safar
ON THE ROAD TOGETHER

Theme: Community Mental Health

Discussion among a group of young women, participating in an EHA youth resilience programme (Photo- Kaaren Mathias)

Editorial

Mental disorders are expected to represent 15% of the global burden of diseases by 2020 and WHO estimates that globally, one in four families is likely to have at least one member with a behavioural or mental disorder. Even if provided with physical and emotional support, these families still have to bear the negative impact of stigma and discrimination. But unlike earlier periods, where treatment of patients with mental illness was limited to the mental hospitals or asylums, the introduction of community based mental health ensured easy access to affordable, quality, mental health care for the affected persons. Community based mental health care focuses on prevention, treatment and care for the affected persons at the community level, along with the necessary psycho-social support systems. These community based services increase social inclusion and can reduce neglect and violations of human rights.

The Government of India launched the National Mental Health Programme (NMHP) in 1982, keeping in view this heavy burden of mental illness in the community, and the absolute inadequacy of mental health care infrastructure in the country to deal with it. The District Mental Health Programme (DMHP) envisaged a community based approach to the problem, which included awareness about mental health problems and treatment of mental disorders in the community. In 2014 the national Mental Health Policy was launched, and this year in April, the new Mental Health Care Act was passed.

EHA is working actively in community mental health in five different North Indian locations. It seeks to increase awareness and reduce stigma of mental illness in the community, as well as support recovery and healing for affected families. This community based care encourages community members to accept people with different behaviours, support them in their journeys to wellbeing, and to collectively advocate for increased access to care.

This issue of Safar gives ideas on how all work in community health and development can seek to include and support people with mental distress and psycho-social disability.

Feba Jacob and Kaaren Mathias

WHAT'S inside...

Chacko's Chai Column

People with 'psychosocial disability' have been part of communities since ancient times. In the Bible, the first recorded instance of mental illness is seen in King Saul, who experienced bouts of severe depression and called on David to play the harp, as the music seemed to bring him relief. Once he was homicidal and tried to hurl a spear at David! David himself feigned 'madness' in front of King Achish of Gath when he suspected that Achish may turn against him (1 Sam 21:13).

Our EHA hospitals have been experiencing a rising number of cases of attempted suicides. However, patients with various psycho-somatic illnesses and depression have been frequenting our units for many years. Wherever psychiatrists or counsellors have joined our units they have had their hands full.

India is one of the countries where mental illness has been mainly associated with superstitious beliefs and stigma. Even educated people tend to deny the existence of mental illness and refuse to go to psychiatrists for help, for fear of being labelled as 'pagal'. Maybe that is one reason why so few psychiatrists exist in our country, with a ratio of 1 psychiatrist for 300,000 people! How can we as EHA make a difference in the lives of literally millions of people, suffering from both common and severe mental disorders, often subjected to ridicule, rejection, isolation and violence due to ignorance and superstition among communities?

Most people desire acceptance, approval, encouragement and security for their own personal lives. When society shuns them and refuses to love them, they end up with various mental disorders, from common to severe, which affect their quality of life. Our Shifa project helps to increase awareness and reduce stigma of mental illness in the community, by training volunteers in understanding mental illness and reducing fears people have about things that they cannot understand or control. This encourages people to accept people with different behaviours, understand them, and even care for them.

The Nae Disha curriculum by Burans project enables adolescents to develop a strong self-image and self-acceptance so they develop resilience and can handle emotional issues better.

The SHARE project has done a tremendous job identifying and assisting patients with severe mental disorders, such as schizophrenia, to access treatment from government doctors and slowly return to a normal way of life.

We still have a long way to go… but it's wonderful to see the significant transformation in the lives of both patients and families through the efforts of our projects. May the love of Christ continue to lead us to those marginalized and neglected people in society who seem to have no one else to care for them. God loves each of them who are made in His image and hence have a real value in His eyes. We often tend to look down on people who are weaker or have different or unusual lifestyles. Let us remember the story of the 'lost sheep' recorded in Scripture, where the good shepherd leaves the 99 others to care for the one lost sheep. May we as His followers do the same in reaching out to our brothers and sisters who are uncared for and unloved in society because they are 'different'.

