



Inclusion of people with psychosocial disability in low and middle income contexts: a practice review

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Abstract

Much of the literature about mental illness in low and middle income countries (LMICs) focuses on prevalence rates, the treatment gap, and scaling up access to medical expertise and treatment. As a cause and consequence of this, global mental health programs have focused heavily on service delivery without due exploration of how programs fit into a broader picture of culture and community. There is a need for research which highlights approaches to broader inclusion, considering historical, cultural, social, and economic life contexts and recognises the community as a determinant of mental health—in prevention, recovery, resilience, and support of holistic wellness.

The purpose of this practice review is to explore the experiences of three local organisations working with people with psychosocial disability living in LMICs: Afghanistan, India, and Nepal. All three organisations have a wealth of experience in implementing mental health programs, and the review brings together evidence of this experience from interviews, reports, and evaluations. Learnings from these organisations highlight both successful approaches to strengthening inclusion, and the challenges faced by people with psychosocial disability, their families and communities.

The findings can largely be summarised in two categories, although both are very much intertwined: first, a broad advocacy, public health, and policy approach to inclusion; and second, more local, community-based initiatives. The evidence draws attention to the need to acknowledge the complexities surrounding mental health and inclusion, such as additional stigmatisation due to multidimensional poverty, gender inequality, security issues, natural disasters, and additional stressors associated with access. Organisational experiences also highlight the need to work with communities' strengths to increase capacity around inclusion and to apply community development approaches where space is created for communities to generate holistic solutions. Most significantly, approaches at all levels require efforts to ensure that people with psychosocial disability are given a voice and are included in shaping programs, policies, and appropriate responses.

Definitions

For the purpose of this paper, the authors use the term “psychosocial disability,” which adopts a social model for understanding mental illness and acknowledges the broader experience of how mental ill-health can affect a person’s ability to participate fully in life.¹

Introduction

Psychosocial disability has generally been researched on the basis of diagnostic categorisation and medication regimes, which has largely led to a medicalisation of the experience.^{2,3,4} In low- and middle-income countries (LMICs), the focus of research has been on the treatment gap, the inequalities in mental health systems, and scaling up access to medical expertise and treatment through task shifting. Whilst these are key considerations, the issues need to be seen through a broader lens that includes the family, community, and social determinants of health and cultural contexts.²

There is a growing body of literature that seeks to understand these aspects of lived experience through exploring supportive networks, social change, and promoting meaning-making of experiences and pathways to participation.^{2,3,4,5,6} However, these studies have been predominantly conducted in high-income countries, and there is very little evidence of the experience of people affected by psychosocial disability in LMICs. There remains a strong need for contextual experiences from LMICs to be recognised and to inform approaches to strengthen inclusion, both locally and globally.

Context and Methodology

TEAR Australia is a movement of Christians responding to the needs of poor communities around the world.² TEAR has long-standing partnerships with local organisations – the Emmanuel Hospital Association (EHA) in India, the Centre for Mental Health and Counselling (CMC) in Nepal, and an unnamed TEAR partner in Afghanistan (TPA). These organisations have a wealth of experience in implementing contextually-relevant mental health work. This paper brings together learning from the experiences of these organisations, and from

the people and communities with whom they work. Emerging themes highlight the key challenges faced by people with psychosocial disability and some possible, effective approaches to strengthening inclusion.

This practice review is comprised of two phases. The first phase was a field visit to EHA, India, and CMC, Nepal. During these visits, the authors met together to set the parameters of the review. Observation and semi-structured interviews were utilised with project staff and communities. A thematic analysis by the authors was then performed on project reports and evaluations from the three projects conducted from 2012 to 2016. This analysis, in conjunction with themes which emerged during the field visits, has formed the content of this paper.

Findings

There are multiple compounding factors impacting people with psychosocial disability, their families, and communities in LMIC contexts, and therefore, a standard model of mental health conceptualisation may not be the most suitable. The work of these local organisations draws attention to the complexities surrounding mental health, such as additional stigmatisation within the caste system, security concerns or natural disasters compounding accessibility, poverty, and additional stressors associated with political uncertainty and social exclusion. Their experiences also highlight the need to work within cultural contexts and frameworks to strengthen inclusion and to provide space for communities to generate solutions. Utilising combined approaches of community development, which enables problem solving at a local level, in addition to strengthening public health systems and policy development ensures strong synergies and holistic approaches to inclusion.

