INCLUSION OF PEOPLE WITH PSYCHOSOCIAL DISABILITY IN LOW AND MIDDLE INCOME CONTEXTS: A LITERATURE AND PRACTICE REVIEW

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2016
ACKNOWLEDGEMENTS

The authors would like to thank sincerely TEAR’s partners, IAM, EHA and CMC for their willingness to share their ideas, work, expertise, learning and enthusiasm. We would like to thank particularly the staff and communities involved in the SHIFA-HCH project (EHA), the Community Mental Health and Psychosocial Support Project (CMC); and IAM’s Community Mental Health project, who tirelessly and patiently shared their experiences, insights and expertise during field trips and ongoing communication.

We would like to express our gratitude to the research reference group, John Willis, Becca Allchin, Ben Rinaudo and Kimberley Fraser, who have supported this process and shared with us their fresh insights, rich and varied experiences and extensive networks, all of which have been valuable resources.

The authors would also like to thank the Australian Government’s Department of Foreign Affairs and Trade. The final development of this paper was made possible through the support of the Australian Aid Program. We acknowledge that the views presented in this paper may not be shared by the Australian Government.
OVERVIEW

INTRODUCTION

TEAR Australia is an NGO that has long-term partnerships with the Emmanuel Hospital Association (EHA) in India; the Centre for Mental Health Counselling (CMC) in Nepal and International Assistance Mission (IAM) in Afghanistan. These three organisations have a wealth of learning from their experiences in implementing community-based mental health work. Afghanistan, India and Nepal are at three quite different points on the journey in managing and supporting mental health, however there are valuable lessons in bringing together the experiences of these local organisations. The organisations’ different approaches have aspects in common, as all three have strengthened mental health awareness and advocate for change for those affected by psychosocial disability. TEAR Australia is committed to ensuring that the voices of people with psychosocial disability and those organisations that work closely with them, are heard for broader learning around international development and effective inclusion approaches.

The experience of psychosocial disability has, in the past, generally been researched based on diagnostic categorisation and medication regimes, which has largely led to a medicalisation of the experience of psychosocial disability (Mulvany, 2000; Dowrick & Frances, 2013; Mulder, 2008). In the last two decades, qualitative methods have increasingly been used to explore the lived experience of people with psychosocial disability (Lester & Titter, 2005; Mulvany, 2000). These studies have predominantly investigated the medical experiences of the person, and they have generally been conducted with improved service delivery as their purpose (Baum, 2006). The results of these studies have helped to gain insights that have strengthened service provision, and opened up choice and ownership of the medical process (Lester & Titter, 2005; Beresford 2002).

There is a growing body of literature which seeks to understand the broader aspects of the lived experience of people with psychosocial disability – exploring supportive networks, empowerment, social change, promoting meaning-making of experiences and pathways to participation and inclusion (Nelson et al, 1998; Longden, 2010; Corstens et al, 2012; Borg & Davidson, 2008; Angermeyer & Schulze, 2003).

However, these studies have been predominantly in high-income countries, with very little broad evidence of the experience of people and families affected by psychosocial disability in low- and middle-income countries (LMICs). With the rise of the global mental health movement, which aims to address the inequities in mental health systems between high-income and low- and middle-income countries, there is a need for local and contextual experiences from LMICs to be recognised and inform approaches and strengthen inclusion (Kirmayer & Pedersen, 2014).

Much of the literature about psychosocial disability in LMICs focuses on the treatment gap: scaling up access to medical expertise and treatment through task shifting (Ventevogal, 2014). Whilst these are key considerations, the issues need to be seen through a broader lens of the family, community, social determinants and cultural contexts. These are crucial for strengthened holistic community development that upholds inclusion approaches.
OVERVIEW

It is not the intention of the authors to label or limit the experience of people with psychosocial disability, but rather to respect their lived experience. For the purpose of this paper, the authors use the term psychosocial disability, which describes the disability experience of people with impairments and participation restrictions related to mental health conditions. These impairments and participation restrictions can affect a person’s ability to participate fully in life. This may be due to how the impairment from mental ill-health has affected them and how it prevents them from engaging in opportunities such as education, training, cultural activities, and from achieving their goals and aspirations. Not everyone with a mental illness will have a level of impairment that can be defined as a psychosocial disability (NMHCCF, 2011).

DEFINITION

These themes can largely be thought of in two categories, although they are very much intertwined—a wider, broader approach to inclusion and more local, community-based initiatives. All three organisations work at both this higher level and at a grassroots level. It is important to note that although these organisations include public health and medical components, they work primarily through a community development approach and are working towards achieving social justice and cohesion.
“As part of creating enabling environments in the community and to sharpen the skills of community based staff, we developed information brochures. The brochures give information on mental health, types of mental health, social change, stigma, gender, disability, communication and change, relationships, and suicide prevention. They are used to help community volunteers have confidence when talking to families and communities about these issues.” (SHIFA-HCH)
KEY FINDINGS

1. The experience of stigma due to having a psychosocial disability is influenced by local belief systems and may also present as shame or self-stigma. Often families also experience a social disconnection.

2. Health-seeking efforts around psychosocial disability in LMICs are usually immense and demand significant amounts of resources and time. This can be complicated by security concerns, natural disasters and complex political situations in some LMICs.

3. Inclusion for people with psychosocial disability is a community development issue, compounded by inequality, poverty, and social factors, which can be causes and consequences of psychosocial disability.

