Hardly Hard to Reach

The Case for Refugee-Led Mental Health Services

Summary and Recommendations

Race on the Agenda
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> ***"There are lots of Tamil people living in Harrow, and most of them are isolated like I was. There's lot of depression in the community. It would be good to open up and let people enjoy the services. This way, the government doesn't have to spend more money on care homes… Compared to care homes, employing nurses etc… this is cheaper to run, no?"***
>
> Female, Tamil, 52, Married, 2 children

Active Lives, Healthy Minds is a three year (June 2016-2019) refugee-led mental health and wellbeing project in West London run by Race on the Agenda (ROTA) in partnership with Account Trust (Nepali community organisation), Network of Eritrean Women UK, Qoys Daryeel – Family Care (Somali community organisation), the Tamil Community Centre and Ilays. The project is funded by The National Lottery Community Fund and aims to improve mental health and the wellbeing of members of the Eritrean, Nepalese, Somali and Tamil communities.

Account Trust is a Hounslow-based community organisation serving the Nepalese community in West London. Account Trust offers English language classes, wellbeing classes and practical and emotional one to one support with benefits, employment, health and housing advice.

Network of Eritrean Women UK is a non-profit women's organisation that focuses on women's empowerment and issues impacting Eritrean women and girls. NEW-UK's main priorities are education, advocating rights, women's health and wellbeing, addressing gender-based violence and creating opportunities for development. NEW UK is the only specialist organisation in the UK supporting Eritrean women and unaccompanied Eritrean children providing cultural and linguistic specialist advice, information, advocacy, workshops and mental health/wellbeing support.

Qoys Daryeel – Family Care was founded in April 2018 to support Somali women and families experiencing family breakdown, domestic violence and substance misuse through individual, and group, mental health peer support work. The organisation was founded in 2018 by Somali women trained by ROTA on the Active Lives, Healthy Minds project. Qoys Daryeel was founded amidst patriarchal structures within the Somali community challenging their existence. Alongside supporting women, they also challenge harmful practices, educating members of their communities and changing social norms.

Race on the Agenda (ROTA) is a policy research organisation that focuses on race equality and issues affecting the UK's Black Asian Minority Ethnic (BAME) communities. ROTA aims to increase

the capacity of BAME and equality organisations to get engaged in policy, develop partnerships and learn from best practice. We also aim to increase the skills and knowledge of BAME individuals to fight discrimination and become champions in helping to promote equality. ROTA informs, influences and increases the awareness of decision makers, policy makers and stakeholders in the public, private, voluntary and community sectors.

Tamil Community Centre is a service-user led community organisation, based in West London, aiming to meet the needs of a wide spectrum of the Tamil community. They focus on issues ranging from domestic violence, immigration mental health and wellbeing, homelessness, addictions such as drug and alcohol abuse and gambling, gender based violence and child abuse, benefits, housing, form filling, translation and interpretation. TCC offers a therapeutic traditional folk dance class, one to one mental health support, practical English language classes, and information sessions in Hounslow, Harrow and Northolt.

Setting the Context: Active Lives, Healthy Minds, Refugee Mental Health and Wellbeing

Members of the Eritrean, Nepalese, Somali and Tamil communities have experienced severe loss and disruption of their lives due to war, civil unrest and natural disaster in their countries of origin, followed by the traumatic experience of flight and then the stress caused by immigration processes and difficulties adapting to new language and cultural settings.