Stigma, Culture, Poverty and Access

. . . people feel shame when they know they have mental health problems because of the social stigma. (TPA)

A significant factor, globally, in the experience of psychosocial disability is that of stigma which diminishes opportunities to participate in community life.² Stigma is complex, and addressing it necessitates a multi-faceted approach beyond simply raising awareness or improving the affordability of treatment.

During a wedding, I had a bad time and everyone came to stare at me, because of this, I avoided many weddings. My relatives ask me why I am not looking a good colour. I want to stay at home and lie down. They tease and laugh at me. (Woman with psychosocial disability, TPA)

It is important to acknowledge the complexities surrounding stigma in light of local belief systems and societal structures.^{2,3} Some local belief systems can promote effective integration and wellbeing, whilst some impede inclusion.² TPA, EHA, and CMC have noted that stigma is often compounded by multidimensional poverty, caste, gender, and other factors.^{2,3}

Rich people go to private clinics or hospitals for service and hide the evidence [of their symptoms]. Poorer or marginalized people... have no information about mental health problem and its treatment so they are either chained or locked in a room or in the street. (CMC)

The type of mental illness experienced can influence the level of stigma experienced and relate to perceived causes such as witchcraft, former life influences, and other beliefs.² TPA, for example, has observed that there seems to be less stigma surrounding depression and anxiety in Afghanistan when compared with psychosis. This reinforces the need for a cultural understanding of stigma frameworks and tailored approaches to leverage cultural strengths to overcome all types of stigma.

As part of creating enabling environments in the community, we developed information brochures. The brochures give information on mental health, types of mental health, social change, stigma, gender, disability, communi-

cation and change, relationships, and suicide prevention. They are used to help community volunteers have confidence when talking to families and communities about these issues. (EHA)

It is important to note that medical information alone may not be effective in reducing stigma. Allowing people with psychosocial disabilities a voice in their communities, and media campaigns that seek to increase general understanding about mental illness are considered more effective approaches.²

Access to effective treatment, however, is still a vital issue for many people with psychosocial disabilities, especially where an absence of treatment may lead to an exacerbation of symptoms, and increased stigma and disability. Among those who do seek treatment, many may initially turn to non-allopathic service providers such as healers or practitioners of traditional medicines due to beliefs around mental health and its causes.¹⁷ TPA and EHA are aiming much of their training and awareness-raising activities towards traditional healers and key religious leaders in order to facilitate an increase in receptivity to mental health services.

Religious leaders may be willing to see that medication has a role in the cure, and the importance of prevention of mental health disorders, and their roles would be to do referrals for medication and rehabilitation apart from spiritual prayer and healing. (EHA)

Disruptions such as security issues and natural disasters can also contribute to the complexity of psychosocial disability in LMICs. The Nepal earthquake and violent conflict in Afghanistan have brought additional barriers to accessing care where, due to trauma and other psychosocial factors associated with such events, there may have been an increased and more urgent need.

Utilising Community Development Approaches

TPA, CMC, and EHA adopt community-centred approaches to strengthen inclusion through understanding and considering the

historical, cultural, educational, economic, and social factors at the community level. This community development approach does not see problems as inherent in individuals, but connects locally-based solutions to wider issues of power, participation, and social and economic justice.^{2,3,4,5} TPA, CMC, and EHA utilise strategies that identify community strengths; uphold inclusive approaches; and value narrative, community connectedness, and a commitment to holistic well-being and development.

- **Context, family and community relationships**

The three organisations work in contexts which have strong family and community values. The involvement of others is therefore fundamental in understanding causes, appropriate treatments, and pathways for participation.²

For these participants, the causes of mental distress were not generally located within individuals, but rather in the quality of the relationships they have with those around them. This is congruent with the concept that mental health and well-being is dependent on, and not separate from, people's social relationships and place in the world, rather than something that people have inside themselves and carry with them wherever they go.¹⁹

A community perspective also highlights the valuable and central role of extended relationships. Guerin and Guerin assert, "Dominant western models for mental illness treatments often focus solely on individuals and their immediate relationships and fail to take account of the importance of extended community relationship."²⁷ TPA, EHA, and CMC respond to this through utilising social network approaches.