Dr Ashok Chacko, *Director - EHA's Community Health and Development Programme*

Devotion

Community Mental Health

[*Rev. Prakash George*]

Mental health is affected by how we think, feel and act. People act on the interpretation of facts and information they have. There are times when they act in the same way as others or as the majority does. Ultimately the action results from the heart. The interpretation depends on their world view, experiences, and knowledge gained from various sources such as religious texts. Communities can act for good or for bad or remain mute spectators depending on the information and facts and the interpretation of the same. For example, we read in Numbers 13 and 14 that 12 spies from the people of Israel were sent to Canaan to spy the land. All returned and reported their observations and facts. Ten interpreted it one way and two interpreted it differently. The people of Israel heard the facts and accepted the interpretation of the 10 with the result that they did not want to occupy the land of Canaan. This also resulted in the people of Israel wandering in the wilderness for 40 years and the people who had seen God's miraculous signs in Egypt not entering the Promised land.

Before entering the Promised land, Moses instructed the people to keep the word of God in heart (Deuteronomy 6: 5-9). God's word residing in our hearts and minds will ensure right action. It is not only for communities, but also for individuals. It is important that as we interact and provide service to the community, we provide the right instructions so that the mental health will be capacitated with the hope they will do what is right. Being sinful we can still do what is wrong despite being instructed from God's word. But we work with hope that communities will do what is right and they will have sound mental health. As Paul says, "Do not conform to the pattern of this world, but be transformed by the renewing of your mind. Then you will be able to test and approve what God's will is – his good, pleasing and perfect will." (Romans 12: 2)

World Mental Health Day (10 October) is a day for global mental health education, awareness and advocacy against social stigma. It was first celebrated in 1992 at the initiative of the World Federation for Mental Health, a global mental health organization with members and contacts in more than 150 countries.

This day, each October, thousands of supporters come to celebrate this annual awareness program to bring attention to mental illness and its major effects on peoples' life worldwide. In some countries this day is part of an awareness week, such as Mental Health Week in Australia.

From pagal[1] to people - community mental health work in EHA

[By Kaaren Mathias (MBChB, PhD),
Mental health programme manager – Emmanuel Hospital Association]

Spending time sitting and listening to a person with mental distress is one of the most effective ways to support healing (Photo- Kaaren Mathias)

I had very little control of my anger and would even throw a knife. I used to tell people to leave me alone, but my husband and family used to take me outside to sit in the sun and would sit with me. They also took me to the doctor. … After some time, I started feeling like cooking and waking children up for school. I started thinking about them. I started trying... So slowly I started getting better.

34-year-old woman with psychosocial disability

Up to 90% of people in India with mental disorders do not have access to evidence-based care, and neuro-psychiatric disabilities contribute up to 11.8% to the overall burden of disease in India (1). The described prevalence of depression in India varies from 5% to 30% (2) yet all agree that there are scores of people in India disabled by depressive symptoms who have little support and access to care.

Some of the challenges of community based care for people with mental distress (PWMD) in India include widespread stigma and discrimination,

under-resourced mental health services (for example India has just one psychologist for six lakh people), and low funding (mental health services were allocated just 1.6% of the health budget in 2011). The District Mental Health Plan (DMHP), launched in India in 1996, has been poorly and incompletely implemented across the country. However, there is increased government action for mental health, with a new Mental Health Policy launched in 2014 and the new Mental Health Care Act passed in 2017.

The Indian context also provides unique opportunities. The vast majority of PWMD in India live with and are cared for by family members, and are often well integrated in their communities with opportunity to participate in community social and religious functions. However, most people with mental illness experience stigma and particularly those with severe mental disorders are socially excluded.

