COMMUNITY HEALTH DIMENTIONS

A SOCHARA – SOPHEA NEWSLETTER Issue No. 4 June 2016

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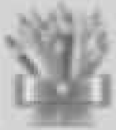


Editorial

The SOCHARA silver jubilee on 16th April 2016 offered an opportunity to look back, look around and look ahead with regard to individual and collective community health journeys. It was also an occasion to express deep gratitude from the team to all fellow travelers, past and present, of the SOCHARA journey.

Looking back brings memories of shared journey's and commitments towards Health for ALL (HFA). We remember the solidarity experienced with so many individuals, organizations and networks; the work undertaken with diverse communities through varied initiatives, including community health approaches to public health problems: and the numerous challenges encountered in this rather *'tortuous road to Health For All'* as described by Dr. Halfdan Mahler. Dr. Mahler was the Director General of WHO at the time of the Alma Ata declaration in 1978 and made this comment in 2000 when he joined the People's Health Movement (PHM). The twenty five year collective organizational life experience of SOCHARA has strengthened the resolve among many of us to continue efforts towards Health for All, with renewed energy and younger HFA enthusiasts. New strategies are required to address both chronic and emerging health and development challenges, while building on the learning from the journey so far. Several challenges including gender issues impacting health and well being; environmental and ecological issues; to name just two were inadequately recognized and understood in 1978. Operational mechanisms for widespread community participation and community action for health at scale, were missing then. HFA aspirations were based on the positive experience of small NGO initiatives. Community health workers and health committees were two simple, but power filled initiatives by NGOs, which worked well in diverse social and cultural settings. There is now greater clarity with regard to some challenges, as well as improved capability in addressing them. Societal barriers in working towards the HFA dream have been experienced, while determined collectives have emerged across all continents, to carry forward the unfinished task which is in the interest of everyone.

Looking around we saw progress in several areas, with new insights. These include the entry of large numbers of young people, enthusiastic, capable and keen to work for HFA; together with efforts at community action for health at a large scale through the National Rural Health Mission now the National Health Mission. While movements such as those of persons with disability or special abilities; the women's movement; the environment movement and other social movements have added great value to the struggle for social justice in health, there is also a more somber picture of unfulfilled promises, adverse effects of climate change, and widening disparities in health despite increase in wealth and knowledge.

Looking forward will be the process that unfolds within SOCHARA with a transition of leadership. This space is consciously being kept open and unfilled in order to be filled by creative new thoughts and actions.

Two workshops held in April 2016 in Bengaluru and Bhopal brought together fellow travelers to share in the celebration and discussions on important themes particularly environmental health, communitization of the health system with Community Action for

Health. The reports in this issue highlight important points raised during the sessions. A '*Faded Pants'* experiment adds insights.

Discussion on **Mental Health** elicits a range of diverse perspectives and opinions, with sometimes very strongly held views and polarities. The October 2014 National Mental Health Policy of India titled **"New Pathways, New Hopes"** was developed by a mental health policy group representing diverse stakeholders including user's, carer's, activists, NGOs, psychiatrists, public health and health policy specialists and health administrators. A process of literature review, review of the District Mental Health Programme (DMHP), visits to various institutions, and wide consultation led to the policy being adopted by the Union Ministry of Health & Family Welfare and launched by the Union Health Minister. Implementation is a major challenge. Active participation by civil society, NGOs, and institutions through a process of engagement with active listening and mutual trust will enable progress. The **Medico Friends Circle (MFC)** an important '*thought current*' on health in India devoted its *41st Annual Meeting, 2015* in Pune, to discuss mental health issues from varied perspectives, based on a series of thoughtful articles written in advance preparation for the meeting. *This meeting is reported in this issue* by team members and community health fellows who participated in the meet. An additional article takes some thoughts forward, drawing attention to the *bio-psychosocial model in mental health care*. A People's Mental Health Forum has been formed in Tamilnadu, and informal meeting spaces are evolving in Bengaluru to share alternative person and strength based approaches to supporting recovery, ensuring access to care and participation in social life.

'*A chronicle of a bicycle journey'* by a Batch 12 community health fellow roots us in rural realities of Karnataka and Tamilnadu with reflections on community health. Excerpts from reflections from another Batch 12 Fellow about the *community health learning programme* and his experience in Kalahandi district Orissa with Swasthya Swaraj, takes readers on another journey. Ms. Uma Chaitanya reports on the Health and Safety of Sanitation workers in Kodur, Andhra Pradesh, drawing attention to the need to improve their working and living conditions.

We hope you enjoy reading this issue of COMMUNITYHEALTH DIMENTIONS and look forward to feedback and interacting with you, as always.

Dr. Thelma Narayan,
Secretary SOCHARA

Participants at the SOCHARA Silver Jubilee, 16th April 2016

The SOCHARA Silver Jubilee

Greetings from Dr. Mohan Isaac, President, SOCHARA

The Silver Jubilee meeting commenced with inspirational opening remarks by the President and Vice President of SOCHARA through a video-recording.

*"**Today is an important day. It is a day for celebration and reflection**.................. Now 25 years is indeed a long period in the life of any organization. What started up as a small cell, by few committed individuals for study, reflection and action in the field of Community Health, evolved steadily and grew to become a registered society called SOCHARA.*

The cell which began in the early 1980's was the Community Health Cell for study, reflection and action on issues related to Community Health. It grew to become an organization and by early 90s it was registered as a registered Society under the Karnataka Registrar of Societies Act exactly on 16th April, 1991. I had the singular privilege of being one of the 11 or 12 signatories to that Society registration.