4. Strengthening the voices of people with psychosocial disability is crucial. Approaches at all levels require efforts to ensure that voices are heard.

5. Pathways to inclusion must acknowledge the cultural context and take into account the importance of family and extended community relationships.

6. The use of dialogue as a medium for change is important in utilising community development approaches to inclusion.

7. Working in collaboration with Government is important and NGOs can have a role in strengthening the Government’s response through supporting mental health strategy implementation.

8. Combined approaches including advocacy at national, district and local levels are crucial to promote the collective voices and experiences of people with psychosocial disability and through the strengthening of networks, collaboration and strategic linkages.

9. Awareness-raising remains an important part of psychosocial disability inclusion in helping people make meaning of their own experiences or the experiences of their family and friends, contributing to a reduction in stigma, and in providing knowledge about specific mental health conditions and access points for treatment and support.

10. NGOs should consider how to build in psychosocial disability awareness, knowledge and skill into their planning on mainstream issues of psychosocial inclusion and ensure that there are strengthened opportunities for inclusion.
EHA, CMC and IAM implement their mental health work through community-based projects. The SHIFA-Herbertpur Christian Hospital (SHIFA-HCH) project is one of EHA’s mental health projects and will be the focus of this paper, along with The Community Mental Health and Psychosocial Support Project (CMC); and IAM’s Community Mental Health project. These programs have been planned and designed through extensive consultation with communities, governments and other relevant stakeholders in their respective contexts. Although each project design is different and tailored to the local context, there are many similar overarching themes and learnings, which can be summarised from the three projects.

The practice review comprised of several phases, including field visits to India and Nepal, and reviewing project documentation. During field visits to SHIFA-HCH, India and CMC, Nepal the authors utilised observation, and semi-structured interviews with project staff and communities. A thematic analysis by the two authors was conducted on project reports and evaluations from the three projects from the time period 2012 to 2016. This analysis, in conjunction with themes that emerged during the field visits, has formed the content of this paper.

A short overview on each of these three projects and the material reviewed for this paper can be found at Annexure A and B.

The literature review looked at published articles and peer reviewed papers, and grey literature was also recognised when directly relevant to the topic. The authors performed a literature search with Sciencedirect, PubMed, and Cochrane using combinations of the following key words: “mental health”, “mental illness”, “psychosocial disability”, “lived experience”, “Low and middle income countries”, “stigma”, “inclusion” and “social distance”. A two-phase process was adopted in order to utilise the most relevant papers. During the first phase, a wide selection of papers on global mental health and psychosocial disability in LMICs were read to develop contextual understanding of the topic. The second phase was to focus the review on the specific topic of inclusion and how the literature related to the themes identified from the practice review.

The paper was reviewed by IAM, SHIFA-HCH and CMC staff during the final phase to verify the authors’ conclusions.
“Even today people feel shame when they know they have mental health problems because of the social stigma.” (IAM)

“Religious leaders may be willing to see that medication has a role in cure and the importance of prevention of mental health disorders and their role would be to do referral for medication and rehabilitation apart from spiritual prayer and healing.” (SHIFA-HCH)

“...psychosocial support could play important role in life of people in post-disaster situation to be able to manage stress of daily life and disaster moment.” (CMC)
Organisations working specifically in the field of mental health in LMICs, such as those referenced in this paper, can highlight both successful approaches and the needs and challenges faced by people with psychosocial disability, their families and communities. The work of all three projects draws attention to the need to acknowledge the complexities surrounding mental health, such as additional stigmatisation within the caste system, security concerns or natural disaster contexts compounding access issues, poverty, and additional stressors associated with political uncertainty and social exclusion. Their experiences also highlight the need to work within cultural contexts to strengthen inclusion and to apply community development approaches, where space is created for communities to generate solutions to their problems.

There are multiple compounding factors impacting upon people with psychosocial disability, their families and communities in LMIC contexts. These contexts are often not well understood when a standard model of mental health conceptualisation is applied. As Mfoafo-M’Carthy & Huls define it: “Mental health embodies the integration of psychological, emotional, and social harmony. It encompasses one’s quality of life and general well-being. Culture, language, ethnicity, and religion play a significant role in the interpretation of mental health causes” (2014, pg.2).

However, often global mental health programs focus heavily on the processes of service delivery, without due exploration of this integration and interpretation. There is a need for approaches to inclusion that consider historical, cultural, social, and economic life contexts relevant to mental health, recognising that the community is a determinant of mental health (Guerin & Guerin, 2012).
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STIGMA, POVERTY AND ACCESS

“Even today people feel shame when they know they have mental health problems because of the social stigma.” (IAM)

A significant factor in the experience of psychosocial disability is that of stigma. Stigma is one of the key barriers to social inclusion and generates a sense of not belonging, not participating in community life and diminished opportunity and capacity to participate (Popay et al, 2008). Stigma is a complex issue, and addressing it necessitates a multi-faceted approach, more than simply raising awareness about mental health issues or improving the affordability of treatment.

Often people experiencing psychosocial disability are labelled as socially inadequate and experience shame, humiliation, and loss of face. This presents as different forms of stigma, but still results in social distancing. Self-stigma, or internalised stigma is also a significant barrier to inclusion in many contexts and it is important to acknowledge the complexities around understanding this in light of local belief systems and societal structures (Knifton et al, 2009).