Hostile environment policies and Brexit, and widespread institutional structural racism have put refugee and migrant communities with intersecting identities and the grassroots organisations working to support them under huge pressure. In addition, austerity cuts have worsened inequalities and barriers for accessing mental health support services. People from migrant backgrounds are often not aware of existing services or do not understand their right to access services. Stigma around mental health and the inability to identify mental health support needs adds an additional challenge. Language barriers further impact people seeking support, with a lack of (well-trained) interpreters, despite this being a statutory right when accessing public services. Many refugee and migrant-led community organisations have seen their funding reduced or centres closed as need and demand for support has increased. At the same time, local authorities are increasingly unable to meet the complex needs of refugee and migrant communities due to local funding cuts, lack of training, and cultural awareness and competence. Community organisations are often left to fill this gap, providing safer, more accessible, responsive, efficient and cost effective services. Services that reduce inequalities and which play an important role in preventing minor mental health problems from becoming more serious can often reduce health crises, costs to the NHS and Public Health. Yet, refugee and migrant-led community organisations and their members are often left out of the commissioning process as well as the design of services and are continually under-funded, despite their ability to directly impact on and access service users.

The Active Lives, Healthy Minds project assisted our partner organisations and the community members they support in developing holistic, intersectional projects and activities to support their mental health and wellbeing in a culturally sensitive and non-stigmatising way. Support was offered on both a one-to-one basis and through group activities. Activities included culturally specific events like Eritrean and Somali coffee mornings, Tamil and Nepali folk dance classes, yoga and breathing exercises, and practical English language classes, alongside information sessions on health and mental health, education, immigration and criminal justice. The project also supported our partner organizations and community members to increase participation in the development and implementation of relevant mental health and health services in North West London, through campaigning and lobbying with decision-makers across West London.

The project supported well over a thousand people from the Eritrean, Nepali, Somali and Tamil communities over a period of three years, with a core group of 150 people attending

weekly activities across the four partner organisations. Through the project, community members learned skills to increase their independence; improve their coping strategies and feel more able to deal with crises and stress; feel less lonely and isolated; increase their confidence; and decreased their stress and distress. At the same time, community members, coordinators and volunteers increased their understanding of different types of mental health support; demonstrated significant learning about the structure and functions of local mental health services; and reported having more successful interactions with other mental health support services where these have been necessary, often times due to having a multilingual advocate from one of the partner organisations join them. Several dozen former service users of the project have become volunteers taking on roles in our partner organisations. Through one to one support, community members improved steps towards recovery. Community members reported reduced use of other crisis and emergency services and, where these are used, that they are used appropriately.

This Policy Report is part of the Active Lives, Healthy Minds project run in partnership with four refugee and migrant-led community organisations. We interviewed 53 community members, coordinators and volunteers from Eritrea, Nepal, Somalia and Sri Lanka. All but two of the interviewees were women. The interviewees ranged in age between 28 and 74. Their immigration statuses ranged from British citizen, permanent resident, temporary resident, spousal visa, to asylum seeker, refugee, and having insecure immigration status. The interviewees had been in the UK between just several months and 25 years. The majority of the women live in West London (Hounslow, Harrow, Ealing, Hillingdon). The interviews were conducted at our partner organisation's centres and other venues used to run activities and were held in community languages. The report also includes findings from the Mental Health Equality Campaign.

Mental Health Needs of Refugee Communities

"Everything got disrupted during the war, my husband got shot by the army, and I left the country.

Being alone in the house – I get lots of flashbacks of unwanted memories… So coming here helps me escape bad thoughts."

TCC service user, Female, 59 from Sri Lanka

Refugees and asylum seekers often have specific mental health needs. Pre-migration experiences of **civil war, torture, violence or gendered violence** mean they are more susceptible to poor mental health outcomes than the local-born population.

Conditions and experiences in the new host country can also have a mental health impact such as unemployment, the asylum process, isolation, family separation and racism. The unemployment rate is estimated at **18% for refugees, three times higher than that of the UK-born** (UNHCR, 2019). Employer recognition of past education and skills, language barriers, past trauma, childcare and employer perceptions contribute to this disparity.

According to the Refugee Council, **61% of asylum seekers experience serious mental distress**. Refugees are 5 times more likely to have mental health needs than the British-born population.

Country-Specific Barriers

Differences in culture can have a range of implications for mental health practice. This can be the way people view and conceptualise health and illness, treatment seeking patterns and issues of racism and discrimination (NCBI, 2018). For our partners, these needs differ depending on the country of origin of their clients.