EHA, for example, employs community-wide approaches to prevention and inclusion, and they have developed culturally appropriate community resources that promote dialogue on mental health prevention and management. EHA has also sought to understand community contexts and then incorporated targeted skill-building into their approach to strengthen family relationships,

parenting, community cohesion, active listening, tolerance, and inclusion.

. . . the peer educator's interaction helps people to build their identity and understand the cultural norms and values and a wider perspective that enables them to be responsible members of their communities . . . the peers will be available as supportive mechanisms and create enabling environments for sharing and interaction. They use appropriate IEC aids within group meetings, trainings, playful events, and community discussions . . . (EHA)

Recognising the valuable role of community and religious leaders is an additional pathway towards change:

Some community leaders in conservative areas initially were hostile to mental health teaching as they believe it is only God's area, but after four days of training they came to accept the training. There are also tensions between mullahs and doctors in the local culture; however, by being respectful to mullahs, this can be overcome. (TPA)

According to our culture, community leaders can help any program in their area. They are the most respected and influential people at the local community level. It is very important that people know mental health problems are treatable like physical problems, so community leaders easily can communicate with people. (EHA)

- **The use of dialogue for change**

The use of dialogue as a medium for change and to promote connectedness to family and community has received significant attention.^{22,23,28,29} EHA and CMC use the principle of dialogism through their support groups, community-based psychosocial workers, and through making counselling available. These approaches create spaces where voices can be heard, thus often breaking down stigma, self-stigma, and other barriers to inclusion.¹⁷ Utilising dialogue, people with psychosocial disability are able to strengthen a sense of agency in their own lives by discussing their difficulties, problems, and successes, and often a new understanding is built up between people.^{27,30,31}

CMC Nepal has also used counselling to support communities following the earthquake in Nepal in 2015. CMC found that despite people having no access to their medications, counselling sessions were helpful in aiding recovery from sleep problems and fear.

- **Collective voice: the role of community-based groups**

Community-based groups provide a place for connection, support, and dialogue and for collective voice and action. TPA, EHA, and CMC play a conduit role in ensuring that the voices of those with psychosocial disabilities and their families can be heard and supported not only within the group, but also at a broader local, district, and national level.

. . . Now I can talk to the doctors and Village Development Committee and ask them to respond to our problems too. (Participant, CMC)

EHA and CMC are working with Disabled Persons' Organisations (DPOs) and mental health advocacy groups towards sharing lived experience of psychosocial disability. These approaches "empower the whole community in its relationships and dealings with professionals and governments so people can better manage their own mental health."¹⁵

. . . community-based organisations utilise their corporate knowledge and skill so that they are active actors in promoting their own group as well as psychosocial wellbeing. These groups are responsible for advocacy, organising meetings, and mobilizing people with psychosocial disability for accessing rights and entitlements. (EHA)

It is important that broad-scale advocacy is accompanied by community-based approaches.²⁴ Often government policies are developed on the basis of epidemiological evidence, but through the work of TPA, EHA, and CMC, these policies are being increasingly shaped by deeper understandings of context and narrative.

An evaluation from the CMC project demonstrated the success of self-help groups (SHGs) in initiating advocacy activities to compel local service providers to implement government policy in responding to the needs of people with

psychosocial disability. CMC- and EHA-supported SHGs are instrumental in these types of advocacy efforts and are facilitating change through widespread awareness-raising and advocacy efforts, and through networking, collaboration, and strategic linkages.