“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.” (Lady with psychosocial disability, IAM)

The stigma of mental health needs to be viewed within diverse sociocultural contexts in order to understand explanatory frameworks, including origins, meanings and consequences (Thara & Srinivasan, 2000).

“I tell them her condition must come from God because she was OK for 5 years. Sometimes she cries because people tease her. The bigger and smaller girls tease her.” (IAM)

One way of understanding explanatory frameworks is through creating space to hear the voices of people with psychosocial disability. This can strengthen understanding of the complexities of context, stigma and pathways to inclusion. IAM, SHIFA-HCH and CMC utilise this approach through ensuring that their programs are designed around listening to communities and people with lived experiences.

IAM, SHIFA-HCH and CMC have noted that stigma can become a greater issue where the caste system, poverty or other barriers to social inclusion are also present. This is reiterated in a case control study from India, which found a significant interaction between stigma, mental illness, gender, caste and multidimensional poverty (Trani et al, 2015). The experience of stigma and discrimination in daily life, in addition to pre-existing social inequality, and poverty, often has a compounding effect (Lin et al, 2011). This may result in the deterioration of the individual’s mental health and sometimes contributes to the decline of broader family and community mental health outcomes. In some cultures, people with low positions in hierarchical social structure experience high rates of mental health problems (Rosenfield, 2012). Social inequality and multidimensional poverty stressors, in addition to stigma, must be addressed as part of a community development approach to psychosocial disability (Lund et al, 2010; Rosenfield, 2012; Trani et al, 2015).

Below is an observation from the CMC project in Nepal, which highlights the extra disadvantages faced by the poor. People from wealthier backgrounds facing mental health issues are more able to access private health services and receive discreet, confidential treatment, and thus reduce the stigma associated with their illness. The poor, however, often already facing stigma associated with their socioeconomic status, may also lack access...
to appropriate care, which can lead to worsening of symptoms and an increase of stigma and isolation.

“Rich people or affluent families go to private clinics or hospitals for service, and hide the evidence [of their symptoms]. Poorer or marginalized people are ignorant or 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, 2015)

The example above identifies lack of awareness of mental health issues and their treatments as an exacerbating factor in relation to stigma. Scarcity of information regarding the causes of mental illness can add further to this stigma. Spiritual causes, former-life influences, witchcraft and other beliefs can increase the social isolation and community misunderstanding faced by people with psychosocial disabilities. An example given by IAM (2016) describes beliefs around causes of one community member’s mental illness ranging from a “poisonous vegetable” to inherited bad luck. While no further information was given around the stigma associated with these causes or directed at this individual, this example certainly indicates a community-wide lack of understanding about mental health issues, which is often a key feature of stigma (Thornicroft et al, 2007).

The experience of IAM, SHIFA-HCH and CMC is that there can be different levels of stigma or self-stigma depending on the type of symptoms or diagnosis. IAM have observed that there seems to be less stigma around depression and anxiety in Afghanistan compared with psychosis and epilepsy*. This is reiterated by the literature, which largely finds that schizophrenia appears to be a more stigmatised disorder, as it remains associated with negative stereotypes (Angermeyer & Schulze, 2003).

This again reinforces the need for a cultural understanding of stigma frameworks and tailored approaches to overcoming all types of stigma.

An example from the SHIFA-HCH project:

“As part of creating enabling environments in the community and to sharpen the skills of community based staff, we developed information brochures. The brochures give information on mental health, types of mental health, social change, stigma, gender, disability, communication and change, relationships, and suicide prevention. They are used to help community volunteers have confidence when talking to families and communities about these issues.” (SHIFA-HCH)

It is important to note from SHIFA-HCH’s example that purely medical information alone, may not be effective in reducing stigma. As Mathias et al (2015, pg.8) assert, “…emerging evidence suggests that stigma reduction intervention promoting a bio-medical model of mental illness may increase rather than decrease stigma”. Further approaches, such as allowing people with psychosocial disabilities a voice in their communities, and mass media approaches that seek to increase general understanding about mental illness, are considered more effective in reducing stigma (Mathias et al, 2015) – both are approaches used in the focus projects and discussed later in this paper.

While an excessively bio-medical, illness-focused approach may worsen stigma and lead to disease labelling, access to effective treatment 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. As mentioned above, however, people with psychosocial disabilities, especially those from poorer backgrounds, may lack awareness of available mental health services. Among those who do seek treatment, many may initially turn to non-allopathic service providers such as healers, practitioners of traditional medicines or astrologers, due to their existing beliefs around mental health and its causes (Kermode et al, 2010). Encouragingly,

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*Epilepsy is considered a mental health condition in Afghanistan, India and Nepal. This is perhaps due to the fact that the resulting stigma and barriers to participation are similar to those experienced by people with psychosocial disabilities.
projects such as IAM’s work, and EHA’s SHIFA-HCH project, 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 cure and the importance of prevention of mental health disorders and their role would be to do referral for medication and rehabilitation apart from spiritual prayer and healing.” (SHIFA-HCH)

As well as accessing ineffective or inappropriate treatments, people with psychosocial disability may seek medical care but find it inaccessible or unsustainable due to a number of factors including costs, a frustratingly time-consuming process of unnecessary tests and investigations, or simply a lack of provision of appropriate information by under-resourced or under-informed health care providers. An instance of this is given in an example below:

“I have been ill for about 10 years. I have seen many doctors. I was even admitted into a bed for 25 days, 3 years ago... I went to many different places, I spent a lot of money.” (IAM)

There are many similar stories from Nepal and India. CMC staff relay a story of a man with depression, who spent large amounts of money on medicine, hospital investigations and different doctors. Because of these costs, he was forced to sell his land and eventually had no money to buy any medication. After the Earthquake affected his district in 2015, health workers found him. He had been homeless for many months prior to the earthquake and was in very poor physical and mental health. CMC trained health workers were able to support him with counselling and access to free medication, however he is still worried about the loss of his property.

