Article

# Participatory lived experience research: Barriers and enablers for social inclusion for people with psychosocial disability, in Afghanistan?

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## Abstract

Mental health disorders are common in low and middle-income countries (LMICs), creating vulnerability to adverse outcomes. Despite this, there is a gap in understanding the perspectives of people with psychosocial disability (PPSD). A mental health project from Afghanistan collected lived experience narratives through semi-structured interviews with PPSD and family members. The interviews focused on individual experiences of barriers and enablers to social inclusion. Four main barrier themes were elicited: symptoms of mental disorders interfering with social inclusion, unhelpful family attitudes and behaviour, unhelpful community attitudes and behaviours and lack of access to quality mental health services. Three prominent enabler themes were also identified: family support and understanding, access to quality mental health services and supportive community attitudes and behaviours. Connection to supportive community and support from family was a critical finding. These results reinforce the importance of hearing from lived experience to help shape both service and community development programmes.

### Key implications for practice

- Engaging with the lived experience of psychosocial disability is beneficial, necessary and possible in LMICs
- Understanding key, context-specific barriers and enablers for PPSD will improve wellness, recovery and inclusion
- In the Afghan context, working with families and communities to promote supportive environments towards mental health will improve social inclusion and access to services.

**Keywords:** Barriers, enablers, lived experience, mental health, psychosocial disability

## Introduction

The International Assistance Mission (IAM) has been working in mental health in Afghanistan for over 20 years. IAM conducted participatory research to empower the Afghan people with psychosocial disability (PPSD) and their families to share their lived experiences of barriers and enablers to social inclusion, to shape IAM's future work in mental health. A social model for understanding mental illness was adopted, to explore broader, lived experiences including family, community, social determinants of mental health and cultural contexts. The research uses 'psychosocial disability', while also acknowledging environmental and social factors influencing PPSD's lived experience. The research seeks a deeper understanding of the barriers PPSD face to full inclusion and participation, as outlined in UN General Assembly (2006).

The global mental health movement has achieved significant momentum, highlighting the inequalities in mental health systems between high-income countries (HIC) and low and middle-income countries (LMICs) (Patel, 2014). The treatment gap, the percentage of people needing, but not receiving adequate treatment, is estimated to be 76% to 90% in LMICs (Patel *et al.*, 2010). Patel proposed three

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strategies to reduce the gap: increased numbers of psychiatrists and other mental health professionals, increased involvement of appropriately trained non-specialist providers and active involvement of people affected by mental disorders (2010). Scaling up access to medical expertise and treatment through task shifting has received considerable attention (Ventevogel, 2014). However, the active involvement of people affected by psychosocial disability has not received as much attention in LMIC.

*'Historically people with mental health problems have lacked a voice. Neither they nor their families have been involved in decision making on mental health services, and they continue to be at risk of social exclusion and discrimination in all facets of life.'*
[World Health Organization (WHO), 2010, p. 2].

For decades in HIC, people with lived experiences of mental illness (personal experience of living with psychosocial disability or caring for someone else) have increasingly participated in planning services and mental health policy review (Lester & Tritter, 2005; Mulvany, 2000). However, Lempp *et al.* (2018) in Ethiopia, Nigeria and Nepal found very low levels of mental health service user participation in mental health decision-making.

Investigating lived experiences of psychosocial disability in HIC has increased over the past decade and has highlighted the experience of stigma and discrimination (Corrigan, 1998; Corrigan, River, Lundin, Wasowski, Campion, & Mathisen, 1999). Literature from LMIC shows experiences of stigma and discrimination are also seen. A study in India found that 42% of people with schizophrenia felt that family members had discriminated against them (Shrivastava *et al.*, 2011). Researchers in Mozambique found three main reasons for the high treatment gap: stigma and lack of awareness, limited material and human resources, and insufficient research capacity (Sweetland *et al.*, 2014). A lack of access to medication, financial problems and the burden of taking care of the patient were found to be commonly occurring obstacles to mental health care in Vietnam (Van der Ham, Wright, Van, Doan, & Broerse, 2011).

Within Afghanistan, mental health research has focussed on the high levels of stress and distress experienced by the Afghan people due to the long standing conflict (Miller & Rasmussen, 2010; Trani & Bakhshi, 2013; Panter-Brick et al., 2008). However, there is little research on the lived experience of psychosocial disability in Afghanistan. In a summary paper on the state of mental health in Afghanistan, Sayed (2011) reports on the high levels of stigma and its consequences for people with epilepsy in Afghanistan.[1] Another study, from Eastern Afghanistan, investigated support seeking behaviour of community members: 98% of people named 'Allah' as their first resource of emotional support and 81% named a family member as their second choice (Scholte *et al.*, 2004).

Generating information about effective interventions to reduce stigma and discrimination in LMICs is now an important mental health priority (World Health Organization, 2013). Understanding these local and contextual experiences from LMICs are important in shaping approaches to scale up access to treatment and strengthen social inclusion (Kirmayer & Pedersen, 2014). To our knowledge, this is the first time the Afghan mental health service providers and project workers have engaged with lived experience research.