Working with Government to Strengthen Mental Health Initiatives

TPA, EHA, and CMC have been in working with specific government departments across multiple sectors advocating on behalf of people with psychosocial disability and their families and supporting governments' plans to strengthen mental health strategies. They have faced many challenges, as mental health is one of the lowest health priorities for governments.^{32,33} Compounding challenges include: funding limitations; the complexity of decentralising services; implementation in primary-care settings; and the low numbers of trained and supervised mental health care workers.³⁴ Much has been written about the treatment gap, with statistics citing that "four out of five people with severe mental illness in low- and middle-income countries receive no effective treatment."³⁵

Despite the challenges, TPA, EHA, and CMC have found several effective pathways for working with governments:

- **Raising the profile of mental health**

TPA, EHA, and CMC are taking a role in advocating for appropriate attention and funding allocation to support services and efforts towards inclusion of people with psychosocial disability.

[We] participate actively in meetings and conferences regarding Mental Health . . . We share . . . information with different stakeholders and advocate about mental health with them. This information sharing is very useful to influence the authorities to pay more attention to the mental health problems in the community and take part in the advocacy events. For example, after prolonged advocacy two provinces have decided to re-start the mental health focal point meetings. (TPA)

Advocacy is . . . one of the core areas for action in any mental health arena because of the

benefits that it produces for people with mental disorders and their families. The advocacy movement has substantially influenced mental health policy and legislation in some states and is believed to be a major force behind the improvement of services. (EHA)

The project manager created a link with the mental health department of Ministry of Public Health. Now they have good cooperation . . . and they are always involved. This facilitated information sharing and building relationship . . . We found it very important to be in contact with the ministry. (TPA)

CMC's advocacy in Nepal has resulted in an increased government budget allocation to train health workers in mental health, and some basic psychotropic drugs have been included on the government's free list.

Local government . . . have allocated funds for mental health. Similarly, four Village Development Committees have allocated budgets for mental health. This evidence shows that the health service management committee have explored and tapped local resources for promoting mental health and integrating mental health services. (CMC)

- **Strengthening implementation of government mental health strategies**

The work of the three organisations in strengthening government initiatives and strategies has included:

1. providing training and technical support — investing in a sustainable solution in which mental health services are integrated into existing hospitals and clinics:

. . . The strength of partnership between CMC and the District Health Office is effective and practical . . . All of the stakeholders interviewed during the field visit reflected that the district health office has started to initiate integrating the mental health into the health services as a result of partnership with CMC. (CMC)

2. coordinating with government directly in the implementation of their activities:

Most LMIC government mental health programs are chronically underfunded, especially

in rural areas.³¹ EHA is working to address this through partnering with government health facilities and supplementing these services through linkages with an EHA hospital:

Government medical officers are very happy and keen to have training regularly but they are hardly able to provide medicine and therefore not keen to practice. [In the] meantime the government are interested in working together with the project and the hospital is committed to run the clinics on a fortnightly basis and provide medication at low prices . . . (EHA)

TPA is coordinating with government and has achieved significant outcomes through the government's adoption of their awareness raising resources which are now integrated into national mental health education materials. These initiatives strengthen the reach of the government's programs.

- **Using evidence to support advocacy initiatives**

TPA, EHA, and CMC advocate for effective health and social systems through utilising data and supporting the sharing of lived experience to increase understanding of need and scope for action.

[The] project initiated two strategies: first a mental health clinic so that project would have evidence based records and data that could show the scope of mental health issues in the region, as well as . . . showing our credential of work in the field of mental health so far. (EHA)

Regarding the integration of the mental health [services] into the basic health services at the district and PHC/HP level, all health service centres (out of 8 service centres visited) have started to keep records of psychiatry morbidity and reporting in Health Ministry Information System regularly. (CMC)

- **Addressing institutional barriers**

In India and Nepal, people with psychosocial disability face barriers in accessing government disability benefits. EHA and CMC facilitate access to these benefits and advocate for wider recognition of psychosocial disability. An example from EHA:

. . . key informants reflected that the beneficiaries have developed confidence to demand services from the health service centres and Village Development Committees but [before] they were not aware on what rights they are entitled to and how to access and claim their rights. (EHA)

EHA and CMC work with local and national DPOs (both psychosocial disability, specific and more general groups) in order to promote rights-based dialogue, challenge institutional barriers and strengthen the voices of people living with psychosocial disability within communities.

