater distress as vulnerable members of communities had come to rely upon them. Similarly, there are examples of training being given to deliver a service without funds to then deliver it. This can present particular difficulties for small, young RCOs that have not developed the capacity to fundraise from other sources.

It is clear, then, that more dynamic partnerships between the voluntary sector, communities and PCTs need to be created to provide sustainable mental health services for all communities.

Hospital care

"The hospital environment is negative."

Zimbabwean RCO, London

"One woman in the community has been sectioned a few times, but seems to feel better in the community because the hospital lacks the cultural dimension."

Sierra Leonean RCO, London

"The health service overuses schizophrenia as a diagnosis. People are not being treated as individuals. They feel as though they are being told off."

Somali RCO, London

"The relationship with mental health services is one of extremes – from nothing being available on the one hand, to over-reaction and sectioning on the other. It is often difficult to find the appropriate middle ground."

Afghan RCO, London

Few of the RCO advocates had experience of working with secondary care services. Many knew about sectioning under the Mental Health Act but most didn't understand the system or its actors in any great detail. Many RCOs were concerned about the high incidence of people from their communities (particularly young men) in mental health wards, but few had the knowledge and in many cases the confidence to make successful interventions.

An advocate from the Congolese community talked of visiting a mental health unit in East

London because he had heard that a member of the community had been sectioned and was shocked at the high proportion of people in the unit who are black – and particularly African. He tried to talk to the psychiatrist but the psychiatrist would not engage with him because he didn't recognise the advocate's role, despite the sectioned man's having no other source of support.

An Eritrean RCO also based in London is often asked to interpret for community members being treated in mental health wards. Often they are asked by the patient if they can advocate on the patient's behalf, but the hospital will usually prohibit this on the grounds of confidentiality. Once again, the RCO is often the only source of support for the patient.

Significant exceptions to the overall negative experiences have been a number of Somali groups with a strong focus on mental health. Despite some of the similar problems of engagement faced by the Congolese and Eritrean RCOs, they were able over time to develop a process that one group defined as 'cultural brokerage'. Cultural brokerage involves recognising the approaches of mental health professionals and working with these professionals and the families of patients in order to secure a balance of approaches.

For the Somali community the family approach usually includes a significant spiritual element and the advocate can also play a key role in involving an imam in the process. The MAAN Somali Mental Health Project groups in Sheffield and Liverpool, and Mind in Harrow have had particularly successful interventions of this kind, bringing together psychiatrists and imams to devise a care plan that mixes talking and drug therapies with reading of the scriptures and the support of family. Evidence from the Somali community clearly demonstrates improved recovery in the majority of cases where family is involved.²²



Somali groups in London, Sheffield, Northampton, Liverpool, Bristol and Birmingham have all shared experiences of trying to advocate for their communities in hospitals against a backdrop of cultural misunderstanding and myopia. These groups have all at times had to explain to clinical staff the importance for a Muslim of observing prayer times, eating halal food and not being placed on mixed-sex wards, and the difficulties for patients that do not speak English, particularly if they are the only person from that community on that ward.

These Somali projects have made incredible strides forward in recent years, not only engaging with mental health professionals, but also with their own community, particularly family members, to provide support for service users during hospital stays and upon return to the community.

22. It is important to remember that, across communities, family involvement does not in all cases assist a service user to recover.

Developing mental health advocacy

The challenges of mental health advocacy

For those many advocates that are attempting to directly improve mental wellbeing in their communities, their greatest assets are the cultural understanding of their communities, the trust that they have been able to build over time through sustained engagement, and the ability to confidently support community members through engagements with GPs.

“We have to gain trust – it’s that simple.”

Somali advocate, London

The biggest obstacles remain stigma, lack of funds, and a lack of in-depth knowledge about mental health and the mental health system in England. Having addressed resource issues in the previous section, we shall focus here on the challenges of stigma and specialist knowledge.

We shall also focus on the mental health of the advocate, and issue often overlooked when addressing refugee mental health.

Mental health knowledge

“How do you recognise a mental health problem? What do you do?”

Somali RCO, London

“We need to know the difference between, for example, depression and paranoia. We don’t even have a word for schizophrenia – so how can I explain it to my community?”

Somali RCO, London

While all advocates recognised the benefits of community activities in promoting mental wellbeing, many lacked information about the more technical aspects of mental health. The following list is drawn from the dominant concerns of all RCO respondents, and forms the core of the training course that Mind delivered in Summer 2009 (see Appendix i).

- Speaking to someone who is distressed
- interpreting effectively
- ensuring confidentiality
- understanding clinical approaches
- helping community members to access and use appropriate services
- supporting individuals in negotiating the complicated mental health system during periods of distress
- balancing clinical and cultural approaches
- understanding medication
- understanding legal rights
- looking after oneself when supporting others
- building and sustaining relationships with service providers and other bodies in order to develop appropriate services
- promote activities and lifestyles that improve mental wellbeing.²³

These issues form the majority of areas of focus of Mind’s advocacy training course. The final two areas are listed below.