*I am delighted to be associated with the Society during the last quarter century. **The Society for Community Health, Awareness, Research and Action (SOCHARA) did during the past 25 years exactly what the registered objectives were,** raising or creating awareness about community health conducting research into various aspects of community health, documenting and disseminating the important and interesting issues about community health, developing and implementing education and training strategies for community health and contributing to policy development in the field of community health and in the larger area of health both nationally and globally and most importantly promoting community health action especially with the non-governmental and voluntary sectors. These were exactly the objectives of the Registered Society of SOCHARA.*

Now as we celebrate 25 years, it is good to reflect on how far we have come and how well we have succeeded. It is said that any good non-governmental organisation should work towards its own redundancy, in other words you work towards creating those changes that are necessary to make your objectives redundant. Have we succeeded in that? Have we become redundant? On the contrary I believe NO – because, the objectives for which the Society was created are very relevant today.

*There are a number of other issues on which CHC & SOCHARA worked during its initial years - for eg: in the field of Medical Education, have we progressed, have we made ourselves redundant? On the contrary, No. Medical Education is one of the fields, which is in newspapers every day. The Medical Council of India is the most corrupt organization, so much so that the Parliamentary Committee has made very serious recommendations about making the Medical Council of India redundant and making new legislation and regulations for Medical education. Similarly numerous other issues that we were working on those days say 25 years ago for eg: TB control program, we are now faced with treatment resistant Tuberculosis which is becoming a big problem. Environmental Health Action and number of other things... they have not yet become redundant on the contrary the relevance of an organization such as SOCHARA has become more important. **So I think we need to continue working with greater rigour and greater strength.***

*SOCHARA itself is going through certain transitions, certain leadership changes. I am delighted to say it is all going on very smoothly and I have great confidence in the process. We have lots of things to be done in this country. **All the objectives for which SOCHARA was created in 1991 are very relevant today so we need to work together.***

Although I am not physically there today, it's my great pleasure to wish SOCHARA a very happy 25th Birthday and wish all the people, who are actively working for SOCHARA to be a great success.

Thank you very much.

The SOCHARA Silver Jubilee

Dr. Chandra.P, Vice President, SOCHARA spoke with passion

*"Dear Friends and colleagues, **hearty congratulations to the SOCHARA team for the hard work of 25 years.** The last 25 years witnessed great critical, social and economic change all over the world, causing rapid deterioration in the lives of the poor and marginalized. **Under the circumstance it has been good that SOCHARA could carry out all programs without compromising with ideology and principles.** National integration through the Community Health Learning Program, motivating youth to struggle for health rights of the people in health programs; communication of health through Community Action for the National Rural Health Mission are some of its praise worthy programs…………*

What we need today is a broad based alliance..... *with health activists, social activists, academic professional bodies, politicians and representatives and progressive forces to forge an alliance and work together to improve the lot of the people and involve the common public in all our activities.*

I am sure and wish that SOCHARA will continue to play an important role *in the alliance to improve the lot of the people of the country. Friends I am disappointed that I am not with you during these celebrations due to compulsions…… but my spirit is with you all. Once again I congratulate SOCHARA for its notable achievements and send best wishes to continue its hard work and progress well.*

Jai Hind!

SOCHARA Silver Jubilee with South Zone CHLP Alumni Meeting, 15th and 16th of April, 2016

A two day event was organised to mark the silver jubilee of SOCHARA's registration. Though the Community Health Cell (CHC) functioned since January 1984, the registration marked the formalization of the group as an independent body with stated objectives providing the mandate and framework for action, governed by various mechanisms. For the silver jubilee event *environmental health* and '*communitization'of the health system in India* were two important thematic areas taken for deeper discussion. The former reflects a critical contemporary health and development challenge. The latter provides opportunity to develop insights regarding a community health approach to addressing health system challenges. Over 190 individuals attended the technical events on the two days, with at least 125 on each day. More friends and family joined the shared meals.

DAY 1: Environment and Health

The session opened with a melodious song by the current CHLP Batch 12 fellows who come from different states. The MCs for the day Adithya and Anusha introduced the day's theme and the two day programme. Self introductions reflected the rich diversity of participants including community and NGO workers from different states, students, academicians, and SOCHARA associates, all from varying disciplines, linguistic backgrounds and age groups.

Panel 1: Tamilnadu Floods: Narratives of the hyper acute and chronic dimensions of disasters

Chair: Prof Shanmuga Velayutham, Chennai

The chairperson mentioned that there were hyper acute and chronic effects, as well as responses to the 2015 Tamilnadu deluge. The floods impacted four districts of the state with Cuddalore being the worst affected. The capital Chennai however was the only one in the media spotlight. Citizen and civil society responses were heroic and widespread across districts, reducing distress and creating opportunities

for policy makers, politicians and bureaucrats to learn lessons.

Impact of Floods on people living with HIV : Ms. Kausalya, PWN, Chennai

Ms. Kausalya from Positive Women's Network (PWN) a national group which joined the *Jan Swasthya Abhiyan* and MNI (*Makkal Nalavalzhvu Iyyakam*) in 2007, narrated her group experiences working with HIV positive women affected by the floods. 1789 families who had lost medicines were reached. 75% of these families were severely affected by the floods. Home visits to 288 families revealed that many required extended support. The reach to health care facilities during the floods for ART (anti-retroviral therapy) was difficult, adding to other distress such as loss of dwelling, documents, medical records, food grains, etc. The previous Tsunami experience had no such consequences, because water receded rapidly and connectivity was re-established. The disaster impacted everyone, with the marginalised being most adversely affected, particularly lactating mothers, pregnant women, people living with HIV/AIDS, persons with disability, and the elderly. Kausalya recommended that marginalised groups including the homeless, *Dalits*, people living with HIV/AIDS should receive priority attention during disasters.

