Refugee Radio
Needs Assessment of Complex Trauma among Refugees and Asylum Seekers in Brighton and Hove

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Refugee Radio is a charity that supports refugees, asylum seekers and vulnerable migrants. The organisation has run a weekly mental-health support group since 2011, focused on those suffering from PTSD as a result of traumatic experiences.

Glossary
BME: Black and Minority Ethnic
PTSD: Post-Traumatic Stress Disorder
EMDR: Eye Movement Desensitization and Reprocessing, a treatment for PTSD
Asylum Seeker: A person who has left their country of origin and formally applied for asylum in another country but whose application has not yet been concluded.
Refugee: In immigration law, a refugee is person who has had their claim for asylum accepted by the government. Outside of this, a refugee can mean any person who has been forced to flee their home, including internally displaced persons.

Summary
There is a systematic failure across Brighton and Hove to respond to the mental health needs of refugees and asylum seekers. This is a local abnormality that is not reflected in national practices and is not simply as subset of broader health inequalities amongst the BME population: this is specifically a repeated and widespread inability or refusal to diagnose and treat PTSD for refugee patients.

Introduction
Refugees and asylum seekers, by definition, come from countries where war, torture and sexual violence are more prevalent and by definition will be more likely to have experienced these themselves. Some studies have found rates of PTSD in the refugee population as high as 50%.

And yet our assessment has uncovered a systematic failure of the local health system to diagnose and treat PTSD in this population dating back for at least 10 years. Our anecdotal evidence from practitioners suggests that this issue is more acute than among similar high-risk groups such as former members of the armed forces.

PTSD is serious and suicide rates are high in this client group. PTSD can be curable through methods such as EMDR but this requires adequate diagnosis and treatment.

Whilst there is co-morbidity with depression, the consistent misdiagnosis of refugees with PTSD as simply having depression is a critical problem. Clinical depression is largely manageable through medication and counselling whereas PTSD is actually curable. There is little evidence that treatments for depression have a positive impact on the alleviation of PTSD. The subsequent knock-on effect of suicide and self-medication is tantamount to a public health issue, and there is a significant cost-benefits analysis justification for increased intervention in this area to prevent the impacts of poor mental-health in this community including integration, isolation and longterm unemployment.

Background

Refugees in our area do not trust health services because they don't understand them, so they delay seeking help until they reach crisis point (Brighton & Hove Joint Strategic Needs Assessment Summary 2011; the State of the City Report 2011; NHS Qualitative Study of BME Mental-Health and Wellbeing in Brighton & Hove 2012). Then it is often too late to help. Refugee communities also fail to secure treatment because of cultural obstacles and the stigma about mental health from their countries of origin (Improving Mental Health For Refugee Communities, An Advocacy Approach, Mind 2009). Even though they are more likely to suffer, they do not talk about it. This affects their ability to get treatment, their opportunities to integrate and can put their asylum claims in danger (Mind, 2009).

In 2012 we contributed to the British Red Cross beneficiary-led needs assessment of refugees and asylum seekers in Sussex. The main gaps in service-provision identified were health and support services for those with mental-health needs. The gap was particularly acute in East Sussex where it was "putting a strain on services and having a damaging effect on those in need, preventing them from integrating and leading a normal life" (Metters, A. Refugees and Asylum Seekers, Sussex Needs Assessment, British Red Cross, June 2012).

Refugees are nearly twice as likely to experience mental-health problems than the average, especially with PTSD (Tribe, R. Mental Health of Refugees and Asylum-Seekers, Journal of Advances In Psychiatric Treatment. 2002 8: 240-247; No Health Without Mental Health: A Cross-Government Mental Health Outcomes Strategy For People Of All Ages, Department Of Health, 2011; A Shattered World: The Mental Health Needs Of Refugees And Newly Arrived Communities, Migrant & Refugee Communities Forum & CVS Consultants, 2002).

Recent research by the Department of Social Policy and Intervention at the University of Oxford indicates that one third of asylum seeking children are likely to suffer from PTSD (Bronstein, I., Montgomery, P. & Dobrowolski, S. (2012). PTSD in Asylum-Seeking Male

Adolescents from Afghanistan. Journal of Traumatic Stress. Volume 25. (Issue 5).p. 551–557).