Ventevogel et al (2012) describe a similar example from Afghanistan, in which a man with symptoms of depression sought medical care and was referred for a series of investigations and prescribed a variety of ineffective treatments. He travelled to a number of distant locations to access the recommended services, cumulatively spending the equivalent of around six months’ wages on inappropriate care. Eventually, his condition was recognised by a local community health worker who had received three days of mental health training, and treated locally.

These examples highlights the risk that the poor can be further economically disadvantaged simply by attempting to access care when either they or local healthcare services lack appropriate information. Conversely, access to effective interventions has been shown to have a positive economic impact on individuals with mental illness and their families (Lund et al, 2011). The anecdote above provides an example of the enormous impact that basic training of local staff can have in increasing the accessibility of such care. While the lack of trained professional staff is a significant issue, initiatives that provide awareness-raising and training programs will be described later in this paper.

Security issues, natural and other disasters, and other factors that influence the availability of care can also contribute to the complexity of mental health in LMICs. IAM in Afghanistan have acknowledged this complexity, and attempts to address this have included bringing staff from conflict zones into safer areas for training, and ensuring that mental health awareness programs reach people in areas of high security risk through targeted television and radio programs. However, training of healthcare workers alone is not sufficient to increase access to care (Hanlon et al, 2014). Furthermore, raising awareness in remote areas or conflict zones, without increasing the availability of care, will not lead to improvements in access to mental health services. Natural disasters such as the Nepal earthquake, and violent conflict common in Afghanistan and other areas, can bring an additional challenge – these issues can prevent access to care where, due to the trauma and other psychosocial factors associated with such events, there may be an increased and more urgent need.
FINDINGS

UTILISING COMMUNITY DEVELOPMENT APPROACHES

Recognising that there is a need for inclusion approaches that consider the historical, cultural and social determinants of health at a community level highlights the need to apply community development frameworks that acknowledge the local and cultural contexts (Carpenter and Raj, 2012; Christens, 2012; Mathias et al, 2015; Tew et al, 2012).

In a systematic review of literature, Tew et al (2012), found three emergent themes deemed central to recovery. These were: 1) empowerment and control over one’s life; 2) connectedness (including both inter-personal relationships and social inclusion); and 3) rebuilding positive identities (often within the context of stigma and discrimination). IAM, CMC and SHIFA-HCH utilise these approaches, which focus on community-centred approaches to inclusion that value narrative, community connectedness, and a commitment to holistic development.

a) Context, Family and Community Relationships

It is important to acknowledge that, while many mental health interventions are known to be effective in a Western setting, psychosocial initiatives in other contexts may need a different approach. Many LMICs, including those in which the focus projects of this paper are based, have strong family and community values and therefore require a social network perspective when responding to issues of psychosocial disability. This is supported by a study in Maharashtra, India:

“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…”

(Kermode et al, 2010, pg.618)

In such settings, where relationships with family and community members are key in understanding the causes of mental illness, and form a crucial part of identity, the involvement of others is fundamental in understanding causes, and appropriate provision of treatments and pathways for inclusion (Tew et al, 2012). IAM, SHIFA-HCH and CMC address these components of psychosocial support through a community development approach, ensuring that the community plays a central role.

One way in which they achieve this, is through working closely with families. During field visits to CMC and SHIFA-HCH’s work, it was noted that having a family member with a psychosocial disability often impacted upon the whole extended family and resulted in a social disconnecting of the family from the community. This has also been noted in Lauber & Rössler’s (2007) review on stigma towards people with mental illness in developing countries in Asia. CMC’s and SHIFA-HCH’s work addresses this through strong initiatives which adopt holistic family approaches, such as family support groups, and inclusion of family members into counselling, self-help and advocacy groups.

“Earlier there was stigma and people don’t want to associate with us, as mental health is caused by a curse, but now people know it is a disease.”

(family member of person with psychosocial disability UP, India)

“We want to work with families who are at high risk of stress because of their social, familial and belief practices. We need to develop special interventions for these families in particular. The project does this through the role of the Peer Educators.”

(SHIFA-HCH)

“[peer educators and volunteers]... also spent time with the family, helping them understand what is happening and helping to problem solve difficulties to decrease family tension.”

(SHIFA-HCH)
A social network perspective also highlights the central role of the community. 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” (Guerin & Guerin, 2012, pg.556). SHIFA-HCH’s work reflects this in their whole of community approaches to prevention and inclusion. SHIFA-HCH has learnt from other similar work in the region and in particular the Burans project which has produced resources for community mental health that promote dialogue on mental health prevention (Mathias et al, 2015).

“... 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...” (SHIFA-HCH).