Causes and impacts of the floods: Arul Selvam, SACEM

Mr Arul Selvam from Cuddalore shared that this deluge was the first experience of its kind for most people in the district. The first episode of rain in Cuddalore was on November 9th and 10th, 2015. It rained 500 mm over two days, which was equivalent to the entire annual monsoon rains, flooding the entire region and destroying catchment areas. Of 44 reported deaths, 32 underwent post-mortem. There is no knowledge about the rest of the deaths. The second government warning was issued for 15th,16th, 17th of November 2015. The second episode of rain caused much disruption of daily life - provision shops were closed, essential supplies cut off. There were instances of people begging for food, because there were no grains, firewood, kerosene to cook food. The rescue came late. Temporary camps established had no sanitation facilities, no special food for elderly and the children.

Cuddalore district has a 57 km coast line, with 683 village *panchayats*. 13,000 acres of agricultural land was destroyed along with huts, roads, cattle, other animals, paddy, banana, tapioca, peanuts, houses, farming land filled with sand, houses filled with sand, etc. This is only partial information, more data is missing. Cuddalore is an industrial zone with many chemical industries. Hazards from these industries, particularly during the floods were large. There were no emergency plans for such disaster situations. The Disaster Management Act, 2005 (DMA) has not included this aspect. Compensation provided was unethically given with unfair distribution. The people who needed support the most, received very little or none. Rescue and relief efforts took place more along highways and the East Coast Road. No management plan is included in the DMA for coastal areas particularly the wetlands, mangroves, and farmlands. Cuddalore is a disaster prone area. Many disasters have taken place and many opportunities to learn lessons have been lost. This should not happen again.

Impact on women workers and relief activities : Sujata Mody, NTUI

Ms Sujata Mody from the New Trade Union Initiative shared her experiences from the Chennai relief work. The relief started three days after the disaster. There was limited rescue efforts from the government. People helped themselves. There were no drinking water facilities. The worst affected were the *Irula* (indigenous) community people, domestic workers, sanitary workers, etc. Some factories did not declare holidays despite the gravity of the situation. Workers were threatened with pay cuts if they took leave. Domestic workers went to work despite the rain because of the fear of losing jobs. Media did not focus on this issue. The city administration focused mainly on food delivery. Among the CSR (corporate social responsibility) activities, the MNC's (multinational corporations) provided relief only to select people, with police protection. The government provided rupees 5000/- as compensation to affected families, which didn't make sense as several families lost about Rs. 2-5 *lakh* worth of property. Street vendors suffered triple damage of house, loss of monthly income and property too. The slum dwellers were relocated to a new area which is 25 km from city

and a long distance from their work places. Sanitary workers from other districts were pulled in large numbers and they carried out immediate relief measures. Their care and hard work despite absence of safety gear was again not recognised.

During the discussion a question about how drinking water facilities were provided during the floods was raised. A communicable disease epidemic prediction was issued. Bottled water was supplied to many areas. Many MNC's provided mobile reverse osmosis water purification plants. Some people however collected rain water for drinking. There was no major disease outbreak.

Panel 2: Rural challenges of agriculture and sanitation: Narratives of the Insidious

Chairperson: Mr.Jayakumar, THANAL, Kerala

The chairperson reflected that everyone loves rural areas for the resources and land, and not for the people who live there. So over time with neglect and agricultural distress people end up getting pushed out of rural areas into urban slums. The major sectors of traditional indigenous knowledge and expertise among people in rural areas of the country are in handloom and agriculture. People have a knowledge pool developed over generations in these domains, but state funding is being systematically reduced over time. The consequent fragmentation and loss of collective community knowledge is an unrecognized problem issue.

Have new technologies helped advance rural communities? One classical case is promotion of the use of pesticides. Village extension officers went to farmers with sprayers promoting pesticides. Of the over 300 pesticides in use, 110 have demonstrated adverse health impacts on humans, as reported in peer reviewed journal articles. Out of these 110, 56 chemicals are proven carcinogens. These are not widely understood.

In the context of **endosulphan poisoning** in Kasargod, when people started experiencing the adverse impacts of pesticides, they believed it was because Shiva was angry. A local physician Dr. Mohan Kumar related it to water pollution and aerial spraying of pesticides. Dr Leelakumari of the agriculture department said it was due to endosuphan sprayed on cashew plantations. There were consequently no crows, fewer ants and *adivasi's* (indigenous communities) and local people could no longer eat their traditional foods. Several studies were done by different institutions to establish the causal relationship. Experts from global networks shared their views. Mr. V.Sachitanandan set up a district level remediation and rehabilitation cell in Kerala and Mr. Achyutanandan put in a lot of money into this cell. The Chief Minister of Kerala declared a hunger strike demanding a global ban on endosulphan. This in brief, is a story of how knowledge can flow across borders in solidarity, bringing about long standing positive impacts and change.

Food security and traditional seeds:
Usha S, THANAL, Thiruvananthapuram, Kerala

Seeds are the most important input or component in agriculture. Every seed is a package of information which is understood by farmers; where it could be grown, how it could be grown. High yielding variety and traditional seeds are varieties. Seed is also food – so there is a direct link through seeds between producers/farmers and consumers/ communities.

Food security exists when all people have physical and economic access to sufficient, safe and nutritious food to meet the dietary needs and food preference for a healthy life. Rice, wheat, maize and potatoes are primarily produced. There are 30,000 edible varieties of food available.