## MATERIALS AND METHODS

### Design

A qualitative study using semi-structured interviews was used to explore the lived experience of people with psychosocial disabilities and their families in Afghanistan.

A list of possible barriers and enablers was compiled by a group of project workers who have worked at community level with PPSD and their families, which created the initial structure for the semi-structured questionnaire. The semi-structured interview initially used open questions asking participants' views on barriers and enablers and then asking more specific questions surrounding barriers and enablers raised. After each interview, the interview questions were adapted to include new content suggested by the participants. The analysis followed a deductive content analysis (Elo & Kynga, 2008) using the established framework of barriers and enablers above.

### Participants

Interviews were conducted with 10 people in two western provinces in Afghanistan: four PPSD and three caregivers from Herat province and three PPSD from Badghis province [Table 1].

**Table 1: Participant list**

| Participant number | Participant description | New or follow-up patient | Marital status |
|---|---|---|---|
| 1 | Young woman with depression, Badghis | New | Unmarried |
| 2 | Young man with epilepsy, Herat | Follow-up | Unmarried |
| 3 | Older man with depression, Badghis | New | Married |
| 4 | Middle aged woman with depression, Badghis | Follow-up | Married |
| 5 | Older lady depression, Herat | Follow-up | Married |
| 5a | Adult daughter of 5 | Follow-up | Married |
| 6 | Middle aged lady with psychosis, Herat | Follow-up | Married |
| 6a | Husband of 6 | Follow-up | Married |
| 7 | Young woman with epilepsy, Herat | Follow-up | Unmarried |
| 8a | Mother of a school age girl with anxiety and speech problem, Herat | New | Unmarried |

Convenience and selective sampling methods were utilised. Participants were selected from the waiting room of the Mental Health Training Centre, Herat City, and from the mental health outpatient room of the Badghis Public Hospital in August 2016. Selective sampling was achieved by looking at the list of attending patients in the triage room on the day of interviews and choosing as diverse a group as possible, based on age, marriage status, diagnosis, new/follow-up and gender. Participants were approached and asked if they were willing to be recorded while interviewed, no one declined. PPSDs attending with care givers were given the choice to be interviewed alone or separately. The interviews were conducted by the first two authors.

## Analysis

The interviews were recorded in, and transcribed into, Dari, a major language of Afghanistan. The Dari transcript was translated into English and checked by the second author who has knowledge of both languages.

Interviews were read through by the first and second authors to gain overall understanding prior to coding. The English interviews were reviewed by the first author and coded deductively according to barrier and enabler categories. Codes with related meanings were grouped into themes. These themes were reviewed by the second author and mutually agreed on. Themes were counted to identify the most significant barriers and enablers by the first and second authors [Table 2].

# FINDINGS

Fourteen themes were identified from the interview transcripts. The most frequently mentioned barrier and enabler themes are reported in detail, followed by a summary of the barriers and enablers mentioned by a minority of participants.

## Barriers to social inclusion

### Symptoms of mental health

Not willing to participate in community life: Participants, all with moderate-to-severe depression described how their depressive symptoms of lack of interest, sadness and lack of enjoyment made inclusion in community life difficult: '*my illness causes me social problems as I just want to sit alone and cry a lot.*' Participant 5. One participant with epilepsy reflected, *'But at the beginning I couldn't go anywhere, I had 3–4 attacks each day.'* Participant 7.

Symptoms that prevent normal participation in religious activities: Symptoms of low energy and tiredness created barriers to actively participate in religious activities important for community inclusion: *'I used to do congregational prayer, but since I got this problem I prefer to do it alone at home. I was reciting holy Quran. But now I feel too tired to do it.'* Participant 3. *'As I feel sleepy most of the time I miss the morning and evening prayer.'* Participant 4. A participant's husband expressed, *'When I come back from the mosque, she is still sleeping, not praying. I wake her to pray and still she does not pray.'* Participant 6a.

Disturbed emotional states prevent normal participation in family life: Participants described anger and frustration resulting in violence or threats towards their families, creating a barrier for them to engage in family life and wider consequences: *'last year, at least 4–5 times a day, I was hitting the children and swearing. I would not let anyone be near me and I broke a lot of things.'* Participant 6. *'I used to hit everyone, my children and my husband, I told them I would burn the house down and leave them. I asked for a divorce. I thought my head would explode.'* Participant 5.

### Unhelpful family attitudes and behaviours

Excluding or restricting from normal life: Participants described feeling not listened to or consulted on family decisions and having their movements restricted, excluding them from normal family life: *'I have a daughter who looks after me, but she doesn't let me go out.'* Participant 6. *'No one consults me for anything, even about my own life.'* Participant 4.

Name calling and judging from family: Participants described feeling ostracised, unaccepted, teased and called names, like 'crazy'. Beliefs about the illness made it difficult for people to accept them: *'My brother said that I must have got a jinn from going out to the fig tree in the night.'* Participant 7.