Creating a dialogue with the community

The final two areas of study are focused more on developing the relationship with the community. They are:

23. A number of RCOs have talked in depth about their interventions through wellbeing work and the vital part that this has played in their communities, as the following examples show. “We have been running a football league for seven years. It involves people and brings communities together. One man with mental health problems has been helped by doing a football coaching course which has given him a new focus.” Kurdish RCO, Plymouth. “People are rejected all the time for paid work, so self-help helps them to survive. I have survived because of community work and so we try to put in our own experience to help others.” Pan-African RCO, Norfolk, who runs an allotment project.

- tackling stigma
- providing mental health information in appropriate formats.

A number of advocates initially felt that there was little possibility that people in their community would speak up about mental health. Some gave examples of where they had tried to run mental health awareness workshops but people had not attended because they were afraid that they would be stigmatised by association. Over the course of this project, however, a number of examples have of good practice by RCOs working around mental health have been highlighted. Some of examples have appeared earlier in this report, specifically in relation to engagement in hospital settings, but the greatest challenge remains the initial engagements – helping a community to create a dialogue around mental health in a format that is sustainable and non-stigmatising.

Allies

A great deal of good work has been achieved by identifying individuals who are greatly respected in the community for their wisdom, compassion and discretion and involving them in mental health work. A number of advocates have involved pastors and imams in awareness work, including one pastor who trained in mental health counselling. The intercession by faith leaders has gone a long way in helping communities understand the value of pursuing different approaches to wellbeing.

Language

Those RCOs which engage successfully with their communities at large on the subject of mental health for the most part do so by not using the phrase 'mental health', which can intimidate community members.

“Don't use the term 'mental health programme' – speak of practical health issues and general emotional wellbeing.”

African RCO, Norfolk

“We hold monthly health sessions involving a Russian-speaking psychiatrist who is successful because he talks about improving self-confidence rather than about mental health.”

Russian RCO, London



Indirect approaches

“Mental Health is a taboo, but we have ways of reaching people. People come to talk to us about one thing, but then another thing comes out of it. We have the information when they are ready to hear it.”

Algerian RCO, London

The approach of one Afghan advocate proved to be a useful model for many of the communities. The advocate took an approach that was based on seeking help from the community. She set up a series of sessions for women to get together to share food and conversation. The sessions began informally, but when confidence had been built, the advocate told the women that she had produced a compact disk for her work, and asked the women if they would give their opinion about it. The women listened to the disk and began to recognise that some of the mental health information was pertinent to them and to their communities and a dialogue developed. The

approach was successful, though, precisely because it was presented in a way that empowered the community, rather than giving them cause to be anxious or secretive. The approach has now been used with communities from different backgrounds, and has the additional advantage of being accessible to those refugees who are not accustomed to reading.

The wellbeing of the advocate

Most advocates recognise the effect that the asylum process can have on members of their community precisely because they have experienced it themselves. However, what many do not realise when they begin to advocate for their community is the impact that this role will have on their own mental health.

Throughout the lifespan of this project, refugee advocates talked of the consequences for their mental health of being a focal point for their communities. RCO advocates are usually unpaid, and are either seeking asylum themselves, or have settled and are trying to support their families

(usually on low incomes), filling their lunch breaks and evenings with work for the community. One advocate in Plymouth felt responsible for the 200-plus families in his community, and yet he was unable to find the right support for himself, unless he travelled to London, a journey which he could not afford. Another London-based advocate had to leave a job in order to support his community.

“I was in therapy myself to deal with the issues that I deal with day-to-day. There is only so much that you can expect volunteers to do.”

Iranian advocate, London

Many community advocates feel trapped between their own wellbeing and that of the community. Unlike many mental health professionals, they have no professional supervision. For many, the symbol of the relationship with the community is the mobile telephone which seems always to be ringing. For many advocates the only way to move on when they are no longer able to help the community is to change their telephone number.

Conclusion

All the elements of this project have been successfully met in accordance with the remit agreed with the Department of Health. We now have a clearer understanding of the factors affecting the mental wellbeing of refugee communities, and the challenges that they face in trying to access and develop appropriate support to address these concerns. We have also delivered robust training in mental health advocacy to a diverse group of advocates from refugee communities, and helped them to develop skills to look after themselves when engaged in this stressful and time-consuming work (see Appendix i).

And yet, what we have achieved is a drop in the ocean when one considers that of the 150 RCOs with which Mind engaged, there are at least 500 more that Mind did not have the resources to reach. Furthermore, of the 150 RCOs that we engaged with, we only had the capacity to provide training for 30 advocates. Of those advocates, few will have the support from a manager or a statutory agency to develop their work, and some will experience mental distress because of the additional challenges that their new training will give them.

This work will only be effective in the long-term if the role of the advocate is recognised by the statutory services with which they hope to engage, and if it is funded on a sustainable basis. Mind

believes the next steps towards recognition by statutory services are to develop a recognised mental health advocacy qualification for refugee communities and to facilitate a robust national network of RCO mental health advocates.