An additional pathway to change that upholds the role of community is working through community and religious leaders. IAM’s work in Afghanistan involves community and religious leaders in education programs:

“Some community leaders in conservative areas initially were hostile to mental health teaching as they believe it is only God’s area but after 4 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.” (IAM)

“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.” (SHIFA-HCH)

The culture, context and social networks of communities are crucial for the promotion of psychosocial inclusion, and the roles of family and community in creating change should be central to any inclusion approach.

“Caregivers groups have sensitized the general public about their cause and provided education and support to people with mental disorders. They have become advocates, educating the community, increasing the support obtained from policymakers, denouncing stigma and discrimination and fighting for improved services” (SHIFA-HCH).

**b) The Use of Dialogue For Change**

The use of dialogue as a medium for change and to promote connectedness to family and community in order to strengthen inclusion has received significant attention through multiple publications (Tew et al, 2012; Seikkula et al, 2006; Arnkil & Seikkula, 2015; de Menil & Glassman, 2016). SHIFA-HCH and CMC use the principle of dialogism to guide their work – through the formation and development of support groups; and through the role of community-based psychosocial workers, including counsellors, who support families and individuals at a local level. These approaches create spaces where voices can be heard and understanding for others increase, thus often breaking down stigma, self-stigma and other barriers to inclusion (Knifton et al, 2009).

Utilising dialogue, people with psychosocial disability strengthen their sense of agency in their own lives by discussing their difficulties, problems and successes (Seikkula et al, 2006; White et al 2016). When dialogue is utilised with family or a community group; a new understanding is built up between the participants in the dialogue (Andersen, 1995).

These approaches have been shown to be effective in not only providing space for people to dialogue and support each other, but also to process traumatic events together. CMC’s work, following the earthquake in Nepal in 2015, highlighted the important role of dialogue and community-based psychosocial workers following a natural disaster:
"... psychosocial support could play important role in life of people in post-disaster situation to be able to manage stress of daily life and disaster moment." (CMC)

CMC’s report also found that despite having no access to their medications (following the earthquake) the people found counselling sessions helpful in aiding recovery from sleep problems, somatisation, fear and shaking sensations.

c) Collective Voice: The Role of Community-Based Groups

Community-based groups have multiple functions, including being a place for connection, support and dialogue, as well as a place for collective voice and action. NGOs such as IAM, SHIFA-HCH and CMC often 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 project)

SHIFA-HCH and CMC are working with Disabled Peoples Organisations (DPOs), mental health advocacy groups and support groups towards strengthening the sharing of information about lived experience of psychosocial disability and inclusion. These community development approaches "empower the whole community in its relationships and dealings with professionals and governments so people can better manage their own 'mental health' issues" (Guerin & Guerin, 2012, pg.564). It is important that advocacy is not only through broad scale approaches, but accompanied by community-based approaches (Ventevogel et al, 2012).

"The community based organisations utilize 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." (SHIFA-HCH)

Supporting a strengthening of contextualised voices is also an important approach for informing and shaping policy and practice change towards inclusion (Ventevogel et al, 2012; Carpenter & Raj, 2012; Kirmayer & Pedersen 2015; Pinfold et al, 2005). Often Government policies are largely developed based on epidemiological evidence, but through the work of IAM, SHIFA-HCH and CMC, these policies are being increasingly shaped by deeper understandings of contexts.

CMC and SHIFA-HCH have supported the development of local Self Help or support groups which are instrumental in these types of advocacy efforts at a grassroots level and also facilitate processes which enable the breaking down of stigma within communities.

"... there remain challenges to ensuring improvements in mental health are sustainable. To address this, since 2012, the project has begun to take on more rights-based thinking with a new emphasis to empower communities and mental health service users and their families, in tandem with continuing to work to mainstream and strengthen Government of Nepal services. This approach has largely involved forming self-help type groups around each of the health posts where government health workers have been trained." (CMC)

An evaluation from the CMC project demonstrated that the SHGs have been successful in initiating advocacy activities to compel local service providers to implement the Government of Nepal policy and strategy to respond to the needs of people with psychosocial disability.

The broader approach of these community-based groups is in facilitating change at a local level, through widespread awareness raising, local advocacy efforts and through networking, collaboration and strategic linkages.
d) Holistic Community Development Practices for Inclusion

In addition to the central role of family and community connections, there are additional community development approaches which more broadly address the social determinants of psychosocial health. There is a need to explore the social determinants within any context, such as gender, or gender-based violence, caste, poverty, and compounding reasons for exclusion. Strategies which address these educational, economic and social factors must be understood and utilized in inclusion approaches (Patel & Kleinman, 2003).

EHA has sought to understand their context and then incorporated skill building into their community development approaches. This includes skill building for strengthening family relationships, parenting skills, community cohesion, active listening, tolerance and inclusion.

“There is strong evidence from global mental health initiatives internationally that skill building, mental health promotion, youth resilience, and community based interventions are all effective and needed in low resource settings” (IAM evaluation 2016)

In a recent article by de Menil & Glassman (2016, pg.2) they assert that “Evidence suggests that community-based models that integrate health care and social interventions can have a positive impact on clinical outcomes and social and economic functioning for affected individuals”. One such model is the BasicNeeds model. This model was founded in 2000 and now operates in over eleven different LMICs. The model is built on community based integrated mental health and development theory and emphasises: “user empowerment and community development, as well as strengthening health systems and influencing policy” (Raja et al, 2012, pg.1).