Physical violence from family: For some female participants, there was violence occurring at family level: *'since my husband married for [the] second time, his behaviour with me is changed and he has started being violent to me. One time the violence was very tough and caused the breaking of my shoulder bone, the broken bone is visible now.'* Participant 4. *'They beat me and hurt me. My husband's brother's wife also beats me.'* Participant 6.

Lack of anyone in family who understands their problems: One participant expressed the barrier as the emotional burden of not being understood: *'I do not feel needy due to lack of food or clothes, but what gives me pain is that in this period of my life no one (in my family) understands me.'* Participant 1.

Family not meeting physical needs: Another highlighted the barrier as a lack of physical help from the family: *'my husband does not provide enough food and clothes for me and my children.'* Participant 4.

### Unhelpful community attitudes and behaviours

Excluding or restricting from normal life: Participants expressed being ridiculed at public community events because of unusual behaviours leading to community exclusion: *'during one wedding I had a bad time and everyone came to stare at me, because of this, I avoided many weddings.'* Participant 6. *'They (community) treat her (Participant 6) differently, they say things like "don't disturb her because she is sick." and "she doesn't behave well with them." People do avoid her, people don't come to our house in the afternoon.'* Participant 6a. *'They (wider community) tell her to not continue this craziness or she*

**Table 2: Barriers and enablers**

| Category | Category of barrier | Number of participants who mentioned this theme (total = 10) | Which people mentioned this theme |
|---|---|---|---|
| **1** | **Symptoms of mental health** | 8 | 1,2,3,4,5,6,6a,7 |
| 1.1 | Not wanting to participate in community life | 6 | 1,3,4,5,6,7 |
| 1.2 | Symptoms prevent normal participation in religious activities | 4 | 3,4,5,6a |
| 1.3 | Disturbed emotional states prevents normal participation in family life | 2 | 5,6 |
| **2** | **Unhelpful family attitudes and behaviours** | 8 | 1,2,4,5,6,6a,7,8a |
| 2.1 | Excluding or restricting from normal life | 5 | 2,4,6,6a,8a |
| 2.2 | Name calling and judging from family | 4 | 1,5,6,7,8a |
| 2.3 | Physical violence from family | 4 | 4,5,6,8a |
| 2.4 | Lack of anyone in family who understands their problems | 2 | 1,4 |
| 2.5 | Family not meeting physical needs | 1 | 4 |
| **3** | **Unhelpful community attitudes and behaviours** | 8 | 2,4,5,5a,6,6a,7,8a |
| 3.1 | Excluding or restricting from normal life | 6 | 4,5,6,6a,7,8a |
| 3.2 | Name calling and judging from community | 5 | 2,4,5a,6,8a |
| **4** | **Lack of access to adequate mental health services** | 7 | 2,3,4,6,6a,7,8a |
| 4.1 | Spending money and not being helped by faith healers | 4 | 4,6,6a,8a |
| 4.2 | Lack of understanding about mental health issues | 4 | 2,4,6,8a |
| 4.3 | Taking medical treatment which does not help | 3 | 2,3,7 |
| 4.4 | Lack of money stops adequate ongoing treatment | 1 | 4 |
| 4.5 | Lack of supportive male relative to help with access | 1 | 4 |
| **5** | **Economic or employment barriers** | 3 | 2,3,4 |
| **6** | **Difficulties with education** | 2 | 7,8a |
| **7** | **Restricted transport options** | 1 | 2 |

| Category | Category of enabler | Number of participants who mentioned this theme (total = 10) | Which people mentioned this theme |
|---|---|---|---|
| **1** | **Family support and understanding** | 10 | 1,2,3,4,5,5a,6,6a,7,8a |
| 1.1 | Help from family with access to medical services (see below for breakdown) | 6 | 1,2,4,5,7,8a |
| 1.2 | Being treated the same as everyone else in the family | 5 | 2,3,5,5a,7 |
| 1.3 | Advice and a listening ear from family | 3 | 1,2,6a |
| 1.4 | Feeling respected and cared for by family | 2 | 3,7 |
| 1.5 | Encouraged by family |  | 5,7 |
| 1.6 | Defended from community by family | 2 | 5,8 |
| 1.7 | Included in family decisions | 2 | 6,6a |
| **2** | **Access to quality mental health services** | 7 | 1,2,3,4,5,6,6a,7 |
| 2.1 | Getting treatment that reduces attacks or symptoms | 6 | 2,3,5,6,6a,7 |
| 2.2 | Treatment that is not expensive | 3 | 4,5,7 |
| 2.3 | Access due to mother's help | 3 | 1,2,8a |
| 2.4 | Access due to father's help | 2 | 4,7 |
| 2.5 | Access due to relative's help | 1 | 5 |
| **3** | **Supportive community attitudes and behaviours** | 5 | 2, 3,4, 7,8a |
| 3.1 | Treated the same as everyone else by the community | 3 | 3,7,8a |
| 3.2 | Social contact with people from the wider community | 2 | 3,8a |
| 3.3 | Not teased or disrespected | 2 | 3,4 |
| 3.4 | Able to marry | 1 | 2 |
| **4** | **Meaningful work, including economic benefits of work** | 3 | 2,7,8a |
| **5** | **Mental Health literacy including self-understanding** | 2 | 2,7 |
| **6** | **Spiritual practices** | 2 | 2,3 |
| **7** | **Inclusion in education** | 1 | 8a |