Somali Community

Past traumas, and religious and cultural beliefs shape how the Somali community commonly define and experience mental health support needs. This, and structural barriers such as poverty and language barriers, also inform how the causes of mental health are perceived and views on seeking treatment (Hussein, 2013). Unresolved trauma – witnessing war and facing forced migration and famine - effects day-to-day life in the UK (UNHCR, 2016).

Culturally, it is commonplace to believe that mental health support needs are a result of individuals not being good practising Muslims. This includes the idea that people suffer from mental health issues due to 'God's will' and families are also stigmatised, accused of not raising their children properly and in Islamic ways. According to a report by the Council of Somali organisations, the foremost health issues that concern the Somali community are khat use (a drug stimulant) and mental health issues (Hussein, 2013).

Structurally; issues such unemployment, welfare dependency and isolation are thought to contribute to poor mental health (Economist, 2013).

Tamil Community

Sri Lanka was involved in war for nearly three decades, which has had a profound effect on the Tamil community. Tamils in the UK utilise a range of individual, spiritual, and social coping strategies but the use of statutory support is limited. Instead, particular importance is placed on collective coping within this community through membership to Tamil community organisations (Dharmaindra, 2016).

A small-scale scoping report by ROTA and the West London Mental Health Trust found that the Tamil community conceptualisation of mental illness and mental health support differ from prevailing conceptions in the UK. Mental health conditions are commonly understood as *padatam.* This is viewed as a bodily process rather than something someone experiences in the brain (ROTA, 2014). Research has also found that the Tamil community has a 'collective experience of trauma.' Their life stories are filled with narratives of deaths of loved ones, displacement and violence (Jones, 2013). This should be reflected in mental health support that should be holistic and culturally specific (Middlesex University, 2014).

Research by Middlesex University in West London highlighted that a prevalence of post-traumatic stress disorder (PTSD), sometimes goes undiagnosed at GP level. This often went unrecognised within some families, due to stigma attached to mental illness. Further, alcoholism and high incidences of domestic violence among Tamil Sri Lankans was noted.

Eritrean Community

Eritrea imposes a mandatory indefinite military service on all citizens by an oppressive regime that deprives them of basic human rights. Leaving Eritrea is dangerous and some of refugees have made several attempts to leave before succeeding. It is common to develop depression, anxiety and post-traumatic stress disorder linked to torture, violence and abuse (MSF, 2018).

Like many other refugee communities, the Eritrean community also faces difficulty in accessing mainstream services such as housing and English language classes. Eritrean refugees are also found to have difficulty in gaining employment (Refugee Council/UNHCR, 2018).

Nepalese Community

Within Nepalese culture, studies show a significant stigma towards mental health difficulties. Mental illness can have an impact on status within the community, negatively impact marriage prospects and bring shame and dishonour upon the family (Jha, Kitchener, Pradhan, Shyangwa, & Nakarmi, 2012). A significant number of individuals identified as 'mentally ill' are thought to experience discrimination and marginalisation and in some cases physical violence (Kohrt & Harper, 2008).

Research has found that structural issues such as immigration status and regular exercise were significantly associated with poor health status for the Nepalese community. Individuals who stay in the refugee/asylum seeker category for over 10 years were 5 times more likely to be experiencing poor health status than individuals who have UK residency (Adhikary et al, 2008).

Accessing Services

Accessing services can be more challenging for refugee and asylum seekers than the British-born population. Language barriers, an unfamiliar health system, a lack of services and community stigma around mental health can all act as barriers to getting support (Refugee Council, 2017). Under the "hostile environment" people with irregular immigration status are sometimes in danger of detention and even deportation when they try to access services