It is comprised of five components including capacity building, community mental health, livelihoods, research and management. This model reiterates the importance of applying community development principles, such as tapping into local resources and understanding the role of poverty (Raja et al, 2012). This model also supports the approach of CMC and SHIFA-HCH in taking a holistic approach to the inclusion of people with psychosocial disability.

“CMC had taken initiation of providing support in income generating activities for the people with mental health problems either from its own token support or linking them with other organizations who support in livelihood.” (CMC)

SHIFA-HCH’s work in linking families and communities to Government benefits also demonstrates a contextual understanding of the role of poverty, exclusion and poor mental health;

“Some progress was made by community members working collaboratively and with outside groups to increase resources for mental health in their community. Through training and information, community members with both physical and psychosocial disabilities worked together to increase access to Government entitlement.” (SHIFA-HCH)

There is some published evidence that the use of cash transfers can result in better mental health outcomes and improve social determinants that are excluding (de Menil & Glassman, 2016). “For greatest mental health effect, poverty reduction interventions should be tailored to vulnerable populations and study the impact of the mechanisms of poverty that seem to most affect mental health, namely education, food insecurity, and housing” (de Menil & Glassman 2016, pg.3).

In understanding the social determinants of health and the context of communities, approaches to psychosocial inclusion can be strengthened at all levels. 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.
FINDINGS

WORKING WITH GOVERNMENT TO STRENGTHEN MENTAL HEALTH INITIATIVES

The role of Governments in creating environments for positive change for people with psychosocial disability, families and whole communities cannot be underestimated. Often mental health is one of the lowest health priorities for Governments (Kohn, 2004; WHO, 2013) and much has been written about the treatment gap with some statistics citing that “four out of five people with severe mental illness in Low and Middle Income Countries receive no effective treatment” (Luitel et al, 2015, pg.2). Saraceno et al reviewed barriers to improvement of mental health services in low-income and middle-income countries (2007) and found that these include the public-health priority agenda and consequent funding; the complexity of decentralisation of mental health services; challenges to implementation of mental health care in primary-care settings; and the low numbers of trained and supervised mental health care workers (Saraceno et al, 2007). These findings have largely been supported by the well-known PRIME (Programme for Improving Mental health care) study (Hanlon et al, 2014).

The experience of TEAR’s partners aligns with these findings, and IAM, SHIFA-HCH and CMC have designed their work around addressing these barriers in each of their individual contexts. Working with specific departments such as the Ministry of Health and across multiple sectors, the work of these NGOs has included advocating on behalf of people with psychosocial disability and their families, and supporting Governments’ plans to strengthen mental health approaches.

a) Raising the profile of mental health

Hann et al, in their 2015 study on ‘Factors for success in mental health advocacy’, mentioned the importance of relationships with advocacy targets as one of the key enabling factors to advocacy (Hann et al, 2015). NGOs such as IAM, SHIFA-HCH and CMC, through building relationships with Governments, can have a role in advocating for appropriate attention and funding allocation to support services and efforts towards inclusion of people with psychosocial disability.

Some examples of how the projects are working with governments to increase the focus of mental health as a priority issue are given below.

“... [The project] tried to involve the relevant directorates in the celebration of World Mental Health Day. Each year [we] support governmental directorate technically and financially to have a campaign and introduce mental health issues to the (Government) officials in western region and Kabul...” (IAM)

b) Advocating for increased budget allocation

CMC’s advocacy in Nepal has resulted in an increased budget allocation to train health workers in mental health and some basic psychotropic drugs
have been included on the Government’s free list. CMC work closely with district health authorities to monitor medication supply and advocate to the Government of Nepal for more effective supplies of drugs.

“Local government … have allocated funds for mental health in coordination with the health facilities management committees of their area/districts … Similarly, 4 Village Development Committees have allocated budgets for mental health. This evidence shows that the health service management committee have initiated to explore local resources for promoting mental health to tap resources for integrating mental health as their primary role.” (CMC)

c) Strengthening implementation of Government Mental Health strategies

The work of the partner projects in strengthening Government initiatives and strategies has included:

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

“…Regarding the strength of partnership between CMC and the District Health Office, it is found 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)

ii. coordinating with Government directly in the implementation of their activities:

Most LMIC Government mental health programs are chronically underfunded and especially in rural areas (WHO, 2013). SHIFA-HCH is working to address this through partnering with Government health facilities and supplementing these health 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 Herbertpur hospital is committed to run the clinics on a fortnightly basis and provide medication at low prices...” (SHIFA-HCH)

CMC also provides ongoing support to trained health workers to support them technically in implementing quality Government mental health services.

IAM 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.

iii. opening channels of communication and information-sharing:

The coordination between Government and NGOs is an important forum for ensuring that the voices of people with psychosocial disability, their families and communities are shaping Governments’ strategic planning and implementation at national, district and local levels. IAM, SHIFA-HCH, and CMC work at the community level and work to create linkages between Government services and SHGs or DPOs, which strengthens inclusion for people with psychosocial disability.