The Indo-Burma region is the centre of origin of rice, which is now used globally. This region has maximum diversity of rice. There were 100,000 varieties of rice in India. Dr.Richaria collected 19.000 varieties of Paddy in Chhattisgarh and found out 8-10% are high yielding and 8-10 % can withstand drought. In terms of topography and climate, rice is grown widely from North China to South Australia. We are reviving traditional rice varieties in Sundarbans, West Bengal which is a poor region, rich in the resilience of the people.

The Green Revolution in the 1960s came with a high yielding package variety of seeds and pushing pesticides and fertilizers to increase production. The approach was to increase production not to increase farmers income and livelihoods. It was not based on our indigenous seeds and the massive

knowledge system in our country. We have lost the collective wisdom of communities. We now depend on HYVs (high yielding varieties), mechanization and intensification of processes. While there is an apparent higher yield, crops need more water and fertilizer, and are prone to pests and diseases. They cannot tolerate floods, droughts and salt. Their character is not stable and we cannot save the seeds leading to a loss of diversity. The quality of the seeds does not stay. The narrowing down has only helped corporates and not farmers. In the village, farmers mix fertilizer with pesticide which is completely unscientific, and as a result farmers and consumers are suffering.

Rice consumes maximum quantities of pesticide after cotton, so contamination is common. Studies reveal 14 pesticides in the market, of which 2 cause cancer. Pesticides have resulted in the destruction of biodiversity of food from the field to fish (poor man's protein), frogs, earthworms and predators. Pesticides have also led to severe health impacts for farmers. The '*cancer train*' which runs from Bhatinda to Bikaner was cited as an example. Punjab has the highest level of arsenic water contamination because arsenic is present in Bran and the Bran Oil program was underway in Punjab.

The '***Save our Rice***' **campaign** was initiated since 2004. Conservation of traditional seeds has contributed to water security, knowledge of food and health in Kerala. There needs to be a connect between consumers and farmers. Biodiversity based on ecological paddy cultivation. They engage in the protection and promotion of traditional knowledge and community wisdom to ensure food security. They also play a role in protection of paddy ecosystems.

Along with food security, we need to ensure nutritional security to the people. THANAL and other groups did not just work with farmers, but also with networks of students, rice millers and women's groups. In the initial years we held discussions across several communities and engaged on all these issues.

Revival of rice diversity in Karnataka and Tamil Nadu was undertaken during festivals. They associated with *Sahaja Samastha* to propagate and support a larger system of environment and sustainability. Building of seed banks in villages is very important, as is bringing back children to agriculture and for the revival of traditional seeds. They have revived 1,200 varieties over the last 6 years in 5 states and developed village level seed banks. Many varieties were more nutritious and had medicinal properties.

Genetic erosion is a huge threat to food security. FAO reports we have lost 80% of agro-biodiversity. Major policy support is needed to revive diversity at the farmer's level. *Beej Swaraj Manch* is a national alliance of seed savers, which has been established to address these issues.

Is our food secure? Is our food safe ? Is our food sovereign?

Sridhar Radhakrishnan, THANAL, Thiruvananthapuram, Kerala

Everyone knows we are living in a period of agrarian crisis. Around 3 *lakh* farmers have committed suicide and millions of consumers live with pesticides in the body- many causing cancer. From 1966 with the Green Revolution what have we achieved? We have increased food produced in the country, yet 30% of people go hungry and 30% of produce is eaten by rats.

We have 90 million households in farming in India (60-70% of India s population) and 30% are in debt. In areas where the green revolution didn't come into play, the loss of biodiversity and agricultural debt is much less.

Let us talk about cotton. In 2002 in the peak of the agrarian crises when farmers were in debt leasing their land and transporting water paying through their noses and then the crop doesn't get the price due to complicated market phenomena. At the same time fertilizer industry is thriving, tractor industry is thriving, food industry is thriving. The central person- the farmer is left out of the loop. Even the current budget doesn't solve the problem, because the problem starts at a global level and is propagated to the local levels.

The choices of food are also problematic, and are not just killing us but killing the agrarian system. Diversity, nutrition, safety, rural livelihood everything is linked to health in rural areas.

The 'Green Revolution' was brought in through a hoax that India was food insecure when the Bengal

Famine happened. India was producing enough food then, and today, however we have not made food equitably accessible. Land is controlled by some people, water is controlled by some people, and seeds were/are appropriated by companies. For instance 90% of cotton is controlled by Monsanto. Though we have 4,000 varieties of cotton, the question is not just about food and crop security, but also sovereignty.

1.2 billion people live in India and the total grain production is 244.8 million metric tonnes. With whatever India is producing today, we only need 40% to feed everyone in India. Even in edible oil and pulses we are more than food secure.

We need to revamp agriculture and ensure adequate food to eat for everyone. A four point formula was proposed to do this:

1) Organic Farming/Agro-ecological agriculture
2) Food Safety: The Food Safety and Standard's Act should be well implemented to make all food safe
3) Ensuring the Right's of farmers to land, water, food
4) Farmers have to have an income guarantee.

The report of the UN Special Rapporteur on the Right to Food, addresses the issues of hunger and the problems of distribution and access of food.

Watershed development in a context of climate change:

Marcella D'Souza, WOTR (Watershed Organisation Trust), Pune, Maharashtra

Parts of Karnataka, Andhra Pradesh and Maharashtra are experiencing drought. Land and water resources are required to meet the need. This is the scenario we are facing in many parts of the country: lands degraded without tree cover and market forces that are pulling the people apart.

Watershed development is the treating of land and water resources so that people can have an opportunity for agrarian livelihoods (and not be forced to move to cities for jobs). This needs to be done by active involvement of all people in the community. The positive impacts of watershed interventions have been improved ground water levels, soil and other benefits for farmers. These were shown to workshop participants with the use of data.