*will become ridiculous.'* Participant 5a. Participants expressed how these community attitudes and behaviours restricted their future marriage possibilities: *'if she [is] starts to speak, maybe she can marry. If she stays like this, no one will take her.'* Participant 8a. *'Maybe it will (affect my chances of marriage), in my idea it should not affect [it], but maybe it will have an effect.'* Participant 7.

Name calling and judging from community: Community belief in the spiritual nature of the illness resulted in participants feeling disbelieved and judged: *'some people say I have an evil spirit and I totally don't believe that. Some people think I am not mentally fast. Some people think I am making excuses for myself when I tell them that I have a medical condition, perhaps they don't believe me.'* Participant 2. This was particularly experienced by participants with epilepsy.

### Lack of access to adequate mental health services

Spending money and not being helped by faith healers: Cultural beliefs about help seeking were a barrier to accessing effective help. First help was from faith healers and sheikhs, and treatments were ineffective on their own. *'I have taken her four times to one faith healer and once to another one. It costs about 50 afs, I don't have much to give, so I give what I can. Today is the first time she sees a doctor.' Participant 8a. The cost of faith healers can be prohibitive: 'they encouraged me to see some faith healer or Sheikh. In the past I believed so, thus I went to many faith healers, but got no positive effect. I spent lots of money paying faith healers, but no help.'* Participant 8a.

Lack of understanding about mental health issues: Participants shared that the lack of clear information about mental health problems made it difficult to access appropriate treatment: *'no one has ever told me anything about mental health, just from the staff at this clinic today I have heard about mental health for the first time.'* Participant 8a. Participant 2 spoke about his illiterate brother saying, *'messages about mental health need to be at the level for the farmers. Some TV slogans [about mental health] are in too high Dari to be understandable. My brother is illiterate and I have to translate for him'*.

Taking medical treatment which does not help: Even when participants with epilepsy did seek medical help, obtaining good-quality treatment was an issue: *'the doctors in the city gave many, many medicines; they didn't really help me much at all.'* Participant 7. *'I first went to a doctor in the city, but they didn't refer me or treat me.'* Participant 2.

Lack of money stops adequate ongoing treatment: Accessing services has an economic burden and some participants expressed this restricted access to adequate treatment: *'I went to a mental health doctor one or two times, but due to the poor economy, I couldn't continue visiting the doctor.'* Participant 4.

Lack of a supportive male relative to help with access: Accessing treatment for women in Afghanistan requires a male companion, which restricts access: *'since I have this problem, my husband never took me to a health facility to treat me.'* Participant 4.

### Economic or employment barriers

The compounding effect of poverty on mental health and social inclusion was expressed: *'since I have this problem, I resigned from my official job.'* Participant 3. The resulting poverty was a barrier to further community engagement: *'it is really the poverty, not my illness, that stops me from studying extra classes'*.

### Low level of education

Poor engagement with education was the most significant barrier to social inclusion for one participant: *'I had to leave school after 6th grade. I decided to leave school because of this problem.'* Participant 7. *'It is difficult for her in class because she can't speak.'* Participant 8a.

### Restricted transport options

Restriction on use of transport due to epilepsy was a barrier: *'I was at my work and my manager told me to take the motorbike and go to some places and I told him I can't ride a motor bike because of the epilepsy.'* Participant 2, who was able to negotiate with his manager to keep his job.

## Enablers of social inclusion

### Family support and understanding

Help from family with access to medical services: Family support in health seeking enabled participants to feel included in society: *'my father is a leader in our community, he himself saw doctors to ask advice about me and the doctor said to send me to the clinic.'* Participant 7.

Being treated the same as everyone else in the family: Participants cited that being treated the same as everyone else enabled them to participate socially: *'they (family) treat me the same as they always did, they still visit us at our house and we go to their houses. No one is afraid of me.'* Participant 5.

Advice and a listening ear from family: Being listened to and receiving advice made some participants feel included: *'if I need to talk about my problems or need emotional support, that mostly comes from my mother.'* Participant 2.

Feeling respected and cared for by family: Meeting physical needs was enabling: *'I don't have any problem from my family, they care well for me, and even my wife helps me to take a bath.'* Participant 3.

Encouraged by family: Words of encouragement from family members helped some participants to feel included in family life: *'my little brother is a mullah, he encourages me that this is a health problem and can be cured.'* Participant 5.