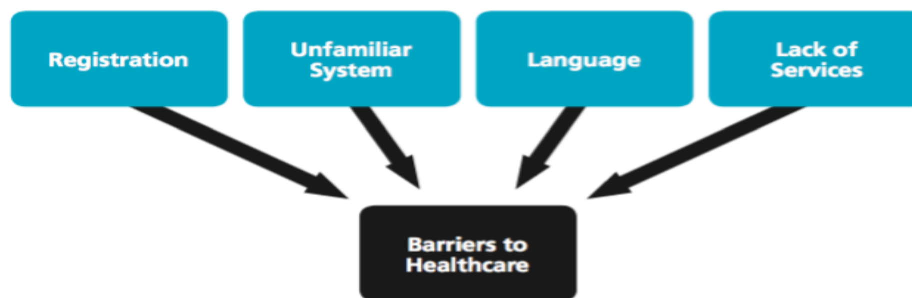

Figure 1, Barriers to accessing health services, Refugee Council/APPG on Refugees (2017)

Interviews with our project partners and the communities that use and co-design their services cited language barriers, a lack of statutory services and inappropriate services as barriers to accessing support.

The Value of Culturally-Sensitive Services: Examples From The Network Of Eritrean Women And Tamil Community Centre

Refugee-led community organisations play an essential role, providing practical support for groups that are not served adequately by statutory services. Refugee communities are frequently referred to as 'hard to reach' by social care and health providers along with other groups that face health inequalities, such as ethnic minorities, disabled people and those on low incomes (Refugee Action, 2018). Our work with our partner organisations found that the framing of refugee communities as 'hard to reach' is misguided. How mental health services are delivered is what makes a difference. Community organisations do not struggle to engage and support refugees because they offer services that respond to their needs.

Traditional Coffee Sessions – Women coming together to discuss issues of concern over coffee is an aspect of everyday life for Eritrean Women. The Network of Eritrean Women UK built on this tradition and added a dimension introducing mental health and wellbeing support into the conversations. The coffee mornings offer an opportunity to introduce various themes into the conversations among women in the community that are otherwise viewed as carrying stigma or invoke anxiety. Coffee sessions provide a non-threatening, non-stigmatising setting that women are familiar with and trust, where they can explore their experiences and emotions in a safe way. Coffee sessions support women to envision new possibilities for their life, make sense of what has happened, to find voice, to exercise choice, and recover agency in the world.

Language Barriers

Language was seen as a common barrier to accessing health services by our partners. In interviews with clients of the TCC service, participants emphasised the need for services provided in their mother tongue. Particularly for mental health services, it is important to be able to express what can be intimate or traumatic experiences in the language they feel most at home with.

"I think it is especially important for domestic violence survivors. They attend other services (like Hestia), but I think, at TCC, they feel more comfortable in expressing their feelings with Rani in their own language. Sometimes it is difficult to express your feelings in another language so I think it is really important to have Tamil speaking people there to help Tamil community." Female, 48, two children

A lack of interpreters, particularly at the GP and at hospitals, led some clients to struggle at health appointments. Three clients felt it had gotten harder to access an interpreter in recent years:

"As I don't speak English well, I need an interpreter, but when asked I wasn't provided with one. There have been cuts to such services. I have stopped asking for interpreters now and usually one of the family members come with me to those appointments. Female, 74, four sons

It is important for us to have services in Tamil as well as free of charge. There are other services provided in Tamil, but they are charging people to attend those services." Female, 74, 6 children

It has become more common to use 'over the phone' interpreters instead of sending an in-person advocate, which is not always adequate (Memon et al, 2016). Sometimes there is no option for an interpreter of any kind, despite this being people's statutory right. They have to rely on family members to support with translation.

"Here in the class, we have no barriers in language. That has made me feel comfortable. Before, you can request an interpreter and he or she will be there in person for the appointment. Nowadays, they just put someone on the speaker-phone and I am not really used to it." Female, 59

Some clients did not access any other services because they had little understanding of English and were, therefore, limited to services that used community languages. Rather than being 'hard to reach', TCC clients were struggling to access statutory services as a direct result of how they are designed. The voluntary and community sector has arguably been more successful in penetrating some of the barriers for the 'hard to reach' and has an important role to play in the understanding of service delivery provision (NCBI, 2010).