Extreme weather events which are not predictable, like heavy rainfall over a few days, affect livelihood. There is also pressure to modernize, to look for more productivity, and quick fixes. Water is also being mismanaged. A study conducted by WOTR showed the inappropriateness of farm ponds for some regions.

Vulnerability assessments have come as a response to inadequate impact of watershed treatment and to climate change. WOTR is undertaking research in this area. Unless we undertake research in critical areas to provide evidence and push the existing methodology further, the government cannot understand what is going on, on the ground to make the necessary changes in policy and practice.

We need to develop a perspective in a very systemic manner. We cannot work in isolation for agriculture or health as they are inter-connected and integrated. Since agriculture was modernizing and shifting towards use of high yielding varieties (HYV), farmers feel they need more tractors and less livestock, so now we have less livestock faecal matter or manure for our soil and soil health is affected. There is a flattening of the lands to allow tractors to move, and soil loss due to deforestation. So we decided to do a systemic study and present it to the government. There is a need for scaling up, while keeping context in mind.

In one area of Ahmednagar District in a drought hit year farmers bio-diversified and shifted to a traditional variety of crops. They survived the drought. In another area where HYV were used the farmers were not able to do this and stay stable or afloat during the drought. There is a need for partnerships and collaborative action with agricultural universities to address these issues.

An adaptive sustainable agriculture approach is needed – with the use of a systemic method of crop intensification, utilising organic methods such as leaves for fertilizers, and micro-irrigation, with men and women farmers working together.

Understanding challenges in rural sanitation :

Prahlad I M, SOCHARA, Bengaluru

Having a toilet can be a challenge. Who will maintain the toilet and keep it clean? Not having toilets on the other hand poses other problems.

In a study conducted by us, out of 24 people using open defecation, a few reported contemplating suicide because of being embarrassed by flashlights, videos and pictures being taken when they go for open defecation. Also, there is no one to accompany women and children out at night.

When holding a discussion on sanitation in the community one lady narrated her story. She was 8 months pregnant and had come to her parent's house, where there were no toilets. She had a stomach ache and went one km away from home to defecate. She went into labour while there. She delivered the baby, fell unconscious and the child died. Following the delivery there was an infection in the uterus, the uterus was removed and she was forbidden from visiting her father-in-laws home because of this.

In another instance a disabled person used to get abused by family members because he had to be carried for open defecation. His relatives who used to carry him out to the fields used to ask him why he is alive. This caused him tremendous pain and suffering.

Local masons demand exorbitant rates which demotivate daily wage earners and agriculture workers. This affects the process of toilet construction. Poverty also contributes to low adoption of toilets. With changing governments, the funding pattern of programmes supporting toilet construction also changes, which creates confusion and delay. People also have assumed that toilets are a luxury, and have never thought about it as an appropriate technology for better health.

There are several political challenges, too, which include corruption, and inadequate focus on disabled friendly and child friendly toilets as part of the national mission. There is no use of having these types of projects if there is no *"communitization"* component with community participation and action.

Panchayats have commissioned dry latrines, even though it has been banned by law if manual scavenging is involved. There are several cultural issues too, such as in some villages stones and leaves are used for anal cleansing. Manual scavenging is still a huge issue, which needs to be dealt with at all levels.

There are also challenges posed by local geography, such as water logging, and building toilets in areas of water scarcity. The one difference between the Millenium Development Goals (MDGs) and Sustainable Development Goals (SDGs) is that the government is withdrawing from social sector responsibilities. The MDGs failed to meet its guidelines by 2015, so the SDGs were created to postpone them to 2030, together with withdrawal by the government.

Translation Sessions were translated into Tamil by different volunteers in recognition of the large group participating from Tamilnadu. On day two a presentation in Hindi was also translated to English. Songs in diverse languages animated the two days.

The Poster Exhibition attracted attention and there was also a sale of publications.

Lunch: After the lively morning session's, lunch provided space for interaction. There was a healthy array of vegan food prepared using predominantly organic products.

Participants on Day 1

PARALLEL WORKSHOPS

1. **Environmental determinants of health: Are you being educated?**

The Workshop was facilitated by Stefi Barna (Azim Premji University) and Manjulika Vaz (St John's Research Institute).

The audience was diverse, including those with experience in environmental education, and those with an interest in environmental health. There was a diversity of expectations, including using education for awareness, advocacy, and action for various age and population groups. A presentation was made as an introductory ice breaker – where key global environmental health concerns were put forward to the

audience. The ethical challenge of disproportionate impact on poorer and marginalised communities was discussed. There is a great degree of lack of awareness among both perpetrators and victims, and both these groups need to act to safeguard and improve health. There is a need for further research to understand our vulnerabilities to be able to act on them. Newer frameworks such as the Planetary Health framework brings various environmental health concerns together, as they are all linked and also stem from common or similar developmental approaches. Education has a role, but university education still focuses on super-specialisation with an information overload. Challenges are faced by teachers (who are under lot of pressure from the board, administration and parents) and students (who are under pressure from the syllabus, peers and parents). Media too has a role to play, and they need to be a positive influence. Education should occur through a process of triggering, reinforcing, and action. There is a need for appropriate reform, including encouraging critical thinking and action by students.

2. Food Systems and Health

This Workshop was facilitated by Dwiji (The Millet Foundation, Bengaluru), Sridhar (Thanal) and Usha (Thanal).

The breadth of the chosen topic and the assigned time for the workshop presented us a fairly tough challenge. The opportunity to be part of SOCHARA's silver jubilee celebrations was incentive enough to accept the challenge.