Funding is of course always a challenge to this type of work, and even more so in the current economic climate. Yet, if one truly understands the role of community advocate in this mental health context, one must also recognise that if well funded to carry out their roles they make considerable financial savings. They will reduce the wastage caused by missed appointments and incorrectly filled-out forms, promote cost-saving early intervention, overcome cultural and linguistic obstacles that handicap the effective delivery of services, and deliver wellbeing advice and activities that will reduce the need for clinical interventions.

Ultimately, then, the success of this work relies on the support not only of PCTs, but of mental health trusts, voluntary sector agencies, communities, and decision-makers in the Department of Health and the NHS. It is only by working together and taking a long-term view that we can reduce not only the mental distress experienced by refugees, but the waste of resources within services that fail to effectively engage with the communities that they are intended to serve.

Appendix i – Mind’s mental health advocacy training programme

Drawing on 14 months’ research and shaped around the issues listed above, Mind’s Mental Health Advocacy Training Programme was developed as a four-day training course timed to best fit with the busy schedules of the RCO advocates and delivered in May and June 2009. There were two training groups, one based in west London and one in east London. The latter group also included advocates from the south coast of England.

Details of the development of the training and selection of participants can be found in Appendix v.

In addition to the programmed training sessions, a key aim of this programme was to give space for the participants to build relationships, informally share their ideas and experiences and to network towards future partnerships. Plenty of time was allocated at the beginning of the day and at lunch and during breaks for this purpose. Trainers were encouraged to arrive early to hear the presentation that preceded theirs and to attend lunch, which helped them to better understand the context, and get to know the training participants.

Day one

Icebreaker

The first day began with an icebreaker activity. Each participant was given a series of cards, each with a different question which he or she asked of another member of the training group. Half of the questions were questions about perceptions of mental ill health and advocacy and half of the questions were questions about the participants’ likes and dislikes. In this way, the participants began to get to know each other and address the key themes of the training.

One of the questions asked was “What is advocacy?”, another asked “What percentage of communities consulted in our research are concerned about mental health?” These questions lead directly into the next sessions.

Advocacy discussion

The participants were given a few minutes to discuss in pairs what they believe advocacy to be. We then shared all the views and debate further, using existing examples of advocacy, including materials used by the United Nations in the Democratic Republic of Congo. The materials were in French and an immediate relationship of support was built as the Congolese and Malian participants translated the material for the rest of the group.

Stigma discussion

The answer to the icebreaker question, “What percentage of communities consulted in our research are concerned about mental health?”, was given to the group. The answer is 100 per cent, which surprised the group, but more importantly gave the participants confidence to speak up about their communities in the discussion that followed.

Presentation: The mental health system in England – part one

Assisted by a slideshow in the form of a flow diagram, access points to mental health services were explained and advice given for successful engagement.

Followed by Q&A session.

Presentation: Working with mental health professionals

An advocate from an established refugee community organisation with a well developed mental health programme gave examples of engagements with mental health professionals and talked about the challenges of establishing services for a community. Included case studies.

Followed by Q&A session.

Facilitated discussion: How we talk about mental health

The groups discussed the language that they use to describe mental health. The facilitator worked with the groups to investigate how this language may affect the way we address concerns about mental health and interact with people who are experiencing mental distress.

Presentation: Some common forms of mental distress

Starting from the position that the words 'stress', 'depression' and 'mad' are overused, misused and used as catch-all terms, a slideshow-assisted presentation explained common forms of distress and explores the concepts of medical and social models, assessment tools and treatments.

The conditions discussed were:

- depression
- post-natal depression
- anxiety
- panic attacks
- psychosis
- schizophrenia.

Followed by Q&A session.

Facilitated discussion: Interpreting

An experienced advocate and interpreter from a refugee community separated the functions of interpreting and advocating and explained effective guidelines for interpreting. The approaches were then discussed with the groups who shared their perspectives and offered alternatives. Few strict rules were set; it was recognised that each circumstance is different, but there are always danger areas of which advocates and interpreters need to be aware. It was stressed, however, that medical professionals and clients must know in advance exactly which role the advocate or interpreter will be taking, and the advocate or interpreter and client must agree on boundaries.

Presentation: A brief history of BME mental health in England

In discussion of black and minority ethnic group experiences of the mental health system in the England, the refugee experience is often overlooked because of the considerable data addressing issues for long-term settled communities. Similarly, many of the RCOs that we spoke with were unaware of BME experiences of the mental health system and did not necessarily identify themselves with the settled populations. This session looked at experiences of mental health services by BME communities and highlighted how perceptions of race and identity and lack of cultural competence among mental health professionals has often led to these poor experiences and ensured that engagement is only at the point of crisis.

Followed by Q&A session.

Presentation: Making sure that our communities feel safe to talk

An experienced mental health advocate from a migrant community talked of his engagements with individuals from refugee and migrant backgrounds from his own national community.