Refugee Radio was founded in response to the results of a consultation exercise in 2008 with over 1,000 refugees, asylum seekers, volunteers and professionals. The consultation revealed massive unmet issues around isolation and integration, even amongst refugees currently accessing governmental and voluntary integration services. At the same time our founders collaborated on a chapter for the book Community University Partnerships (Routledge, 2008), with Research Fellows from the Universities of Sussex and Brighton. This revealed social exclusion and cultural isolation amongst refugees that bordered on segregation.

Refugees in our area do not feel like they are part of things. During one evaluation in 2010 they told us they have been scapegoats. Respondents to our questionnaires stated that they felt vilified and discriminated against. They feel they are still seen as outsiders. This prevents them from participating in their new community, creates intergenerational barriers and a heritage of exclusion for the future.

There is also exclusion through poor employment opportunities and knowledge of services. There are about 6,000 asylum seekers and refugees just in Brighton and Hove. Our 2012 research shows they are underemployed, unemployed, often on benefits, not realising their potential. They lack access to education and training. They have low horizons. People who trained as doctors, lawyers and teachers are now driving taxis. These problems have intergenerational effects.

Refugees and asylum seekers are further isolated and inhibited from participating in society by social and language barriers. This prevents them from engaging confidently with the host community and accessing support. There is a need for activities that enable refugees and asylum seekers to cross these barriers and communicate with the host community

Refugees and asylum seekers have a particular set of issues before they even arrive in the UK which determines aspects of their lives and their ability to integrate in the community. But rather than support their integration, the ever-changing policy on asylum has unfortunately had a negative impact on community cohesion (Community Cohesion and Migration, Refugee Council, January 2008). This cohesion is further undermined by financial barriers. A joint report by Oxfam and the Refugee Council reveals that refugees and asylum seekers are suffering from poverty levels and hardships unacceptable in a civilised society. Asylum seekers' basic needs are not being adequately met by current state provision (Poverty and Asylum in the UK, Oxfam, July 2002).

Refugees and asylum seekers are further isolated and inhibited from participating in society by social and language barriers (Building Bridges: Local responses to the resettlement of asylum-seekers in Glasgow, Scottish Centre for Research and Social Justice, 2004 & Learning to Live Together: Developing Communities with Dispersed Refugee People Seeking Asylum, Joseph Rowntree Foundation 2005). This prevents them from engaging confidently with the host community and accessing support (A Civilised Society: Mental Health Provision for

Refugees and Asylum-Seekers in England And Wales. Mind, 2009). To compound this, the media coverage of refugees and asylum-seekers is frequently negative (a report by ICAR 2008, quoted in A Civilised Society- MIND, 2009).

Reports like these demonstrate the need for activities that enable refugees and asylum seekers to cross these barriers and communicate with the host community. This way they can promote a more positive understanding of their situation and the hardships they need to overcome. Otherwise, the consequences of the hostility towards refugees and asylum-seekers and the restrictive policies on healthcare, support and employment are to socially exclude and marginalise an already vulnerable group of people, both exacerbating existing health problems and causing mental distress (ibid).

Disabled refugees and asylum seekers, including people physically and mentally harmed by torture in their home countries, already find themselves isolated in Britain without proper support from social services (Disabled People in Refugee and Asylum Seeking Communities, Social Policy Research Unit, University of York, September 2002). Health issues, isolation, communication difficulties and a lack of basic information about services and benefits are among the major problems they face (ibid). Again, this demonstrates a link between communication and health/social engagement.

Refugee and Asylum Seeker Interviews

In 2014-2015 we interviewed a selection of refugees and asylum seekers through the auspices of the Refugee Radio Community Resilience Project. The interviews were designed and conducted as a participatory research project with an asylum seeker who was volunteering with Refugee Radio. We interviewed people who were beneficiaries of the project as well as people who were not using the project to ensure balance.

In all of these cases people who obviously suffered PTSD were not diagnosed by their GP. This includes people who were prescribed painkillers for the effects of visible torture. They were not given any information about the condition. Approximately 70% were prescribed sleeping tablets. 50% were prescribed anti-depressants although there is no support that this is effective. 100% of those who did receive a diagnosis from their GPs were told they had depression. 100% of all cases received no information on PTSD. Just one case received EMDR and this lasted for one session.