We had decided to shape the workshop into a brain storming session with the objectives of (a) starting the process of building a logical framework to assess how sustainable and desirable a particular food system is relative to the others and (b) raising awareness and strengthening the participants' understanding of sustainable food systems and it's various aspects.

The lead presentation focused on identifying broad categories under which one could classify the various parameters used to assess a food system. A few concrete examples of such parameters for each category was presented to clarify the meaning of each. The group broke into sub-groups to go over a pair of categories each. Each was tasked with (i) identifying as many questions that one would ask of a food system when assessing whether it is sustainable or not and (ii) divide a total of 20 points between all identified questions so as to encourage discussion of the relative importance of each question.

During the presentation, looking at the participants one could see a lot of expressions change from casual and curious to enquiring, thoughtful and questioning. At the start of the group activity, participants were not sure how they would go about analysing food systems within the categories their group was slated to discuss. But as the groups discussed their respective topics, one could see the participation & intensity increase. Under the pair of topics assigned to each, the three groups listed a whole bunch of questions that one could ask of a food practice or food item to identify whether it would be part of a sustainable and healthy food system. Though only one of the three groups was able to go beyond listing the questions and get to assigning points to each of the identified questions. The expressions on the faces of and experiences shared by the participants at the end of the discussion were much more confident and happy with some of the ideas picked up in the workshop.

It was a little disappointing that we could not reconvene and summarize the discussion and share salient points with other subgroup members – we ran out of time as the sub-group discussions went on much longer than planned. We were happy that we were able to achieve the objectives that we set out with. The questions that emerged during the discussion shall go towards building a model and hopefully the questions from the workshop shall keep popping up in the participants' minds whenever they come ponder on the issues of food, sustainability and health.

3. Sustainable sanitation and WASH in healthcare

Workshop facilitated by Prahlad, Uma and Alfred (SOCHARA), and Tejaswi (WaterAid).

Dr. Tejaswi presented results of a study on the WASH approach in public health care systems, where facilities provided in the Government hospitals in Andhra Pradesh were found to be unsatisfactory. Waste management is not practiced and toilets were not in a usable condition.

Ms. Uma Chaitanya spoke of sustainable sanitation and human factors involved. It was based on a study conducted on sanitation workers in Railway Kodur, Andhra Pradesh, mentored by the Dr. TM Samuel Memorial Medical and Dental Centre team. The sanitation workers coming from socially marginalized communities are ignored by all, with irresponsible behaviour by citizens making their conditions worse. The importance of human dignity, dignity of work, and the need to promote safe working conditions for these workers, provide access to health care, along with the environmental and eco-friendly sustainable sanitation was discussed.

Mr. Alfred presented a study on Anganwadi centers and sanitation with a focus on waste management. A lack of waste management facilities, child friendly toilets and water to wash hands before eating food were some of the problems observed.

Mr. Prahlad spoke about problems faced by women due to open defecation; the realities in the field and about the work of SOCHARA and its partners in building toilets using low cost affordable and appropriate technology by making use of locally available materials with community participation.

4. Climate, Society and Health

This Workshop was facilitated by Lalitha Vadrevu and Shibaji Bose (IIHMR, Kolkata)

A video was shown of the Sundarbans region titled *"Children of a Lesser God"*. The archipelago is a unique ecosystem home to the royal Bengal tiger, which spreads from Bangladesh to the eastern part of west Bengal. 4 million people inhabit its 110 isles. They struggle on rain-fed mono-crop agriculture, and forest produce from reefs and estuaries. More than half of the farming community is suffering from poor physical infrastructure with 399 km of railway line and poorly tarred roads, people have to depend on mechanized boats. They regularly face monsoon storms, floods and cyclones. A tropical cyclone hit the Sundarbans with a base speed of 130 mph and about 300 people lost their lives in the Sundarbans. The cyclone destroyed homes, leaving behind homeless children and destroyed livelihoods. Several isles ceased to exist. The transport infrastructure collapsed; jetties and boats were shattered. The video gave us a snapshot of the people living in the Sundarbans. They have been working in Sundarbans for 5 years. The work is based on the premise of evidence that climate change is causing significant difficulties for people living in vulnerable areas. Some of the technicalities concerning climate change, and how evidence can be communicated to people to affect change were discussed. 20, 000 hectares have shrunk to 3,000 hectares in some of the islands. Climate change translates to a very harsh reality for these people because of the loss of income. The health system is ill-prepared to cater to their health needs. Sundarbans has 19 administrative blocks which are vulnerable to climate change and its impacts.

Climate change has manifested here through rise in sea levels, increase in sea surface temperature, shift in monsoon patterns, and increased risks of disaster.

The challenges are many - in health and healthcare; with geographical inaccessibility; boats surface only twice a day; climate uncertainty; erratic weather pattern and saline water intrusion in agriculture fields. There is a changing demographic composition, with mass out-migration. There are families and villages with no men because they have migrated out for better opportunities.

A 'knowledge intervention' model was initiated, based on the premise that we need scientific evidence to say and show the linkage of how climate change affects the community to engage with policy makers. The concepts of climate, climate variability, vulnerability, exposure, sensitivity, resilience and adaptive capacity were discussed. Two research designs were used: cross sectional studies and longitudinal studies. The broad research questions were

- How does climatic adversity affect communities in terms of its impact on livelihood?
- How vulnerable are communities to climatic adversities?
- What is the scale and distribution of climatic events in the region? (GIS studies, spatial intercollation)

Mixed method research approaches were used, including qualitative and participatory techniques such as hazard ranking, perception mapping, transect walks, seasonal calendars, and timelines.