Defended from community by family: Some participants and their relatives felt socially included by their relatives defending them publicly: *'I am the one who tells them* *[boys and girls on the street] not to be violent and tease her.'* Participant 8a.

Being included in family decisions: Being included in major family decisions was experienced as inclusion: *'I was not happy for my daughter to be engaged to one boy and they accepted what I said about that.'* Participant 6.

### Access to adequate MH services

Getting treatment that reduces attacks or symptoms: Participants living with epilepsy said that effective medical treatment allowing them to work increased their social inclusion: *'since coming to this clinic, things have improved for me. Since I started coming here I was able to start working as a tailor.'* Participant 7.

Treatment that is not expensive: The participants talked of effective versus ineffective services: *'I went to many doctors and then my husband told me there is a new clinic opening, and I came to this clinic. They gave me just 1 tablet that only cost 80 Afghani (about $1.20 USD) and I became better.'* Participant 5.

Access due to help from family: A variety of family members helped with access issues to mental health services, which participants linked to feeling included socially: *'today I could convince my mother that I need to go to hospital and that I have a problem.'* Participant 1. *'The times I went to doctors I got a loan from my father.'* Participant 4. *'One of my relatives who had same problem advised me to see mental health doctors in Herat.'* Participant 5.

### Supportive community attitudes and behaviours

Treated the same as everyone else by the community: Participants expressed connection to a supportive community as being treated the same as everyone else in society and having their illness understood: *'there is no difference in their behaviour, they are the same with me (as others). Because I am positive with them, they are positive to me. They have seen it (her epilepsy) and they know that this is a medical problem.'* Participant 7.

Social contact: Participants described how social contact with others in the community enabled social inclusion: *'I have no problem with people not wanting to be near me. My friends visit me, we sit together and speak.'* Participant 3.

Not teased or disrespected: Some participants with depression had not had experienced teasing or disrespect: *'no one called me words like crazy.'* Participant 3.

Able to marry: Eligibility for marriage was an issue for single participants: *'if I have enough money, I think I will be able to marry the same as everyone else.'* Participant 2.

### Meaningful work including economic benefits

Participants with well-controlled epilepsy shared that paid employment was their most significant enabler for social inclusion: *'I would say it is not such a big problem now, as I can now work. Perhaps it affects my life 20%.'* Participant 2.

### Mental health literacy

Increasing mental health literacy of the family enabled social inclusion: *'before we came to this clinic they (family/community) said she has a jinn, now they see that it is not jinn, but is physical problem.'* Participant 7.

### Spiritual practices

Participation in religious observation, in the same way as others, enabled male participants to feel socially included: *'I do Namaz (prayers) same as everyone else, there is no issue with Namaz.'* Participant 2.

### Inclusion in education

Education was valued as way of enabling social inclusion for a child participant: *'her father says she doesn't need to go to school, as we have no money, but I push all my daughters to read and write, including her, so that they can have better life.'* Participant 8a.

## DISCUSSION

It is unsurprising that lack of access to adequate mental health services is seen as a significant barrier and its presence as an important enabler. However, this small study shows that 'access' is a complex phenomenon, not simply a matter of more facilities or mental health professionals. The family had a key role for enabling access; through knowing about available mental health facilities, rather than only consulting local faith healers and practically supporting travel and treatment costs. The *Mental Health Gap Action Plan* provides countries with the support to adapt programmes for context (World Health Organization, 2016), and our work shows the importance of developing tailored programmes to address factors preventing or enabling access. Access factors are multifaceted and not only issues of health, requiring coordination, interdisciplinary working and a wider psychosocial understanding of the mental health context at all levels. The absence of 'social workers' in the Afghan mental health context limits this kind of wider understanding (Babury & Hayward, 2013). An increased focus on the social determinants of health could result from social workers, occupational therapists, peer workers or non-medical, community-based support workers working alongside counsellors and doctors. Incorporating PPSD in this process would show the urgent need for change and express the complex realities in the narrative.

The study did not specifically ask about stigma but instead asked for examples of helpful and unhelpful attitudes and behaviours in the family and community connected to social inclusion. There were differences in the barriers and enablers faced by people with different diagnoses and genders. The older man with depression experienced no barriers related to unhelpful family or community attitudes and behaviours. His family and community enabled his inclusion. The woman with psychosis experienced the most significant barriers. The two participants with epilepsy had experienced family and community barriers which reduced after effective treatment.

The complexity of stigma necessitates a multifaceted approach, including raising awareness, improving the affordability of treatment (World Health Organization, 2013) and building community cohesion. Scarcity of information regarding the causes of mental illness adds to stigmatising attitudes that are barriers to inclusion. Spiritual causes, former life, witchcraft and other beliefs can increase the social isolation and community misunderstanding faced by people with mental illness (Thornicroft, Rose, Kassam, & Sartorius, 2007). Medical information alone may not be effective in reducing stigmatising attitudes and behaviours. As Mathias, Kermode, Sebastian, Koschorke, and Goicolea (2015, p. 8) assert, ‘ . . . *emerging evidence suggests that stigma reduction intervention promoting a bio-medical model of mental illness may increase rather than decrease stigma*’. In our study, participants had experienced significant barriers that were unrelated to medical knowledge alone, such as exclusion, restriction and violence. Allowing people with psychosocial disabilities a voice in their communities and mass media approaches to increase general understanding about mental illness are considered more effective in reducing stigma (Mathias *et al.*, 2015).