He described the difficulties of engagement (largely owing to stigma), how he overcomes those obstacles, and some rules that he feels important, not only to ensure the confidentiality of his clients, but also to protect his own free time when working with a community that is small and close-knit.

Followed by Q&A session.

Day two

Discussion: Reflections on previous day's training

This session was left completely open, but in both groups the focus was on the challenges of engaging both with individuals within their communities and the communities at large in a mental health context.

Presentation: Talking therapies

A practising psychotherapist talked about the challenges and also the benefits for refugee communities of using talking therapies as a way to address mental distress.

Followed by Q&A session.

Presentation: Culturally appropriate services

A presentation of how culturally appropriate services can be developed for a particular community, using an example of a PCT service led by a member of the community who adopted a consultative approach to develop an effective user-focused service.

Followed by Q&A session.

Presentation: The mental health system – part 2

An in-depth look at secondary mental health services and the professionals that operate within the system.

Followed by Q&A session.

Presentation: What's it like inside the mental health system?

A service user's perspective of life using mental health services, including on mental health wards.

Followed by Q&A session.

Facilitated discussion: How do we talk to someone who is in a distressed state?

An informal discussion led by a service user about approaches to working with someone who may be unable to help himself or who is at risk of harming themselves or others. The focus was not only on the distressed person, but also on the fears of the advocate.

Facilitated discussion: Faith and mental health advocacy

An advocate from a Muslim community talked about his work with service users, families, imams and mental health professionals and leads a discussion that addresses the challenges for advocates of all faiths.

Day three

Icebreaker: Something about our communities.

After having spent a week apart, the group informally share things about their communities that they suspect the other participants might not know.

Presentation: Understanding medication

A slideshow-assisted exploration of prescription drug use in mental health. The presentation looked at different types of medication, how they work and how they interact with other medication, dosage, safety issues and side-effects. There was a particular focus on antidepressants, antipsychotics and drugs for anxiety and sleep.

Followed by Q&A session.

Workshop: Designing a mental health awareness event

Working in groups, the participants explored the possibilities for running an event that will effectively engage the community with the support of an experienced community development worker. Broadly, the session followed a 'what, when, who, where, how?' approach, and included a segment on the need for effective evaluation. Particularly stimulating was the sharing of cultural approaches and the recognition of similarities between communities.

Presentations: Projects that help deal with stress

In all of its work, Mind stresses the importance of non-clinical approaches to addressing mental health problems. In these sessions we welcomed groups that are working with refugees (and in some cases are run by refugees) to explore some of these alternative approaches and to explain how in some cases it can be relatively easy to begin such a group.

The projects that we worked with during this training pilot were a refugee-led allotment project from Norwich, a football project in east London with a specific focus on supporting people who are experiencing mental distress and a long-established scheme run by Mind in Harrow to provide supported access to sport and leisure activities for mental health service users.

Followed by Q&A session.

Presentations: Trauma and post-traumatic stress disorder (PTSD)

In exploring trauma and PTSD we sought the involvement of professionals with radically different approaches, one clinically focused, the other with a non-medicalised community approach. The sessions demystified the issues and explained alternative pathways to recovery.

The sessions were framed so as to ensure that the participants felt safe and able to engage or disengage easily. Additional breaks were provided during the afternoon so that the participants could have private space or the opportunity to speak informally with the speakers.

Followed by Q&A.

Presentation: You're looking after everyone but who is looking after you?

Timed to follow the trauma session in order to address some of the personal issues raised by that session, this session also revisited some of the advocacy boundary issues raised in the first two days of the training. Areas covered included boundary-setting, sharing feelings with peers and supervision where available.

Followed by Q&A session.

Day four

Discussion: How do we feel about advocating in mental health?

The participants discussed their hopes and fears for addressing mental health in their communities.



Presentation: Rights and the Mental Health Act

An introduction to the Act with a slideshow to illustrate the process. There was also a collection of hand-outs including Mind's rights guides for later reference.

Followed by Q&A.

Presentation: Understanding Mind's networks

A guide to Mind's local associations (LMAs) and how their services can be accessed, with input from LMA staff.²⁴

Followed by Q&A.

Presentation: The role of the approved mental health practitioner and the community mental health team

An explanation of the roles of the AMHP and CMHT, how they can be accessed, and the relationship between them, the service user and their families.

Followed by Q&A.

Presentation: The role of the independent mental health advocate

The role of the independent mental health advocate (IMHA) is a new role established by the Mental Health Act 2007 to ensure independent support for anyone sectioned under the Mental Health Act 1983. An experienced advocate newly converted to the IMHA role explained the role and responsibilities and the challenges of embedding this new advocacy function. Routes to becoming an IMHA were also explained.

Followed by Q&A.

Presentation: Understanding the role of PCTs

Staff from local primary care trusts talked about their engagement with refugee communities and their approach to commissioning mental health services.

Followed by an extended Q&A that gave the training participants the opportunity to begin a process of engagement with the PCT.