Setting

The community health and development programme of EHA began a focus on mental health in 2010. EHA currently has four psychiatrists in Uttarakhand, Bihar, Central Uttar Pradesh and Assam, and five community mental health projects located in Fatehpur in central Uttar Pradesh, Bijnor and Saharanpur districts, western UP, Dehradun district, Uttarakhand and East Champaran district, Bihar, India. In all our projects, we spent the initial months seeking to understand the realities of life, health and ill-health for PWMD. Key learnings in context analysis are listed below:

[1] Pagal in Hindi is a term used to refer to people who are 'crazy' or 'mad'

1. Help-seeking efforts are monumental - PWMD and their families are making enormous efforts to find care. Most of the families spend high resources of time and money seeking help and in our base-line study in Dehradun we found that nearly 80% of people with depression had been to a health provider in the last three months (3).
2. PWMD and their families are particularly vulnerable to exploitation, irrational care, excessive investigations and medicines at the hands of private providers.
3. Community members have very little knowledge about mental illness. E.g. post-partum psychosis may be understood by some as contagious, by others as a 'drama' to avoid work.
4. PWMD have a dominant experience of social exclusion which ranges from more subtle distancing and negative judgements to verbal violence (public ridicule and taunting), economic violence (disinheritance), and physical violence. We have written about experiences of exclusion and inclusion in depth (4).
5. PWMD have a hugely increased premature and preventable mortality. This includes young people with untreated epilepsy as well as related to neglect and low knowledge (e.g. people with schizophrenia with treatable infections who were not taken to access curative care).
6. The social and political determinants of health such as low education, poor housing, being a member of an oppressed caste, and debts hugely increase risk of mental illness (3).

Working with people with mental distress in support groups is another effective strategy (Photo- Kaaren Mathias)

Programme objectives and learnings

- To be an organisation that provides welcome, effective evidence-based care, and healing for people with mental disorders in all our clinical services.
- To build capacity in community based mental health at all levels.
- To understand and support effective community based mental health promotion.
- To contribute to national understanding and knowledge of effective community based mental health promotion and community based services.

The characteristics of PWMD identified in our five mental health projects are summarised in Table 1.

Table 1 – Overview of PWMD identified in EHA community mental health projects as at March 2017 (as Fatehpur is in starting phase they are not included here)

LOCATION	TOTAL PWMD	NUMBER CMD	NUMBER SMD	NUMBER EPILEPSY	NUMBER OTHER EG INTELLECTUAL IMPAIRMENT
SAHARANPUR, UP	578	330	122	96	33
BIJNOR, UP	1315	286	330	656	43
DEHRADUN, UTTARAKHAND	656	492	78	77	9
EAST CHAMPARAN, BIHAR	445	280	113	52	0
TOTAL	**2994**	**1388**	**643**	**881**	**85**

Key learnings

1. We needed to provide mental health services (clinical and community based) to assure PWMD that there are steps that can manage symptoms and bring healing. This in turn was critical to help build a group of PWMD consumers to advocate with government providers.
2. Government services are stretched with very high out-patient loads, and are highly variably in quality and do not provide any talking therapy.
3. Addressing proximal and distal mental health determinants such as employment, stigma and discrimination and social inclusion seems critical but is more difficult than providing clinics.
4. Building capacity of project team and community members and developing resources to support this has been essential and needed large training resources.
5. Building knowledge and awareness of mental health among community and health providers such as ASHA workers has been important to identify people affected.

EHA - Model of care for people with mental distress

The EHA model of care conceives of three key steps, illustrated below in Figure One:

Figure 1 EHA Model of Care of people with mental distress

Wellness skills
Self-care and agency
5 Kadam (steps)

Talking therapy - support group, therapeutic group, counselling and CBT, IPT

Medicines - needed for some people with common mental disorders and most people with severe mental disorders. Part of this step is acknowledging the power of Dua and Dawa (Prayers and Medicines) for many PWMD

Step One - All people with mental distress need support and capacity building to build their own skills such as social skills and friendships, stress management, gratefulness, problem solving, and effective interpersonal communication skills. We have developed a manual titled "Nae Disha – building youth resilience" to build emotional resilience and personal mental health skills. Another resource (5) that we have adapted uses five steps - Give, Connect, Keep learning, Get active and Take Notice - to prompt actions for mental well-being (see Figure 2).