Adaptive capacity was assessed through: socio-demographic indicators, livelihood strategies, with indicators regarding social support and networks. Climate change sensitivity was assessed through: health conditions/ morbidity prevalence, food and water shortage, and perceived impacts of climatic shocks.

Key audiences and stakeholders include: academicians and research community, policy makers and advisors, RMP (registered medical practitioners) associations, NGO/CBO (community based organizations) think tanks, community opinion leaders, media, key opinion leaders and opinion makers

A comprehensive media strategy was made, including establishment of connections with the Sunderbans local media. The villagers learnt to take photos and started taking pictures and holding meetings. They had state meetings in press clubs where they shared stories translated from Bengali to English.

The photo voice experiment set goals of enabling people to record and reflect on the community's strengths and concerns, and to promote critical dialogue and knowledge about important issues through large and small groups. The women who participated were crab and fish collectors.

KALAJATHA (FOLK THEATRE) – AN EVENING TOGETHER

Under the fading evening light, a folk theatre performance in Kannada was conducted in the open air amphitheatre by a team from KGVS (*Karnataka Gyan Vigyan Samithi*), Kolar, on the theme of sanitation and health. This performance was recently created and performed in 20 villages of two *taluka's* of Kolar District, Karnataka in March 2016 as part of a comprehensive primary health care initiative by SOCHARA in collaboration with various stakeholders. One of our community health fellows Ms. Aruna had helped with script writing. The performance was appreciated and the artistes, some of whom were local college students were felicitated for their contribution over the last few months. A **Fellowship Dinner** was an occasion to celebrate with friends and family members of SOCHARA staff.

Kalajatha in Addgal PHC area

DAY TWO

Theme: SOCHARA Silver Jubilee event and communitisation

Participants were welcomed by Dr. Sunil Kaul a member of the SOCHARA Executive Committee and Mr. SJ Chander, moderators for the morning session. A "*silver jubilee song*" for SOCHARA with lyrics by Samar Khan was sung by the Batch 12 community health fellow's group, setting the tone for the celebration. The presence in the hall of several persons who were associated with the Community Health Cell (CHC) in 1984 and during the registration of SOCHARA 1991 made the day memorable. Due to a health emergency, the invited chief guest, Dr. B Ekbal, Convenor of the *Jan Swasthya Abhiyan,* was unable to join the proceedings.

A photo-journey of SOCHARA's creation, activities and processes over the past 30 years was presented by different team members using 150 slides from the archives. Before the presentation, Dr's Thelma and Ravi were felicitated by the younger team members. Key themes and inflection points over three decades were covered: the Community Health Cell 'study-reflection-action' experiment; an external group review process leading to the formation and registration of SOCHARA; the initial team and advisors; axioms of community health; the community health approach; building solidarity and health movement; policy engagement; community health learning programmes; the development of team clusters in Chennai and Bhopal;

documentation and communication. Each theme was presented in 10 slides, by ten team members.

Following this, grateful Homage was paid to SOCHARA associates who have passed on – including Dr's CM Francis, George Joseph, Ravi Kapur, Rama Rao, Uma, Sreedharan, Pankaj Mehta, Paresh Kumar, Ajay Khare; and two CHLP alumni Arun Gupta and Hanumanthappa. Core team members over the years, starting with Mr Gopinath, Mr Krishna Chakravarty, Mr. V N Nagaraja Rao and Dr. John Clarence along with current administrative and accounts team members, were gratefully acknowledged for their important contributions to the organization and its work and ethos.

Participants were then invited to share their thoughts. Several persons, including former team members shared their experience and good wishes. Fr Claude DSouza, sj, stated the importance of the need for continued work towards "Health for All". He felt that development was an invisible art that has no ending. He was glad that SOCHARA did not build an institution. Valli Seshan appreciated the "rich" SOCHARA archives, and discussed the importance of referring to archives to guide us in future work. Fr John Vattamattom, SVD, former Director of CHAI (Catholic Health Association of India – with 3,500 member health institutions) recalled the association of CHC team members in the community health orientation and work of this large national network. Dr Shirdi Prasad Tekur using rope tricks, explained his learning about "community" during his time at SOCHARA with an understanding of the oneness among all people that derives from spirituality. Dr Rakhal Gaitonde shared about the value of non-hierarchical functioning and rigour in work that he learned from SOCHARA. Dr Rajan Patil, and Dr Arvind Kasturi shared about the good times and important lessons learned while at SOCHARA when working on community based approaches to vector control and the overview of training health workers respectively. The report of the latter was titled COFFEE. Rajan was reminded of a *Shahiri,* "I was blessed to be part of this group, which has left indelible memories." Dr. SK Ghosh from the National Institute of Malaria Research, ICMR, spoke of the importance of vector control bringing in the context of the Zika virus and spoke of his long association with SOCHARA in this regard. Mr Gopi senior team member of APD (Association of Persons with Disability) shared reflections about the sense of equality and simplicity experienced when interacting with the SOCHARA team. Mr. EP Menon spoke about the organization and its people being *Desh Premi's.* Dr. Mani Kaliath spoke of his journey with SOCHARA and beyond, including his work on health of the urban poor and in community mental health which is where he finds his heart and mind together. Prasanna Saligrama shared his journey with the PHM Secretariat to leading the MP CPHE team. Former office team members who were present – Mr. Kumar, Mr. Anil, Ms. Pushpa, and those who could not make it were thanked. The current office staff too were recognized and thanked for all the hard work. Several participants from the large group from Tamilnadu thanked SOCHARA and also recited a poem from Tagore and sang a song composed for the occasion. Several persons who recognise SOCHARA members as mentors also expressed their wishes.