Awareness-raising

EHA, CMC, and TPA implement awareness raising activities through a community development lens and seek to raise awareness of psychosocial disability to strengthen community dialogue, resilience, and problem solving. The organisations utilise different methodologies, including IEC, promoting World Mental Health Day, training teachers, and working with key change agents such as village leaders and religious leaders to increase understanding at a community level. A recent evaluation of TPA's work found that:

[The project's] multi-faceted approach to building awareness has been effective. The training targeted influential people within society . . . to enable systemic change. (TPA)

The different awareness-raising mediums have had a number of positive outcomes, including increasing utilisation of services and care, reducing stigma, and promoting rights-based awareness.^{36,37}

People started coming themselves to seek treatment. Bridging treatment gap with education on Mental Health has brought change in people's negative attitude towards mental ill people. (EHA)

She asked patients and their family members how they came to know that there is a clinic about the mental health and how they know generally about the mental health. About half of the patients said that they know from TV program (from TPA's work) regarding mental health. (TPA)

Trainees noted that their own increased awareness brought about changes in themselves and those around them. Some highlighted their own changes in attitude to people with mental illness . . . (TPA)

The challenge is to continue awareness-raising, not only regarding signs and symptoms and where to seek medical assistance, but importantly, around wellbeing, inclusion, and rights, to enable balanced conversations at community level.

Mainstreaming

TPA, CMC, and EHA leverage learning from their mental health work and build these learnings into more general development programs:

EHA is using this and another project as a pilot to see how it can integrate mental health into mainstream health services. The learnings from here appear to be feeding into their wider work. (EHA)

Integration with other programs . . . will [help people] understand the importance of mental health program and take interest how mental health is integrated with nutrition, family planning, immunization and institutional delivery government nationalised program. (EHA)

TPA has been invited to give mental health training and awareness materials to organisations such as private health clinics, INGOs, and the education sector. Their work with teachers and students is important in raising awareness and mainstreaming mental health knowledge.

It is also important to consider already marginalised groups in mental health awareness and inclusion responses. In Afghanistan, it was found that women who stay home, those with low literacy, and people in more rural regions lack access to awareness raising initiatives and knowledge. (TPA)

CMC has been involved in conducting training for teachers in deaf schools. The training materials are interpreted into sign language and therefore accessible to this potentially marginalised group. Similarly in Afghanistan:

[TPA] received a request from a blind school to train their teachers and students in

mental health, they promised to print the mental health materials in Braille and [TPA] conducted training for the teachers. (TPA)

These are valuable examples of how pathways to accessing information on mental health and inclusion may need to be modified to include other marginalised groups.

Implications for Practice

This collaborative review of the efforts of local NGOs to promote for people with psychosocial disability provides many implications for current and future practice, including:

- The importance of creating platforms that strengthen the voices of people with psychosocial disability
 - Seeking to understand the sociocultural context towards inclusion
 - Recognising the role of the family
 - Promoting collective action at a grass-roots level
- Strengthening public health systems and policy development — NGOs play a key role in collaborating with governments and networking at district and national levels to bring about change
 - Promoting linkages with people with lived experience and affected communities to inform organisational actions and approaches

Conclusions

The shared experiences of TPA, EHA, and CMC provide useful and insightful ways in which to explore some of the barriers and enablers to the inclusion of people with psychosocial disability across three LMIC contexts. Their approaches provide opportunities for further research into the lived experience of people with psychosocial disability in LMICs.

Strengthening the voices of people with psychosocial disability and seeking to understand the sociocultural context towards inclusion remains crucial. Creating change through collective action at a grassroots level, in addition to strengthening public health systems and policy development, ensures a holistic approach to inclusion. Non-Government Organisations play a key role in collaborating with governments and

networking at district and national levels to bring about change. Their linkages with people with lived experience and affected communities should inform their messages and approaches to these broader collaborations.

The key findings from this paper highlight the key barriers and pathways to inclusion and should be used as a tool for further exploring local contexts when planning towards strengthened inclusion for people with psychosocial disability. Listening to the collective and individual voices of people with lived experiences in their own contexts is the most important beginning.

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