The lived experiences of the barriers and enablers elicited in this study were influenced and shaped by unique societal challenges faced by the wider community in Afghanistan. Gender-related issues in Afghanistan, such as restriction on women’s movements outside of the house, forced early marriage, multiple wives, high levels of gender-based violence and low levels of female education were reflected in the stories of women’s lived experience and influenced the way barriers interacted with each other. More than half of the female participants had experienced family-based violence and referred to their experience of violence as a barrier to their personal recovery. This demonstrates the need for a primary prevention approach in Afghanistan, addressing the issues of gender discrimination, gender-based violence and gender stereotyping, as well as policy and legislation changes (World Health Organization, 2002). Violence towards children as a symptom of mental distress was evident and reported by others (Miller *et al.*, 2006). This study showed the need for screening and help for PPSD to prevent violence against children, although this is only one of the factors causing Afghanistan’s high levels of violence against children. Social exclusion mechanisms in Afghanistan relate to individual’s failure to conform to societal and religious, role-based norms (Trani & Bakhshi, 2013). In our study, mental health symptoms such as anhedonia (lack of enjoyment of anything) impacted societal norms of visiting and receiving visitors and was expressed as a significant barrier to social inclusion. When assessing recovery and mental health function in the Afghan context, attendance at important community and religious events was a key factor.

The ‘what matters most’ approach analyses the most significant local cultural components and how they touch mental health (Mascayano, Armijo, & Yang, 2015) and would help to further breakdown the specific cultural components of stigma. Cultural and gender-based norms of public compliance with modest dress and behaviour contribute some of the high levels of stigma faced by people with epilepsy and psychosis, particularly for women. Further study of these issues would be helpful.

Economic stress as a barrier highlights the relationship between poverty and mental illness and the costs involved in health seeking in these contexts. Our results agree that poverty is deemed to be both a cause and consequence of mental illness, interacting in a negative cycle (World Health Organization, 2010). Other studies found economic stressors were significantly impacting individual and family resilience (Panter-Brick, Eggerman, Gonzalez, & Safdar, 2009) and that a regular income was a factor affecting the mental health status of the Afghan women (Shin, Kim, Liw, & Kim, 2009). This was supported by our study, where the paid occupation of two people with epilepsy was their most significant enabler of social inclusion. The results point to a need for organisations to support families and take account of access to development opportunities and economic pathways (Lund *et al.*, 2011; Rosenfield, 2012; Trani et al., 2015).

From the research process, the project team from Afghanistan learned that it was possible to ask about, record and analyse people’s lived experience with participants sharing more freely than expected. The research and project team have gained experience in the value and practice of engaging with lived experience and can more clearly see its role in shaping their project design.

There were new insights for the team into the unique role of mothers providing support and encouraging access to services, despite not usually being the decision maker of the family. There were also new insights into the relationship between violence and the experience of mental illness in Afghanistan.

There were signs of change in the situation in Afghanistan including engagement with public health messages, *‘the problem I have, I have seen written on billboards in the city as “mergi”, in my family we call it “mergi”’* (Participant 2), and motivation to change their society: *‘I discuss with people and try and persuade them that epilepsy is a disease’* (Participant 2). Another sign of change articulated an active approach to living with a psychosocial disability: *‘now it doesn’t affect my life so much, as I now understand I have to live with it. If I don’t go to weddings, it is not helping – if I can’t go out I feel worse, so now I have decided to go everywhere’* (Participant 7). These positive changes encouraged the project team that PPSD in Afghanistan would be able to advocate for changes in their communities and government, even for policy changes.

The new insights gained from this research informed some significant changes to the IAM Afghan Mental Health Programming including better practices of involving lived experience in our work, programming and advocacy for policy change addressing the social components of mental illness and to reduce violence against children and support positive parenting.

Mental health programmes should seek to understand the intersectionality's which not only predispose a person to developing mental illness, but also impact on that person's lived experience of the illness and has significant ramifications for treatment, recovery and inclusion (De Menil & Glassman, 2016).

## Limitations

The findings of this pilot study cannot be generalised because the research group was small and the qualitative nature of the study, but the findings suggest further study. As participants were selected from health facilities, there was bias towards people who already access mental health services, unrepresentative of all those with psychosocial disabilities in Afghanistan. Different results, following analysis and prioritisation, may have been obtained if PPSD themselves had been included in these processes. Asking open questions about barriers and enablers to social inclusion did not always lead to clear answers, necessitating prompts of possible barriers and enablers, inducing possible bias towards the ideas we suggested. A further refining of the questionnaire would have been useful. Work with more educated PPSD may have helped this process but would not have been representative of the situation in Afghanistan. In addition, participants may have not wanted to speak too negatively about close family members or activities connected to the organisations' project work. Future studies could consider asking people with psychosocial disabilities what would increase enablers and decrease barriers for improved inclusion and involve them in the design, analysis and the prioritisation process.