Therapeutic Traditional Folk Dance Class - Dance and movement have long been known to have physical and psychological benefits for people with mental health support needs. Rani Nagulandram, co-founder and wellbeing coordinator at the Tamil Community Centre, has been running therapeutic folk-dance classes for many years in South Harrow, Hounslow and Northolt for a group of 20 to 25 Tamil women from various abilities and ages. The class integrates yoga, traditional Bharathanatyam dance and religious music. For one hour, the women are fully focused on the traditional music and the dance and yoga moves, allowing them to take their minds of their day to day life and struggles. Attending folk-dance classes does not only improve women's health and mental health, but also provides a non-stigmatising, relaxing environment where women have the opportunity to interact and socialise. Women feel less stressed, sleep better and feel healthier. They have created friendships among their fellow participants that stretch beyond the folk-dance class, reducing loneliness and isolation. At the same time, the folk dance classes are often leading to women sharing their struggles and receiving one to one support.

‘Service Users’ As ‘Experts By Experience’

An expert by experience is someone who has personal, lived experience of using mental health services. They have invaluable knowledge that should be used to inform service design. Involving clients in the delivery and co-production of mental health services help services respond better to the client groups needs. Flattening the hierarchical distinctions between mental health practitioners and consumers of services helps people to recognise and share their strengths and knowledge.

At TCC, some clients interviewed used the service but also helped deliver sessions to their peers, creating a symbiotic service.

“It’s important for me to interact with other Tamil women. Especially after losing my mother – I enjoy helping older women to attend GPs, translate or interpret for them… seeing mothers make me happy… Me coming here is good. This is a foreign country, I mix with everybody. I don’t have any barriers to mixing with other people. But still, you have a feeling… need for your own community… like the feeling or need you have for your mother. Dance teacher’s mother is always makes kanji (porridge) and make us eat… simple things like that make a big difference.” Female, 53, two children

A Holistic Approach to Services Delivery

A holistic approach to service delivery looks behind treating one symptom in silos. It takes into account how a range of social and contextual factors - such as loneliness, language barriers, past traumas, immigration status and poverty - can impact the mental health of users and co-creates services to serve multiple needs. For our project partners, whose client groups conceptualise mental health differently, a holistic approach is vital to effective service delivery.

“***If I were home without anything to do, I’ll be needlessly worrying about things, but coming to the classes helps me feel relieved on top of learning and making friends. I also feel relaxed mentally. Before coming here I wasn’t able to move outside of the house due to my husband passing away, but now, I can’t seem to stay in. Coming to TCC and talking with other people has helped me overcome my depression. I was stressed. I was alone in the house while my daughter, son-in-law and grandchildren, left for their work and school.”*** Female, 71, three children

The short appointments with a GP and cuts to translator services, has made holistic services from the voluntary sector more vital for these communities.

"***Oh compared to the physiotherapist, I think this (community service) is much more than just exercise. This is more like a get-to-gether for our community, we talk, interact, share information and news. That is the difference.***" Female

"***The support from GP and the dance class are totally different. You hardly get a chance to talk for ten minutes with your GP, but coming down here is making a difference. When you go to your GP for psychological help, you want to put a lot of thought into your words and say as much as you can, tell her everything within ten minutes…***" Female, 48, one son

The activities they provide, such as dance classes improve wellbeing whilst support with immigration, domestic violence, English language and accessing statutory services goes further. It increases participation in public life and increases independence.

"We had a problem with the Council housing and TCC helped solve that problem at the Civic Centre." Male, 67, two children

The following is a case study that illustrates how the holistic services provided by our partners have supported their clients.

A., Tamil woman, 34, separated, 1 son (5)

A. was referred to TCC by a Social Services team in West London. She is currently living in a hostel with her son. When A. first arrived at TCC she was in a dire emotional state, feeling depressed, tearful, complaining of chest pains, aches and pains, lack of sleep, lack of appetite, memory loss, and difficulty focusing and concentrating.