Step Two - In addition to this, some people with mental distress can benefit significantly through talking therapies. We are keen to explore options on the therapeutic potential of SHGs and other community based organisations as they are not dependent on mental health professionals who are in short supply across most of India.

Step Three - Adding further to personal skills and talking therapies, for some PWMD, there is significant benefit from short or long-term use of drugs. Ensuring that all PWMD have the opportunity to access mental health services and specialists is also key for all of our programmes.

Summary

Working in community mental health in rural North India is both exciting and overwhelming. Stories like that quoted at the opening of this article remind us of the slow steady opportunities for healing with the support of family and friends. There is huge need and opportunity to bring healing and transformation for thousands of PWMD and families who are currently

isolated without care or support. It is clear that we must acknowledge the cultural context and give psycho-social support as well as the care of bio-medicine. Models of care are working drafts and continue to be developed iteratively. Documenting and writing about what we are learning seems morally required in a context where there is very little written about effective community based mental health programmes in North India. We journey on with small steps.

References

1. World Health Organisation. Mental health atlas 2011. Geneva: WHO; 2011.

2. Poongothai S, Pradeepa R, Ganesan A, Mohan V. Prevalence of depression in a large urban South Indian population--the Chennai Urban Rural Epidemiology Study (CURES-70). PLoS One. 2009;4(9):e7185.

3. Mathias K, Goicolea I, Kermode M, Singh L, Shidhaye R, Sebastian MS. Cross-sectional study of depression and help-seeking in Uttarakhand, North India. BMJ Open. 2015;5(11).

4. Mathias K, Kermode K, San Sebastian M, Korschorke M, Goicolea I. Under the banyan tree - exclusion and inclusion of people with mental distress in rural North India. BMC Public Health. 2015;15(446).

5. Mental health foundation of New Zealand. Five steps to well-being. Wellington: Mental Health Foundation of New Zealand; 2012.

Rani, a Burans community worker in Mussoorie, seeks to listen to a distressed community member (Photo- Kaaren Mathias)

Success Story

From SHARE project
David Abraham, Project Manager

Om Prakash

Om Prakash, 32 years, was a semi-skilled labourer suffering from psychosis for the last three years. He was very aggressive and would physically abuse his wife. He had to leave his job because of this mental disability.

Om Prakash's family admitted him to a private psychiatric clinic in Moradabad district for about eight days. He was given shock treatment but there was no improvement in his health status and he continued to behave aggressively.

SHARE project staff came to know about this case and made regular visits, encouraging the family to access treatment from government doctors. As a result, they took him to a Government Mental Hospital where he started taking medication, and after a few weeks he began responding to his wife and children. Seeing the improvement in Om Prakash's health, his wife dropped the idea of leaving him. Over time there were significant changes in his behaviour. He started working in the fields earning money for his family, began to have social interaction with friends and neighbours, and started taking responsibility, thus returning to a normal way of life.

Afsana Khatun

Afsana Khatun, 30 years, was a semi-skilled worker who earned money from making Bidi (locally made cigarette).

A few years ago Afsana ran a small shop in her house. Her earnings of about 6000/- Rs was stolen and she became upset, very quiet, restless, and sleepless. Later she started developing psychotic symptoms and was admitted to hospital, but she discontinued her medication. The SHARE team had conducted mental health awareness in Afsana's village and with the encouragement of the SHARE team she started taking medication again.

Now Afsana is alright, doing her day to day routine work at home and also doing her previous work making bidi to earn money. In this way social inclusion is taking place.

Story of Task Force Group, Nayi Roshini Project, Duncan Hospital, Raxaul

Nalini Khristi, Nayi Roshini, Mental Health Project

Nayi Roshni project, Duncan hospital located in Raxaul, works on the social determinants of mental health and various mental disorders. In this project the local people work with and for their own people and the so called Task Forces form the backbone of the project. Each of the participating communities builds up a Task Force consisting of four men and four women who are chosen by the communities themselves. Now, 41 out of 65 Task Force Groups are active in their communities and we found that many success stories are coming out of their work.