## CONCLUSION

This research shows that engaging with lived experience of psychosocial disability is possible in LMIC and having people share their personal experiences can be a significant part of the strategy to reduce barriers and increase enablers of social inclusion. The barriers to social inclusion at family and community levels are significant and work to change attitudes and behaviours will require varied interventions.

Enablers such as personal coping mechanisms, employment and participation in religious activities should be leveraged as key factors in wellness, recovery and inclusion. Access to development and economic pathways should be a core component of new approaches.

In conclusion, it is vital that a medical approach to mental wellness through improved access (more healthcare professionals, more access points, affordability) is augmented with a social determinant approach which strives to nurture an enabling environment for people living with psychosocial disability through dialogue and action with families and society, and most importantly, with the people themselves.

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## Presentation

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## Author contributions

Criteria for inclusion in the authors'/contributors' list: EA and AFN developed first draft of the paper; EA, AFN, HF and BA collaborated for the final draft. EA, EBA, HF and BA have agreed this manuscript.

## Conflicts of interest

There are no conflicts of interest.

## REFERENCES

Babury, M. O., & Hayward, F. M. (2013). A lifetime of trauma: Mental health challenges for higher education in a conflict environment in Afghanistan. *Education Policy Analysis Archives*, *21*, 68.

Corrigan, P. W. (1998). The impact of stigma on severe mental illness. *Cognitive and Behavioral Practice*, *5*(2), 201-222. doi:http://dx.doi.org/10.1016/S1077-7229(98)80006-0.

Corrigan, P. W., River, L. P., Lundin, R. K., Wasowski, K. U., Campion, J., & Mathisen, J. (1999). Stigmatizing attributions about mental illness. *Journal of Community Psychology*, *28*(1), 91-102.

De Menil, V., & Glassman, A. (2016). *Making room for mental health: Recommendations for improving mental health care in low- and middle-income countries*. Centre for Global Development. Available at: https://www.cgdev.org/sites/default/files/deMenil-Glassman-mental-health_0.pdf.

Elo, S., & Kynga, S. H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, *62*(1), 107-115. doi:10.1111/j.1365-2648.2007.04569.x.

Kirmayer, L. J., & Pedersen, D. (2014). Toward a new architecture for global mental health. *Transcultural Psychiatry*, *51*(6), 759-776. doi:10.1177/1363461514557202.

Lempp, H., Abayneh, S., Gurung, D., Kola, L., Abdulmalik, J., & Evans-Lacko, S., *et al.* (2018). Service user and caregiver involvement in mental health system strengthening in low- and middle-income countries: A cross-country qualitative study. *Epidemiology and Psychiatric Sciences*, *27*(01), 29-39.

Lester, H., & Tritter, J. Q. (2005). "Listen to my madness": Understanding the experiences of people with serious mental illness. *Sociology of Health & Illness*, *27*(5), 649-669.

Lund, C., De Silva, M., Plagerson, S., Cooper, S., Chisholm, D., & Patel, V., *et al.* (2011). Poverty and mental disorders: Breaking the cycle in low-income and middle-income countries. *Lancet*, *378*(9801), 1502-1514.

Mathias, K., Kermode, M., Sebastian, M., Koschorke, M., & Goicolea, I. (2015). Under the banyan tree – Exclusion and inclusion of people with mental disorders in rural North India. *BMC Public Health*, *15*(1), 446.

Mascayano, F., Armijo, J. E., & Yang, L. S. (2015). Addressing stigma relating to mental illness in low-and middle-income countries. *Frontiers in Psychiatry*, *6*(38), 1-4.

Miller, K. E., Omidian, P., Quraishy, A. S., Quraishy, N., Nasiry, M. N., Nasiry, S., & Yaqubi, A. (2006). The Afghan symptom checklist: A culturally grounded approach to mental health assessment in a conflict zone. *American Journal of Orthopsychiatry*, *76*, 423-433. doi:10.1037/0002-9432.76.4.423.

Miller, K. E., & Rasmussen, A. (2010). War exposure, daily stressors, and mental health in conflict and post-conflict settings: Bridging the divide between trauma-focused and psychosocial frameworks. *Social Science & Medicine*, *70*, 7-16. doi:org/10.1016/j.socscimed.2009.09.029.

Mulvany, J. (2000). Disability, impairment or illness? The relevance of the social model of disability to the study of mental disorder. *Sociology of Health & Illness*, *22*(5), 582-601.