A. experienced severe verbal and psychological abuse, brutal physical violence, marital rape and forced isolation for seven years by her former husband. In 2011, she entered an arranged marriage. Her abusive husband's family thought that if he would marry he would be 'cured' from his severe mental health support needs, give up alcohol, gambling and other bad habits and be able to maintain a job.

For four months, TCC volunteers supported her to apply for indefinite leave to remain under the domestic violence rule and to apply for her divorce. They helped her navigate these legal systems and referred her and advocated for her with law centres and statutory services like the GP on her mental health and social services on her housing and NRPF support.

A. also attends a folk dance class on Monday, practical English classes on Wednesday and Thursday and activities on Friday, including a folk dance class, chair-based exercises and a shared lunch. Alongside these weekly activities, volunteers have provided one to one emotional and psychological support. A. has also been engaged in group discussions which helped break down her isolation from the community.

A.: "With the help of Rani and her volunteers I have regained my sense of safety. Before I would not be able to sleep, I used to suffer with really bad headaches and was living in fear. My husband's family attempted to kidnap me and my son and threatened me to return to my ex-husband. They can now no longer come near me and the attempts at kidnapping stopped. Now I feel relaxed and no longer afraid to go out on my own. I feel freer to leave the house now, I am no longer afraid. I feel safe. Before, I was hardly allowed to leave the house by my husband and his family. Now I am almost always out. I have regained my freedom. I feel so much happier now. I feel so much better. Before I did not have any freedom, I was constantly oppressed by my husband. If it wasn't for Rani, I would not have had the confidence to leave him. Rani gave me a feeling of being supported. I feel cared for. I have met many new people who have become our friends. I do not feel alone any longer."

Recommendations

The below recommendations are based on six years of partnership working with refugee and migrant communities and the organisations supporting them with their mental health and wellbeing. These working ethics can be applied in any setting and organisational structure, from community-led to voluntary sector to statutory services.

1. Use an Intersectional Approach when working with people from a refugee and migrant background**.** This includes being aware of the multiple forms of marginalisation faced by community members by creating awareness and consideration of how gender, class, gender identity, sexual orientation, age, ethnicity, refugee or asylum-seeker status and levels of English language proficiency intersect and inform people's experiences. For example, a Somali Muslim Woman will have a very different experience of life in general and while accessing statutory mental health support than a white middleclass man.

2. Use a holistic, social model for supporting people from a refugee or migrant background with mental health challenges. People's mental health and wellbeing are influenced by social, economic or cultural challenges or marginalisations in life such as migration status, access to education, exclusion, employment, benefits, housing, experiences of domestic violence, and the criminal justice system. In order to provide sustainable support, services need to focus on the barriers causing or aggravating mental health support needs. Services need to develop an understanding of how stigma, language and cultural differences impact on people's ability to access 'mainstream' services. Holistic services look at all these factors influencing a person's life and look for solutions rather than seeing the person as the problem. Systems need to change, not people caught up in cycles of political, social and economic oppression.

3. Work in a linguistically-inclusive way Language is a main barrier to accessing and receiving appropriate mental health services for people for whom English is not their first language. Due to language barriers, many community members lack knowledge/awareness of services. Services should provide knowledge about services in community languages. In many languages there is no word for 'counselling', 'mental health', or concept of 'advocate' and as a result mental health problems are often difficult to articulate. Due to a lack of awareness of mental health issues, people may be unable to identify as having mental health support needs. Despite people having the statutory right to receive interpretation services for health and mental health appointments, the reality is that either people are not made aware of this right, interpreters are not provided, or the interpretation is of a poor quality. Interpretation for mental health requires additional training to be effective for community members. Training professionals from a refugee and migrant background could help bridge this language gap.

4. Be culturally sensitive and community specific Rather than using a one-size-fits-all approach, services should be designed with and for specific refugee individuals and communities. Experiences of coping with mental health support needs are individual in nature. People's objectives for coping with or recovering from mental illness are also different.