Presentation: Next steps

The final session of the programme looked at further opportunities for development and for sharing information, skills and funding, including reminders of the routes to engage with local Mind associations, PCTs and umbrella and capacity-building groups.²⁵

The training programme closed with the sharing of contact information and the awarding of certificates.

Evaluation and next steps

Evaluation forms were given to the training participants at the close of each day in order to inform the development of future training programmes. Significant feedback was also given verbally and in letters and emails in the months after the course, including successes achieved by advocates as a result of their new knowledge. A number of advocates who met on the training course are now working together to develop joint funding bids for mental health projects.

Mind continues to engage with the participants as resources allow, and to make them aware of training, funding and employment opportunities inside and outside of Mind's network. A number of the participants have expressed interest in developing their skills further by working towards becoming IMHAs, and Mind will support them in this regard.

24. More information about local Mind associations can be found in Appendix vii.

25. Details of these capacity-building bodies can be found in Appendix viii.

Two months after the completion of the training course, the Diverse Minds unit developed a refugee awareness event for Mind staff. The session was aimed at explaining the particular mental health needs of refugees and the need for Mind to ensure that these issues form a key part of future policy. The session was cofacilitated by Diverse Minds staff and volunteers, Abdi Gure from Mind in Harrow (a key facilitator from the advocacy course) and Malathy Muthu, Hassan Diabate and Luul Abdullahi Ali, participants on the advocacy course.

Mind intends to continue to develop its work with refugees and asylum-seekers in future projects to improve the mental health of their communities through the methods outlined in this document and through ongoing engagement with PCT and other statutory and voluntary services.²⁶ We welcome the involvement of agencies, community organisations and individuals committed to the support of refugee communities, who can contact Diverse Minds at diverseinds@mind.org.uk

26. Information about Mind's recent refugee work with PCTs and local Mind associations can be found in the report *A civilised society: mental health service provision for refugees and asylum seekers in England and Wales*, Mind (2009), which is available online at www.mind.org.uk

Appendix ii – statistics

This section contains monitoring data for the RCOs consulted during the research phase of this project.

Country / region of origin

Africa

Pan-African	19
Arabic-speaking	4 ²⁷
Great Lakes Region	3
Francophone Africa	2
Swahili-speaking	2
Somalia	23 ²⁸
Sudan	7
Eritrea	4
Etiopía	4
Zimbabwe	4
Congo	4
Burundi	2
Algeria	1
Angola	1
Gambia	1
Ghana	1
Ivory Coast	1
Liberia	1
Libya	1
Sierra Leone	1
Zambia	1

Middle-East

Kurdish	6
Arabic-speaking	4 ²⁹
Iran	3
Iraq	3
Turkey / Kurdish	2

Asia

Vietnam	6
China	5
Sri Lanka (Tamil)	4
Afghanistan	3
Tibet	1

Latin America

Latin America	6
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Europe

Bosnia-Herzegovina	3
Jewish	1 ³⁰
Roma	1
Russia	1

Of the above groups some have additional areas of focus:

LGBT	1
Women	12
Disabled	2
Elderly	5
Children / Youth	2

Location of RCOs in England

London	72
Leeds	10
Bristol	7
Manchester	6
Birmingham	5
Newcastle	5
Nottingham	4
Leicester	3
Peterborough	3
Liverpool	2
Norwich	2
Plymouth	2
Sheffield	2
Southampton	2
Borehamwood	1
Bradford	1
Luton	1
Northampton	1
Portsmouth	1
Salford	1
Slough	1

27. Arabic groups that encompass North African and Middle-Eastern communities. The figure represents the same four groups listed in the Middle East section.

28. Including Bajuni and Bravanese communities.

29. The figure represents the same four groups Arabic-speaking groups listed in the Middle-East section.

30. Survivors of the Holocaust, refugees and their families.

Appendix iii – RCO activities

- Assistance with asylum applications and appeals
- housing
- health
- education
- interpreting and letter-writing services
- social events to bring together the community and combat isolation
- family support and parenting classes
- activities for young people
- assistance to visit relatives in hospitals
- counselling
- lunch clubs for the elderly
- IT access and training
- English language classes
- day trips
- British culture sessions and excursions
- befriending
- mentoring
- women's groups
- health promotion sessions
- healthy eating classes
- exercise and sport activities
- mother tongue classes for children
- supplementary classes to help newly arrived children to catch up with the school curriculum
- drop-ins
- mental health advocacy
- mental health workshops
- HIV-AIDS counselling
- oral history and reminiscence projects
- football – in order to engage with other communities
- massage therapy
- confidence-building classes
- art classes
- legal advice
- meditation
- community newspaper
- radio station
- sewing
- walks
- horticulture
- music and dance classes (in one case identified as focused on combating depression.)
- supported walks
- swimming
- horticulture
- basic skills classes
- debt advice
- gambling advice
- substance misuse advice and signposting
- combating violent extremism
- job-seeking advice for refugees with status
- drama classes
- cooking
- practical support for individuals facing destitution
- improving access to community mental health teams
- reminiscing
- campaigning to end detention and removals
- workshops on PTSD.