The Task Force members receive training about mental health and its social determinants. This training capacitates them to teach groups and to interact with people suffering from mental disorders. In their day-to-day interactions they identify people suffering from mental disorders or at risk of developing a mental disorder. The Task Force Groups address local issues related to domestic violence, familial conflicts, alcoholism, and suicide attempts. They are helping to deal with issues related to the rights of people living with mental disorders. Moreover, they identify and refer patients to the hospital for adequate management. The majority of patients do not have the money for medical treatment. The Roshni Project staff motivated 20 Task Force Groups to address the problem and they began to save money that could be used for people who are poor.

These groups are working voluntarily. We have provided banners and ID cards for each group so they do not face difficulties doing their work.

A telephone interview with Ms Laboni Roy

Assistant Director (Projects), Iswar Sankalpa, Kolkata

[*By Feba Jacob, Editor, Safar*]

Safar - *Could you please share about your organization's work in the area of Community Mental Health?*

Ms Laboni Roy - Iswar Sankalpa is a non-profit organization started with an objective of ensuring the dignity and holistic well-being of homeless persons with psycho-social disabilities on the streets of Kolkata. These people mainly belong to economically backward and socially marginalised families. They are often seen, in various states of mental distress and physical abuse, around railway stations, bus stands, pilgrim centres and on street corners, separated from and/or abandoned by their families. What led to the beginning of Iswar Sankalpa was the scene of a man scrounging for a meal from local garbage vats. The journey of Iswar Sankalpa thus started from 2007 to address this issue of mental illness or psycho-social disability with an emphasis on social recovery with medical intervention.

Safar - *What are your organization's key initiatives in community mental health?*

Ms Laboni Roy - A pilot study in 2007 initiated the process of identification and mapping of homeless persons with psycho-social disabilities on the streets of Kolkata. As well as identifying persons with mental distress, we also started to enquire about the resources for these people to survive. For example, people such as tea stall owners with whom these people are in contact, and from whom we could learn more about the person with a mental disability.

Mental health camp

We started to conduct mental health camps for isolated individuals in the streets in highly populated areas, to help them by giving care and medicines. With the help of social workers and community people, we brought people with mental disability to the camp where the psychiatrist diagnosed their illness. Our approach of love and care brought changes within the community where there was a lot of stigma and fear. We continue to run these medical camps. The social worker assesses how the client meets their daily hygiene needs and if s/he is involved in any work, and often tries to identify a caregiver from the surrounding community who volunteers to care for the client in various ways such as providing daily medicines, providing food, involving him/her in some work, or providing a shelter for the night. So along with identification of ill people we emphasize finding caregivers through awareness camps, CBOs, and medical camps. Our medical camps and awareness meetings help to identify more clients, and also to educate the local community on mental health related issues.

Outreach programme

In June 2007, we started the outreach programme "Naya Daur", a mental health intervention project with a difference. This is a community based outreach programme providing psycho-social interventions for homeless persons with psycho-social disability. With the help of community caregivers and community resources this programme continues to operate.

Social rehabilitation - *Drop in rehabilitation centre*

From 2007-2009 the main purpose was giving homeless people proper care and treatment. In 2009, we found that people who received constant care and treatment started asking to learn something. While working on the streets we found that police treat these people as criminals or as law breakers, so we started advocating to the police that they are not law breakers but people

with psycho-social disabilities. In 2009 a Drop-in-Rehabilitation Centre (DIC), officially named as the Dr. K. L. Narayanan Rehabilitation Centre, was started at a space provided by the Kolkata Police within the premises of Hastings Police Station – the first of its kind in the country. These centres are a therapeutic day-care centre for the physical, emotional, psychological and social integration and well-being of homeless persons with psycho-social disability. They started making paper packets. Now the Kolkata Police have been increasingly involved in the project and are key partners in identifying people needing care, and are a necessary part of the legal process involved in taking care of persons on the streets. The drop-in centres are within the community and local people as well as the police can see that these people are not law breakers but are like us, receiving treatment and care.