> Mr K: *"The health authority don't see. People look different so they see them different. Doctors have to learn from the patient. Have to learn from him and understand him but it is not like that in the NHS. They have to separate the, patient by patient as they have different experiences- torture, war, lost friend- what matters is how it affects them. Like lottery- need to try to do it. The local authority is too far from understanding PTSD. Have to learn from people. I have good days and bad days."*
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> Mr K suffered torture, including visible injuries such as the removal of several fingernails. He presented to the GP in 2003 with insomnia and nightmares. It should have been obvious from the injuries and the fact he was an asylum seeker that

trauma had been present and that PTSD was likely, but the GP stated that he did not understand why Mr K. felt in danger in Brighton. He prescribed painkillers, Metazapine and sleeping tablets for 10 years before referring Mr K. to a psychiatrist who told him the problem was because he was an asylum seeker and that it would go away if he was allowed to stay in the UK (when in fact it actually got much worse at that point). The only diagnosis was that he was "under pressure from the Home Office". With his own research in the library he discovered PTSD as a proposed diagnosis. He has met many refugees who are self-medicating with drugs and alcohol. He has not been able to work or maintain a relationship. His experiences in detention and as a failed asylum seeker made his problems much worse. "Four, five years in the cage of trauma. Didn't go out. So angry as a refused asylum seeker appealing refusal. Everything felt out of control. With nothing to do you just harm yourself."

Mr M: Witnessed his parents' execution by rebels who then recruited him as child soldier. His sister was lost and he has never found her. Escaped to another country where he lived as a street child and was beaten half to death by police. Escaped to the UK where he was imprisoned and then hospitalised in an attack by another traumatised refugee who was self-medicating with drugs. Presented to the GP with stress and insomnia. It should have been rudimentary to deduce by the visible scars on his face and the fact that he was a national of his country and yet living in the UK that trauma had been present. He was prescribed anti-depressants that did not help and sleeping tablets. He was referred to the BME psychotherapeutic counsellor who provided a few months' counselling and a session of EMDR. A year later on his Aunt's death, he discovered that she was secretly his real mother. He was referred for bereavement counselling. He stated that he has never heard of PTSD. He has made suicide attempts and six months ago was incapable of work. He has received no other treatment.

Mrs H: Suffered from domestic violence, war, displacement, torture and sexual violence. During the months we worked with her she was incapacitated by bouts of crying at every weekly support group meeting. She had never heard of PTSD. She was prescribed anti-depressants. They did not help.

Mr S: Suffered from torture and rape in prison including electric shocks and genital mutilation. He also suffered from a public beating due to his sexuality. He presented to a GP as an asylum seeker with insomnia, nightmares and night-terrors: "I wake up at night. Shout, scream". But he was refused any treatment whatsoever and was told "When you get your asylum you will be fine." Over a year later he saw another GP and was prescribed diazepam, what he believed were "sleeping tablets" but are in fact just tranquilisers. After help from his housing support worker he was able to get a referral to the local BME psychotherapeutic counsellor, for 6 sessions. He found that the counsellor allowed him to talk and helped him most through the referral to Refugee Radio. He has attempted suicide in the last year and feels suicidal now. He stated that he had never heard of PTSD. He has received no other treatment and remains incapable of work. His experiences in the UK have compounded his feelings:

"Detention. Very bad, nearly similar to torture- people shout, treat you like criminal, locking you inside, banging doors, no difference between prison."

Mr I: Suffered from torture in prison, a shooting by the police and a machete attack. He has severe mobility issues. He saw Dr Wastia of St Peter's Medical Centre who referred him to the BME psychotherapeutic counsellor. He only waited a few weeks for the referral and found the support helpful. Was prescribed painkillers, sleeping tablets and anti-depressants. Stated that he had not heard of PTSD.

Mr Q: Suffered from torture in prison. Presents with morbid preoccupation with the past and insomnia and nightmares. Receives no treatment. Has no knowledge of PTSD. Copes with the insomnia by driving a taxi at night, often in a state of exhaustion. Is one of dozens of former refugees from his country driving a taxi at night.