Appendix iv – case studies

Effective engagement between communities, PCTs and mental health trusts

Derman

Derman was set up in 1991 in the London Borough of Hackney by members of the Turkish, Turkish Cypriot and Kurdish communities in order to deliver bilingual health advocacy to the communities. It has built partnerships with the PCT and local GPs and now also provides mental health advocacy, individual and group counselling and (since 2008) a mental health outreach service. Derman has also recently produced an excellent report addressing male mental health entitled Voice of Men, which was developed through relationships with UCLAN and NIMHE (Derman, 2008).

Arabic Families Service

The Arab Families Service in the London Borough of Kensington and Chelsea is principally a child and adolescent mental health service, but recognises that for the community it serves (all Arabs and all Muslims) such a service must consider the needs of the family. A case was made for a community-focused service, funding was awarded and the service was developed with the mental health trust. Its counselling service is run by a member of the community and all of its clinicians are Arabs or Muslims. As the service adapted to the user-led approach and took the work into the community (for example, family homes, women's centres and mosques) referrals increased by 25 per cent, purely by word of mouth.

ACANE

Support from a PCT-funded community development worker enabled the this African RCO in Newcastle to work with their community to give

training to understand depression and to identify the benefits of healthy eating, exercise, and talking about one's problems. These concepts are now embedded within the RCOs community activities, and the involvement of imams and pastors has increased engagement with the issues.

The Southwark Day Centre for Asylum-Seekers

The Southwark Day Centre for Asylum-Seekers (SDCAS) supports refugees who have been denied access to services elsewhere. SDCAS employs two mental health development workers who support their clients to access mental health services in the London Borough of Southwark. Crucially, SDCAS continues to develop new partnership approaches with the PCT and other mental healthcare providers.

Vietnamese Mental Health Services

Vietnamese Mental Health Services (VMHS) was established in 1989 (as the Vietnamese Mental Health Project) after two years of research into the mental health experiences of the Vietnamese community in London. VMHS now works with a number of agencies to provide a range of culturally appropriate services to the Vietnamese community across the UK, some of which are adapted from existing mainstream approaches. Recently VMHS has worked closely with the East London NHS Foundation Trust to develop better tailored access to psychological therapies for its community, largely through the training of workers within VMHS.

Bosnia and Herzegovina Community Association

The Bosnia and Herzegovina Community Association in Hertfordshire has a community development worker paid for by the Hertfordshire Partnership NHS Foundation Trust. The CDW has delivered mental health workshops and worked

with the community to address issues around PTSD and the risks of ignoring mental distress. Crucially, this work has been presented in tandem with the Association's drop-in and sports and educational activities as part of a wider wellbeing approach.

Bedfordshire African Community Centre

After discussions at Luton's multi-agency refugee forum, Bedfordshire and Luton Mental Health and Social Care Trust provided focused mental health training for staff and workshops for the community. Four workers have been trained to deliver low-level counselling assessment and referrals. The service is promoted by an outreach worker with support from churches and mosques in the community.

Appendix v – delivering the training programme

Given the level of engagement of RCOs and the support of Mind’s advisory group and other partners, developing the training programme was relatively easy. Leaving aside the technical details of delivering of a training course, the principal areas that needed to be addressed were as follows:

- the participants – choosing which individuals to train
- the trainers – choosing appropriate facilitators
- the location
- the delivery dates.

The participants

The funding guidelines for this project specified that while the research stage should be England-wide, the training delivery should be focused on London and the South-East, thus narrowing the base of RCOs from which to draw our participants.

From this point Mind based its choices on:

- **Need** Some RCOs in London have been in existence for in excess of 20 years and are well engaged, funded and resourced. Mind wanted to work with groups that currently need more support to develop community programmes and effectively engage with service providers.
- **Level of Interest** Many groups showed interest in our training plans from our initial discussions. Mind recognised, however, that some small community groups may feel anxious about engaging with a large agency that is unknown to them on a subject as sensitive as mental health, so Mind tried to take an approach that would build trust and encourage the groups to become involved in Mind’s work. This approach was usually to meet the group leader or advocate for an informal discussion either at their premises or in a local café.
- **Capacity** Some groups struggled to free up staff to take part in the training. Mind was able to offer financial support to facilitate involvement,

but this was rarely an adequate solution, as the person that would most benefit from the training was usually the person that would be most missed if absent from the community for four days. A solution to this problem was often to send a volunteer (in two cases volunteers who are studying psychology) for part or all of the course, but a volunteer who was well engaged with the worker and sufficiently confident to be able to effectively pass on the learning. For the most part, however, Mind attracted the advocate that we had hoped to work with, and they informed their clients of the course break-times when they would be available to talk by telephone.