“The health facilities management committees and Village Development Committee have supported [the SHG] to conduct awareness campaign at community level. This helped enabled people with mental health issues to be better included and integrated within their communities.” (CMC)

“The project manager created a link with the mental health department of Ministry of Public Health. Now they have good cooperation with the project and they are always involved and give ideas and feedback about most of the project activities such as printing magazines, brochures and flipcharts. This facilitated information sharing and building relationship with the other stakeholders. We found it very important to be in contact with the ministry and we will continue being very active in this regard.” (IAM)
**FINDINGS**

**WORKING WITH GOVERNMENT TO STRENGTHEN MENTAL HEALTH INITIATIVES**

**d) Using evidence to support advocacy initiatives**

IAM, SHIFA-HCH and CMC also work in advocating for effective health and social systems through utilising data and supporting the sharing of lived experience stories to increase understanding of need and scope for action.

“Wealth this new development in the field of networking, [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 area of Sadoli block as well as ...showing our credential of work in the field of mental health so far.” (SHIFA-HCH)

“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)

**e) Addressing institutional barriers**

Many LMICs have existing laws and policies which are major barriers to the inclusion of people with psychosocial disability. Drew et al highlighted how people with mental health and psychosocial disabilities “experience violations of many civic, cultural, economic, political and social rights” and that this constituted “an unresolved global crisis” (2007, pg. 1664). In India, for example, a person perceived as having a mental impairment may lose their right to vote, marry, and choose to have children, inherit land or make a will (Carrol et al, 2011).

In Nepal, a diagnosis of a psychosocial disability is a barrier to career choices. This reinforces the need to strengthen the voices of people with lived experience. This is also relevant in fragile contexts where applying rights based approaches’ though valuable, have recognised complexity.

In both India and Nepal, people with psychosocial disability are often not permitted to access disability Government benefits. SHIFA-HCH and CMC facilitate people with psychosocial disability to access these benefits and advocate for wider recognition of psychosocial disability. An example from an SHIFA-HCH project is given here:

“While discussing about the increased awareness of the beneficiaries on their rights, most of the key informants reflected that the beneficiaries have developed confidence to demand services from the health service centres and Village Development Committees but they are not aware on what rights they are entitled to and how to access and claim their rights.” (SHIFA-HCH)

SHIFA-HCH and CMC work with local and national DPOs – both psychosocial disability-specific DPOs 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.
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**Awareness-raising**

Awareness-raising initiatives are closely linked with advocacy and form a key component of efforts to break down stigma (Pinfold et al, 2005; Mehta et al, 2015). SHIFA-HCH, CMC and IAM’s work share commonalities in their effective awareness-raising approaches. All three organisations implement these activities through a community development lens and seek to raise awareness of mental illness and psychosocial disability in order to strengthen community dialogue, resilience and problem solving.

The organisations utilise different awareness-raising 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 IAM’s work found that:

“[The project’s] multi-faceted approach to building awareness has been effective. The training targeted influential people within society as well as students at the right level to enable systemic change.” (IAM Evaluation 2016).

The different awareness-raising mediums have had a number of positive outcomes including; i) increasing utilisation of services and care; ii) reducing stigma; and iii) promoting rights-based awareness. Some examples are given below:

“[The] awareness in terms of knowledge perception and attitude has been raised. Individuals and families started taking treatment from Herbertpur Christian Hospital run clinic locally. 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.” (SHIFA-HCH)

“She asked patients and their family member 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 patient said that they know from TV program which CMHP have one hour weekly regarding the mental health.” (IAM - An IAM staff member interviewed people at the health clinic)

“This type of awareness also has helped reduce stigma and discrimination against the mentally ill. People now see these persons as normal sick persons who need timely treatments.” (SHIFA-HCH)

There are several stories from IAM, SHIFA-HCH and CMC where people who have been involved in training have reflected on the training and seen the value in it for their own lives.

“It’s almost 25 years that I have been working as a teacher in different schools and have participated in many workshops... The reason that this workshop is valuable is because I have been suffering some health problems for the past 4 years and I have visited many doctors inside the country and also abroad. I took different kinds of medicines and prescriptions but it didn’t help me to get rid of my problems. By participating in this workshop, I realized that the cause and the root of all my physical problems may have been mental problems which I never thought about. I highly appreciate all whom are involved in conducting these mental health workshops, the content of these workshops is a big support and has a high value for vulnerable people.” (IAM - teacher attending training in Herat, post-training evaluation form)

“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...” (IAM Evaluation 2016)

The challenge is to continue awareness-raising not only about signs and symptoms and where to seek medical assistance, but importantly around inclusion aspects and social determinants so that balanced conversations at community level are entered into.
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MAINSTREAMING

In strengthening inclusion approaches for people with psychosocial disability, it is important to consider the role of other organisations, multiple Government sectors and different actors within each context (Raja et al, 2012; Hanlon et al, 2014). This aligns with a community development approach, which does not see problems as inherent in individuals, but connects locally-based solutions to wider issues of power, participation and social and economic justice, which are supported by a range of stakeholders. The importance of mainstreaming knowledge and practice of inclusion are particular features of IAM, CMC and SHIFA-HCH’s work.

IAM, CMC and SHIFA-HCH implement a variety of community development projects within their organisations. They are able to leverage learning from their mental health projects and build these learnings into more general development programs. Learning from mainstreaming can also then be fed back into mental health projects.