Restoration

Eventual re-integration of the person back into the community – and if there is one, the family - is also a significant goal of Iswar Sankalpa. The goal of rehabilitative activities is to empower every client to create an independent living. When they get involved in these activities and therapies they become more communicative and responsive and give their home addresses and family details, which leads to restoration to their families. This is done in collaboration with the Kolkata Police and other government agencies. The philosophy behind the restoration process is to facilitate and foster independent community living of our clients, so that they may live a productive, dignified life in society, and are able to become contributing members of society.

Shelter homes

Considering the safety and security of women we also started a shelter home. Homeless women with psycho-social disabilities who live on the streets are very vulnerable to different kinds of abuses, and the community care model leaves them at risk of physical and sexual violence. Thus the first shelter for urban homeless women with psycho-social disabilities, Project Sarbari, was founded on April 2010 in collaboration with the Kolkata Municipal Corporation.

Urban mental health programme

The Urban Mental Health Programme (UMHP) was initiated in partnership with the Kolkata Municipal Corporation. This project aims to integrate mental health services with physical health care services in the primary health care setting. UMHP focuses on the preventive aspects of mental illness and health – and thus leads to quicker intervention.

Safar - *What are the challenges you faced while working with communities in this field? How did you overcome them?*
Ms Laboni Roy - Well, the stigma attached to mental health conditions is the major challenge faced in every stage of our work from the beginning till now. The person is stigmatized and excluded from his family. Stigma exists across all economic and socio-cultural statuses. But as we started working, the increase in the number of community caregivers was a significant indication that the stigma has been reduced. This is an ongoing process and we continue to engage with people.

Safar - *What are the ideal roles and responsibilities of NGOs in community mental health?*
Ms Laboni Roy - NGOs can address this issue and identify persons with psychological disability in the community they work in, and can provide psychiatric services or other therapeutic services for the identified persons. NGOs, as they work at the community level, can identify community volunteers who help them to work more, at the ground level. If the NGOs are working in mother and child health, awareness on mental health can also be increased because many mothers and children are suffering from psychological issues which are not identified.

Thank you so much Ms Laboni for your input!

CHDP NEWS

- ★ A training on Disaster relief management was organized at Naveenta, Delhi from 15th to 17th March 2017
- ★ CHDP Annual reporting meeting was held at Dehradun from 21st to 25th of April 2017
- ★ A WOTR (watershed) training was organized at Premjyoti Hospital from16th to 18th May 2017
- ★ A training on Child protection policy was conducted at Naveenta, Delhi on 25th July 2017
- ★ A WOTR (watershed) training programme was organized at Lalitpur from 22nd to 24th August 2017
- ★ Nae Disha - building youth resilience training was held at PTS Dehradun from 11th to 14th September 2017

Upcoming Events

CHDP Half Yearly Reporting Meeting
Date: 20th to 22nd November 2017
Venue: Naveenta, Delhi

NEXT ISSUE OF SAFAR
Safar Issue 25 is focusing on
40 years celebration of CHDP
Editor – Feba Jacob
Co-editor – Kaaren Mathias
Layout & Graphic – Suanlian Tangpua
Proofreading – Jane Mountier
Translation – Renuka Milton

HR MOVEMENTS
By Hemlatha

Appointments

Ms Pooja Pillai	Project Coordinator	Burans Project, Dehradun
Ms Kakul Shelly	Project Officer	Burans Project, Dehradun
Ms Pooja Rani	Community Coordinator	Burans Project, Dehradun
Ms Vijeta Katariya	Project Coordinator	Burans Project, Dehradun
Ms Jyoti Khosla	Project Coordinator	Burans Project, Dehradun
Mr Bright Luke	Project Officer	CHDP Herberpur
Ms Geeta	CBR Worker	CHDP Landour, Mussoorie
Ms Poonam	Community Coordinator	CHDP Landour, Mussoorie
Mr Jerry Martin	Project Officer – Documentation	CHDP Landour, Mussoorie
Ms Kanchan Hembrom	Community Coordinator	CHDP Madhipura

Click to download this issue in .pdf