- **Origin of community** Mind wanted to try to work with a breadth of different backgrounds, not only to share the learning across communities, but to increase our knowledge and also to facilitate engagement and understanding across communities, particularly those communities operating in the same geographical area.
- **Geography** Mind wanted to work with communities across the London and South-East region to improve our understanding of and engagement with communities across the region. Wherever possible Mind sought to build relationships between RCOs and our local Mind associations.
- **Gender** The majority of the RCO respondents to our mapping survey were men, and Mind was keen not only to obtain women’s perspectives but also to ensure that they were not marginalised in ongoing engagement. Ultimately, 70 per cent of the training participants were female.

The trainers

Mind’s trainers were sought principally through three channels – Mind staff, colleagues from local Mind associations, representatives from PCTs and other professionals with expertise working with refugee communities that we had built relationships with over the course of researching the project.

A complete list of the trainers can be found in Appendix vi.

The location

To enable ample easy access to the training and to ensure that each participant had plenty of space to express his or her views, Mind split the training into two groups of 15, based at two different locations.

The two locations were chosen for ease of access by public transport for the participants and because they were well known to many of the participants, and as much as possible close to most participants. All participants were remunerated for travel costs and participants from outside London were given hotel accommodation.

The delivery dates

Mind realised that to have the course spread out so that each group had one day's training every month would make it easier for all participants to

attend and create minimal impact on their community work. Conversely, Mind felt it important to have continuity, in our view best achieved by keeping the training days close together. Mind also felt that this approach would more effectively enable the participants to make connections and build relationships.

The answer to this dilemma was actually given by the lifespan and the natural arc of the project, which broadly gave a window of May – early August for delivery. Taking into account Refugee Week (a period of intense activity for many RCOs), school holidays, public holidays and the importance of Friday prayers to the Muslim participants who made up a large part of the groups, the days were almost self-selecting. Run over two and a half weeks, each group would have a block of two days, followed by a break of a week and then another block of two days.

Appendix vi – contributors

Advisory group

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Ann Byrne Women's Therapy Centre

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Nasser Eid Harrow Kuwaiti Community Association

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Amjad Taha Refugee Health Forum, Westminster

Philomene Uwamaliya Liverpool Primary Care Trust

Amada Vergara Latin American Golden Years Day Centre

...and a particular thank-you to the many refugees not listed here who gave up their valuable time to talk to us about their communities.

Appendix vii – accessing Mind, its networks and information

Mind

15–19 Broadway
Stratford
London E15 4BQ

T: 020 8519 2122
e: contact@mind.org.uk
www.mind.org.uk

Mind Cymru

3rd Floor
Quebec House
Castlebridge
5–19 Cowbridge Road East
Cardiff CF11 9AB

T: 029 2039 5123

Diverse Minds

Information about Diverse Minds is contained on Mind's website, including how to join the Diverse Minds network, but can be quickly accessed here:

www.diverse minds.org.uk

Mental health information in different languages

Mind produces mental health documents and audio files in a number of different languages. This information can be found here:

www.mind.org.uk/help/foreign_language_resources

Local Mind associations

Local Mind associations are mental health charities which run independently from national Mind, but which have signed up to the key policy and campaign messages of Mind and are expected to meet certain quality standards. Each association is unique and they range from very small organisations to very large ones which have hundreds of staff and volunteers. Information on all of the associations and their service can be found here:

www.mind.org.uk/help/mind_in_your_area

Appendix viii – other useful contacts

National refugee support organisations

Refugee Council

240–250 Ferndale Road
Brixton
London SW9 8BB
T: 020 7346 6700
www.refugeecouncil.org.uk

Refugee Action

The Old Fire Station
150 Waterloo Road
London SE1 8SB
T: 020 7654 7700
e: info@refugee-action.org.uk
www.refugee-action.org.uk

British Red Cross

44 Moorfields
London EC2Y 9AL
T: 0844 871 1111
e: information@redcross.org.uk
www.redcross.org.uk

Therapeutic support

The Medical Foundation for the Care of Victims of Torture

111 Isledon Road
Islington
London
N7 7JW
T: 020 7697 7777
www.torturecare.org.uk

The Refugee Therapy Centre

1A Leeds Place
Tollington Park
London N4 3RQ
T: 020 7561 1587
e: info@refugeetherapy.org.uk
www.refugeetherapy.org.uk

Nafsiyat – Intercultural Therapy Centre

Unit 4
Clifton House
42/43 Clifton Terrace
London N4 3JP
T: 020 7263 6947
e: admin@nafsiyat.org.uk
www.nafsiyat.org.uk

Solace

150 Roundhay Rd
Leeds, LS8 5LJ
T: 0113 249 1437
www.solace-uk.org.uk

Community-specific mental health support

Vietnamese Mental Health Services

Thomas Calton Centre
Alpha Street
London SE15 4NX
T: 020 7639 2288
e: info@vmhs.org.uk

UK Lesbian & Gay Immigration Group

32–36 Loman Street
London SE1 0EH
T: 020 7922 7812
www.uklgig.org.uk

Derman

For Kurdish and Turkish communities.
The Basement
66 New North Road
London N1 6TG
T: 020 7613 5944
e: services@derman.org.uk
www.derman.org.uk

Shalvata Therapy Centre

For Holocaust survivors, refugees and their families.