“SHIFA-HCH, 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.” (SHIFA-HCH)

“Integration with other programs ... will (help people to) understand the importance of mental health program and (to) take interest how mental health is integrated with nutrition, family planning, immunization and institutional delivery government nationalised program.” (SHIFA-HCH)

IAM has been invited to give mental health training and provide awareness materials to private health clinics and several INGOs. This mainstreaming of mental health knowledge is important in promoting inclusion more widely. IAM’s work also includes working closely within the education sector. Their work with teachers and students is important in raising awareness and mainstreaming mental health knowledge.

“IAM with close cooperation with Education directorate conducted different Awareness ceremonies in 6 schools where girls and boys came up together and got information about mental health. These gathering were a great time to get together and share information about the topics of mental health awareness week. In one girl’s school the students produced a drama about family conflict and its mental health effect on children. IAM distributed magazines, brochures and gave the soft copy of the mental health awareness materials to the principal of school to distribute to all students.” (IAM)

It is also important to consider how to include 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 appear to lack access to awareness raising initiatives and knowledge (IAM Evaluation, 2016).

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

“IAM 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 IAM conducted training for the teachers.” (IAM)

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.

Networking, sharing knowledge and mainstreaming mental health knowledge within a LMIC context is crucial for inclusion of people with psychosocial disabilities, both within communities and for the purpose of advocacy to address broader issues of inclusion.
The experiences of IAM, SHIFA-HCH and CMC provide a useful and insightful way in which to look at some of the barriers and enablers to the inclusion of people with psychosocial disability in community development across three LMIC contexts. Their approaches are supported by literature and provide opportunities for further research into the lived experience of people with psychosocial disability in LMICs.

The importance of strengthening the voices of people with psychosocial disability and seeking to understand the sociocultural context towards inclusion remain crucial. Combined approaches, which work at a grassroots level in creating change through communities’ collective action, in addition to strengthening public health systems and policy development ensure a holistic approach to inclusion. NGOs 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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“Integration with other programs ... will (help people to) understand the importance of mental health program and (to) take interest how mental health is integrated with nutrition, family planning, immunization and institutional delivery government nationalised program.” (SHIFA-HCH)

“IAM 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 IAM conducted training for the teachers and students in the second half of the year.” (IAM)
Community Mental Health Project (CMHP), a project of the International Assistance Mission (IAM), operating in provincial towns and rural villages of the Western Region of Afghanistan. The project has been running for five years. It works off a very low base of awareness and service capacity, in a population where the prevalence of mental health issues is high. The approach utilises available mass media (e.g. local radio and television) to build public awareness of mental health and challenge stigma around psychosocial disability. It systematically trains community leaders and public officials (e.g. religious leaders, health professionals, teachers, police and judiciary) to build a base capacity to respond more constructively and proactively to community members with psychosocial disability. Working closely with the Government of Afghanistan, many of the project’s materials have now been integrated into the government’s own systems.

SHIFA Mental Health, a project of Emmanuel Hospital Association (SHIFA-HCH, EHA), operating in rural villages in the north-west of Uttar Pradesh State, India. Four years into its implementation, this project works into a context where mental health services (both locally and at a district level) are not available apart from a few private, but often inaccessible psychiatrists. The Herbertpur Christian Hospital (www.hch-eha.org) assists the project to run fortnightly clinics to support the provision of mental health services to these communities. People with psychosocial disabilities may have entitlements under Government poverty alleviation schemes, but of which they are often not aware, or from which they have been excluded. The project seeks to empower people with psychosocial disabilities to better access the services and entitlements that are their rights, and to mobilise their families and communities in support and advocacy.

Community Mental Health and Psychological Support, a project of the Centre for Mental Health and Counselling (CMC Nepal), has operated for over 10 years in rural districts throughout Nepal. Traditionally, the project has sought to increase capacity in medical and therapeutic efforts on two main fronts. Firstly, through high-level advocacy and participation in policy formation, to see mental health properly represented in national health policy, structure and provisioning. Secondly, through systematic training and supervision of front-line government health personnel in selected districts, to build capacity to diagnose, treat and refer people with mental illnesses. The project is currently integrating a social approach to mental health in its areas of coverage, recognising that the working interface between mental health services and community may not (probably will not) be sustainable without development on the community side. The project is organising and empowering people with psychosocial disabilities and their families to effectively interface with services, support one another and challenge exclusion in their communities.
THE FOLLOWING IS A LIST OF THE REPORTS AND EVALUATIONS THAT FORMED THE BASIS OF THE PRACTICE REVIEW

Community Mental Health project – IAM
- Project annual report 2013
- Project annual report 2014
- Project annual report 2015
- 2016 TEAR Australia field visit
- Project Evaluation report August 2016
- Transcripts of semi-structured interviews with people with lived experience of psychosocial disability in Afghanistan (x7).

Community Mental Health and Psychosocial Support Project – CMC
- Annual project report 2013
- Annual project report 2014
- Annual project report 2015
- Community Mental Health and Psychosocial Support Project Evaluation 2014
- Report of the Psychosocial Intervention to the Earthquake Survivors 2015
- 2015 TEAR Australia field reports (x2)

SHIFA-Herbertpur Christian Hospital – EHA
- Annual project report 2013 - 14
- Annual project report 2014 - 15
- Project Evaluation, 2014
- Response to recommendations, 2014
- 2015 TEAR Australia field reports (x2)


REFERENCES


“There is strong evidence from global mental health initiatives internationally that skill building, mental health promotion, youth resilience, and community based interventions are all effective and needed in low resource settings” (IAM evaluation 2016)