5. Involve community members and the organisations supporting them at every level Services should be designed, developed and run by community members. Services should work to develop more meaningful, real service-user involvement and power-sharing in the design, development and delivery of mental health services and in all aspects and levels of decision-making. Services should also support the development of a stronger sense of ownership of mental health support provision. Statutory bodies and voluntary sector organisations should consider working in partnership with refugee and migrant-led community organisation to deliver integrated mental health services.

6. End racist policies and practices Refugee and migrant communities will continue to suffer as long as immigration systems continue to be structurally racist and the Hostile Environment and Austerity policies continue to exist Everyone working with people from a refugee or migrant background should develop an awareness of how these policies influence people's mental health and wellbeing and should consider engaging in advocacy and campaigning to change the current political environment.

Acknowledgments

We would like to thank our funder the National Community Lottery Fund for funding our work on the Active Lives, Healthy Minds project. We are indebted to the coordinators and volunteers at our partner organisations: Account Trust, Network of Eritrean Women-UK, Qoys Daryeel – Family Care, Ilays, and the Tamil Community Centre. In particular we would like to thank Kumar Thapa, Monaliza Amanuel, Helen Kidan, Asmahan Ali, Khedijah Ali-Mohammed Nur, Marso Abdi, Sado Saeed, Rani Nagulandram, and Nirmala Rajasingam for their insights and support documenting the stories of community members. We would like to thank all Eritrean, Nepali, Somali and Tamil community members for sharing their experiences and for their contributions to and participation in the project. We would also like to thank our partners on the Mental Health Equality Campaign, especially HEAR, Centre for Armenian Information and Advice and the Council of Somali Organisations. At Race on the Agenda, we would like to thank Kimberly McIntosh for her direction on the policy report, Muna Hassan for her desk-based research, analysis of the interviews and report writing, Laurie Lijnders for sharing three years of learning, and Andy Gregg and Eleanor Stokes for their proofreading. We would like to thank Elilajan Jeyakumar and Katija Adan for conducting and transcribing the interviews. Their knowledge, time, language skills and support have been invaluable.

For more information on the Active Lives, Healthy Minds project see
https://www.rota.org.uk/content/active-lives-healthy-minds-project-0

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"We should not exist if the system would function. My dream would be that we would be a luxury, that the women would not need us. It is not only important for the women, it is also important for the society. If we were not involved in supporting these women the society will have to carry these women. We are here to say: it is ok to be who you are and to suffer and to go through this, we just need a solution, and we have to find a way to break this circle".

"For example, one of the women I supported, she was abused by her husband. She escaped, but there is no accommodation, the only place she could go to was the homeless shelter, she doesn't have money because her abusive husband oppressed her economically and did not allow her to open a bank account, she asked the job centre for support and they want a bank account, she went to the bank and they asked for a home address, but she does not have a home and they do not accept the shelter address. She can't go to back to her abusive husband. She is in a deadlock. Everyone is abusing her, she is in a circle of abuse: the bank is abusing her because she does not have an address, the job centre is abusing her because she does not have a bank account so they are not paying her, the shelter is keeping her there, but they can't give her money, because they do not have any money. The doctor initially refuses to register her because she is in a homeless shelter, when they do she can't get there because the doctor's practice is far away and she does not have money for public transport. She can't start English class because she isn't registered. She was in a devil's circle and we broke it with her".

"What we do is, I take her out of the homeless shelter, she is no longer in crisis. I take her to the coffee mornings, I speak to her, drink coffee with her, reconnect her with other women and she feels no longer alone, I link with the shelter and they now know there is an organisation that supports Eritrean women and I help with interpretation. As long as these obstacles are placed in women's way, we are needed, there is no straight way for a refugee women coming to this country. We need to exist, not should be. We give moral support. We often feel limited in what we can do too. We can't magically find housing. It is not smooth walking, running, falling down, standing up, but we will walk with her. That is what we do. I will come with my knowledge, I will be a sister to you, that is all that they need sometimes."

Monaliza Amanuel, former Project Officer, Network of Eritrean Women UK