T: 020 8203 9033

e: hsc@jcare.org

www.jewishcare.org/what-we-do/holocaust-survivors-and-refugees/shalvata-therapy-centre/

Chinese National Healthy Living Centre

29–30 Soho Square

London W1D 3QS

T: 020 7534 6546

w: www.cnhlc.org.uk

Chinese Mental Health Association

2nd Floor

Zenith House

155 Curtain Road

London EC2A 3QY

T: 020 7613 1008

e: info@cmha.org.uk

www.cmha.org.uk

Capacity building

The Basis Project

Refugee Council

240–250 Ferndale Road

Brixton, London SW9 8BB

e: basis@refugeecouncil.org.uk

www.thebasisproject.org.uk

Evelyn Oldfield Unit

London Voluntary Sector Resource Centre

356 Holloway Road

London N7 6PA

T: 020 7700 8213

e: administrator@evelynoldfield.co.uk

www.evelynoldfield.co.uk

London Refugee Voice

Cocoon House

Market Approach

Off Lime Grove

London W12 8EE

T: 020 8743 8246

w: www.lrv.org.uk

Campaigning and legal

Time to Change

Time to Change is England's most ambitious programme to end discrimination faced by people who experience mental health problems.

15–19 Broadway

London E15 4BQ

T: 020 8215 2356

e: info@time-to-change.org.uk

www.time-to-change.org.uk

Medical Justice

Medical Justice is a network of volunteers who challenge medical abuse in immigration detention.

86 Durham Road

London N7 7DT

e: info@medicaljustice.org.uk

www.medicaljustice.org.uk

Medact

Medact is a global health charity tackling issues at the centre of international policy debates. It has a network of health professionals that shares information and best practice to improve the health of refugees and asylum-seekers.

The Grayston Centre

28 Charles Square

London N1 6HT

T: 020 7324 4739

e: info@medact.org

www.medact.org

Still Human, Still Here

The Still Human Still Here campaign is dedicated to highlighting the plight of tens of thousands of refused asylum seekers who are destitute in the UK.

<http://stillhumanstillhere.wordpress.com/>

Refugee and Migrant Justice

An organisation of lawyers committed to securing justice for asylum-seekers and other migrants in the UK.

Nelson House

153–157 Commercial Road

London E1 2DA

T: 020 7780 3200

<http://refugee-migrant-justice.org.uk>

References

Derman (2008), *Voice of Men – Mental health needs assessment of Turkish/Kurdish and Cypriot/Turkish men in Hackney*, Derman

Department of Health (2005), *Delivering Race Equality in Mental Health Care: An action plan for reform inside and outside services and the Government's response to the independent inquiry into the death of David Bennett*, Department of Health

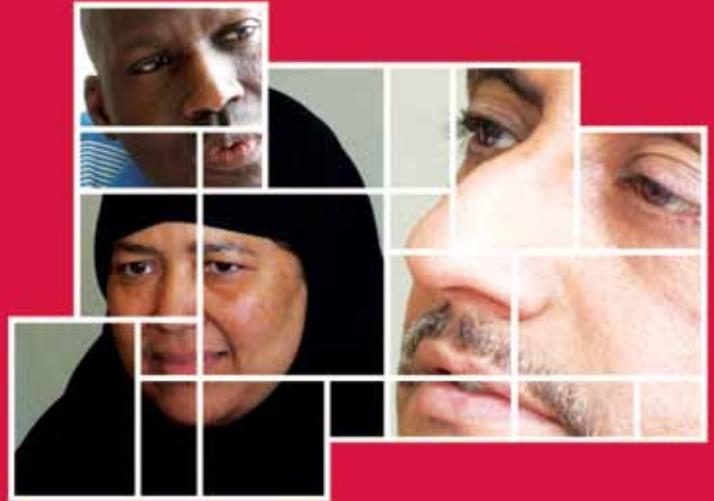
Mind (2006), *With us in mind – service user recommendations for advocacy standards in England*, Mind

Mind (2009), *A civilised society: mental health service provision for refugees and asylum seekers in England and Wales*, Mind

Vietnamese Mental Health Services (2001), *Mental Health – A Vietnamese Perspective*, VMHS



**For better
mental health**



For details of your nearest local Mind association and of local services, contact Mind's helpline, *MindinfoLine* on 0845 7660 163, Monday to Friday 9.00am to 5.00pm. Speech impaired or deaf enquirers can contact us on the same number (if you are using BT Text direct, add the prefix 18001). For interpretation, *MindinfoLine* has access to 100 languages via Language Line.

Mind, 15–19 Broadway, London E15 4BQ
T: 020 8519 2122 F: 020 8522 1725
w: www.mind.org.uk

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time to change

let's end mental health discrimination