Panter-Brick, C., Eggerman, M., Mojadidi, A., & McDade, T. W. (2008). Social stressors, mental health, and physiological stress in an urban elite of young Afghans in Kabul. *American Journal of Human Biology*, *627*(20), 1042-0533. doi:10.1002/ajhb.20797.

Panter-Brick, C., Eggerman, M., Gonzalez, V., & Safdar, S. (2009). Violence, suffering, and mental health in Afghanistan: A school-based survey. *The Lancet*, *374*(5), 807-816.

Patel, V. (2014). Transforming lives, enhancing communities – Innovations in global mental health. *New England Journal Medicine*, *370*, 498-501.

Patel, V., Maj, M., Flisher, A. J., De Silva, M. J., Koschorke, M., & Prince, M., Wpa Zonal & Member Society Representatives. (2010). Reducing the treatment gap for mental disorders: A WPA survey. *World Psychiatry*, *9*, 169.

Rosenfield, S. (2012). Triple jeopardy? Mental health at the intersection of gender, race, and class. *Social Science & Medicine*, *74*(11), 1791-1801.

Sayed, D. (2011). *Mental health in Afghanistan: Burden, challenges and the way forward*. Washington: The International Bank for Reconstruction and Development/The World Bank.

Scholte, W. F., Olff, M., Ventevogel, P., de Vries, G., Jansveld, E., Lopes Cardozo, B., & Gotway Crawford, C. (2004). Mental health symptoms following war and repression in Eastern Afghanistan. *Journal American Medical Association*, *292*(5), 585-593.

Shin, S.-M., Kim, H. J., Liw, L., & Kim, S. (2009). Depression and PTSD in Pashtun women in Kandahar, Afghanistan. *Asian Nursing Research*, *3*(2), 90-98.

Shrivastava, A., Johnston, M., Thakar, M., Shrivastava, S., Sarkhel, G., Sunita, I., & Parkar, S. (2011). Impact and origin of stigma and discrimination in schizophrenia: Patient perceptions. *Stigma Research and Action, 1Stigma Research and Action*, *1*(1), 67-72.

Sweetland, A., Oquendo, M., Sidat, M., Santos, P., Vermund, S., Duarte, C. S., & Wainberg, M. L. (2014). Closing the mental health gap in low-income settings by building research capacity: Perspectives from Mozambique. *Annual Global Health*, *80* (2), 126-133.

UN General Assembly, Convention on the Rights of Persons with Disabilities. 13 December 2006. A/RES/61/106, Annex I, Available at: http://www.refworld.org/docid/4680cd212.html.

Thornicroft, G., Rose, D., Kassam, A., & Sartorius, N. (2007). Stigma: Ignorance, prejudice or discrimination? *British Journal of Psychiatry*, *190*(3), 192-193. doi:10.1192/bjp.bp.106.025791.

Trani, J.-F., Bakhshi, P., Kuhlberg, J., Narayanan, S., Venkataraman, H., Mishra, N. N., & Deshpande, S. (2015). Mental illness, poverty and stigma in India: A case–control study. *BMJ Open*, *5*(2), e006355. doi:10.1136/bmjopen-2014-006355.

Trani, J.-F., & Bakhshi, P. (2013). *Vulnerability and mental health in Afghanistan: Looking beyond war exposure. Brown School Faculty Publications. Paper 40*. Available at: http://openscholarship.wustl.edu/brown_facpubs/40.

Van der Ham, L., Wright, P., Van, T. V., Doan, V. D. K., & Broerse, J. E. W. (2011). Perceptions of mental health and help-seeking behavior in an urban community in Vietnam: An explorative study. *Community Mental Health Journal*, *47*(5), 574-582. doi:http://doi.org/10.1007/s10597-011-9393-x.

Ventevogel, P. (2014). Integration of mental health into primary healthcare in low-income countries: Avoiding medicalization. *International Review of Psychiatry*, *26*(6), 669-679.

World Health Organization. (2002). *Gender and mental health*. Available at: http://apps.who.int/iris/bitstream/handle/10665/68884/a85573.pdf?sequence=1.

World Health Organization. (2010). *Mental health and development: Targeting people with mental health conditions as a vulnerable group*. Available at: http://apps.who.int/iris/bitstream/handle/10665/44257/9789241563949_eng.pdf?sequence=1.

World Health Organization. (2013). User empowerment in mental health – A statement by the Regional Office of WHO Europe. *In Mental health action plan* 2013–2020. Available at: http://www.euro.who.int/__data/assets/pdf_file/0020/113834/E93430.pdf.

World Health Organization. (2016). *mhGAP intervention guide for mental, neurological and substance use disorders in non-specialized health settings: Version 2.0*. Geneva: WHO. Available at: http://apps.who.int/iris/bitstream/handle/10665/250239/9789241549790-eng.pdf;jsessionid=3515AA4F83DBB8958F05C28264E85DBC?sequence=1.

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[1] In Afghanistan, epilepsy is considered a mental illness;, for this reason, the study includes people with epilepsy in the category of people with a psychosocial disability.