Stakeholder interviews

We have discussed this problem with a range of local stakeholders, some of them in one-to-one meetings and some in group meetings with the Refugee Radio Community Resilience Project Support Group:

- Melanie Barnard, Clinical/Operational Manager, Mental Health Armed Forces Champion, BHT Threshold Womens Services & Mental Health & Wellbeing Services
- Candy Barrett, Health Visitor Specialist: BME Team
- Lucy Bryson, Community Safety Manager – Refugees and Migrants
- Kelly Cahill, Talking Therapies Lead for the Brighton and Hove Wellbeing Service;
- Dr Liam Connell, Director, Centre for Research in Twenty-First Century Writing and co-ordinator of the 2015 Conference on Migration and Marginality
- David Pinder, BME Communities Development Worker, The Trust for Developing Communities
- Angela Etherington, Peer Support Worker, Mind
- Rob Jarrett, Chair of Adult Care & Health Committee and the Health and Wellbeing Board
- Hanno Koppel, Black Minority Ethnic Psychotherapeutic Counsellor Brighton and Hove Wellbeing Service
- Ben Monro, Destitution Project Assistant, British Red Cross
- Magda Pasiu, Health Watch Engagement and Communications Co-ordinator
- Dr Ines Santos, Senior Clinical Psychologist, Major Trauma Team, Clinical Health Speciality, Complex Care Pathways
- Katherine Turner, Doctors of the World
- Dr Adrian Whittington, Director of Education and Training, Trust Strategic Lead for Psychology and Psychological Therapies Training, Workforce and Governance, Consultant Clinical Psychologist

It was clear from these meetings and interviews that there is still a significant need in the local area of Brighton and Hove as well as East and West Sussex around refugee mental health and especially PTSD. We have been told that health is a priority and that trauma services are available but we have also been told that vulnerable people are not accessing mainstream health services and that in our area, as opposed to London, trauma services are not treating refugees in numbers that reflect the demographics of the local refugee population. We are also told that the safeguarding managers at the Royal Sussex A&E are coming across increasing numbers of people who have been trafficked into the area and

that there are around two dozen Syrian refugees being resettled in the area in the coming months, both of which indicate an increased and/or varied level of need in the future.

Referrals

We contacted various people within the NHS to ascertain the best referral routes for refugees with PTSD. We were advised to request GPs to complete BIC referral forms or that patients could complete these themselves. They would then be assessed as to their stability and personal resources and if they presented with symptoms of PTSD they should progress to treatment. We decided to undertake referrals ourselves to test if we could assist people into the longterm treatment that they wanted to access and also to see if we could find out where the systematic blockages might lie.

We made referrals for two individuals in 2015, both of which triggered assessments. The first assessment resulted in the patient being referred back to the local BME psychothereaputic counsellor, who had seen him the previous year for counselling. The patient did not mind seeing the counsellor again but had specifically wanted to access EMDR therapy through the new Trauma Clinic. We were not present at the assessment meeting so are presuming a decision was made that the patient needed to stabilise first before he could progress to EMDR but no follow-up plans were made so it is unclear how that would ever subsequently happen.

For the second assessment we opted to accompany the patient. The assessment resulted in a referral for a course of EMDR therapy. It is worth noting that the patient did present as suicidal but this was not seen as a stability barrier. This is entirely appropriate in this case but raises a further question as to why the first referral did not proceed. Another point worth noting is that the patient professed no knowledge of PTSD at the assessment even though this had been discussed at considerable length over the proceeding months and even hours before the assessment. This raises a question mark over some of the anecdotal reports of GPs not addressing PTSD at initial presentation, as it could be that the patients are simply unable to recall the term (for reasons presumably including level of English and level of education as well as symptomatic problems with memory).

Recommendations

1. As the prevalence of PTSD in this population is so high, the test threshold must reflect the known probability.
2. Therefore any patient from a refugee-producing country who presents to a GP with <u>any</u> mental health issue or any visible injuries/scarring should be screened for PTSD. This is compatible with NICE guidelines [CG26].
3. Refugees or asylum seekers with symptoms of PTSD should not merely be diagnosed with depression, prescribed anti-depressants or referred simply for counselling.
4. Those who do not English as their first language should be provided with written advice on PTSD, ideally in a bilingual format so that it can be understood both by the patient and by anyone assisting them in the future
5. Those who are diagnosed with PTSD should have a clear referral pathway to suitable long-term treatment such as EMDR.

6. Those who are deemed assessed to be inappropriate referrals for EMDR due to insufficient stability and personal resources should have a clear pathway for reassessment following alternative treatment.