A **video-documentary on the Community Health Learning Programme** titled "*Campus without Walls*" was released by Anusha (on behalf of Ms. Valli Seshan). Copies were given to a few members, including Dr Regi from Tribal Health Initiative (THI). He stated that SOCHARA fellows are always welcome to THI as they are serious about learning and about engaging with community health. Dr Ravi recognised the importance of strong field mentor organisations (85 officially listed on SOCHARA's website) towards the learning of fellows at SOCHARA. A short 10 minute version of the video was screened, which provided details about the structure and content of the programme, and also showed the clips of pedagogical techniques used and the engagement of fellows in the community. This is available on the website www.sochara.org. Krishna and his son, Abhishek (the documentary maker) from Bangalore Media Centre were acknowledged and thanked.

The batch of fellows that just graduated (12th batch) were awarded certificates by Dr Regi. The morning session was closed with a sharing by Dr Ravi, giving thanks to the many persons and organizations who have contributed to the growth, development and continuity of SOCHARA.

Panel discussion: Communitization of Health Systems

Chair: Dr Thelma Narayan

The chairperson spoke about the how the ideas behind communitisation have been mentioned in both the Indian and International People's Health Charters. The concepts of communitisation predates Indian independence finding mention in the Sokhey Committee report of the late 1930s which spoke of the need for community health workers (CHWs) in each village. She also mentioned the widespread presence of local health practitioners of *lok swasthya parampara's* (local health traditions) in the country; various NGO's implementing the idea of CHWs and village health committees; the experiences of *Jana Swasthya Abhiyan* (People's Health Movement India) which led to a realisation of need for accountability in health, education and livelihood; and the critical analysis of the state that emerged in the 1970's and 80's in the aftermath of the Emergency which contributed to the evolution of the communitisation component of NRHM with piloting in 9 states. She then introduced the panelists who made presentations on various aspects of communitisation of the public health system and in education.

Dr. Rakhal Gaitonde spoke on ***"Community Participation: A relook in the light of experience".*** He highlighted the need to revisit the concept of community participation based on the experiences in the Community Action for Health (CAH) in Tamil Nadu which have been created by the activists and animators involved. He briefly traced the history of CAH in Tamil Nadu including its evaluation through comparison between districts where it was implemented and not implemented, and the subsequent obstacles faced, starting with an insistence from the Officer in Charge that the focus of CAH be on politically important entitlements, with direct feedback to higher-ups and no emphasis on training. He then spoke about how once the process was stopped in 2012 he started reflecting on three aspects, namely, *participation*, *community* and *state* to understand the reasons for the changes that took place. Speaking about participation he mentioned the difference between buzz and fuzz words with the latter referring to words that take different meanings in different contexts. This was applicable to community participation with different stakeholders (health system, district health officer, community) understanding it in different ways leading to a mismatch between expected outcomes and the purpose it was meant to serve. While earlier, the concept of community participation was associated with social justice and emancipation, now it is associated with governance which is a neo-liberal concept of managing systems, as against changing and transforming systems. He then explained the chains of equivalence: what words are used with community participation and domesticating community participation. Speaking about community he said that they are comprised of heterogeneous groups, so what does it mean for participation - different sections have differential access. There is a need to acknowledge that not all communities were involved in the CAH process. Further, NGOs are domesticating protest. Speaking about the state, he mentioned about it being a neutral arbiter and an executive committee of those in power. Since there are a range of workers in the state, some with vested interests, it provides an opportunity to them to gain legitimacy through vested processes.

Mr. Ameer Khan spoke about the ***"Communitisation of the health system"*** with a focus on CAH processes in Tamil Nadu representing the experiences of animators, activists and *panchayat* presidents. He started by providing reference to various policy documents and other reports that have espoused the idea of communitisation. He then spoke about National Rural Health Mission (NRHM) providing space for community participation and that it was supported by mechanisms such as the Advisory Committee on Community Action. The framework within NRHM was planned for restructuring of power, which also became a major issue, with contention during implementation. Initially communitisation was piloted in nine states in 2007 as community based monitoring and planning, however, in 2009 there was an evolution of the idea into Community Action for Health which went beyond monitoring. The setting up of Village Health and Sanitation Committees enabled the process of monitoring, preparing rank cards and collation, and creating district health plans. The partners in this process were the public health system, elected representatives, NGO's, VHWSNC (village

health, water, sanitation, nutrition committees) and the community. The idea was to being all these partners together to find solutions for health. Training and orientation of VHWSNC served to mobilise the community which then took up the responsibility of monitoring and collecting data on the experiences of using health centres. An opinion poll was conducted using an in-depth tool to capture aspects of quality and equity in terms of caste distribution of utilisation of various services. Such measurements helped in going beyond numbers. The opinion tool was the basis of preparing rank cards, and the outcomes seen were improved postnatal care among others. The challenges were not many at the village level but from sub-centre level onwards or upwards there were issues mainly resulting from differences of opinion with the health system resisting the shifting of power. At the NGO level, the challenges were related to lack of resources, and not being able to question higher levels. The results of the CAH process will depend upon whether the government is listening to people and its willingness to shift power.

Dr. Thelma remarked that attempts were made to factor in caste, class and gender into the operational mechanisms of NRHM. As a result of the NRHM there have been improvements in maternal and infant health in terms of decreased maternal mortality rate and infant mortality rate over the last decade.

Dr.K.Shanmugavelayutham speaking about ***'Communitisation of Child Rights'***, mentioned that community participation is a part of both the 73rd and 74th Amendment of the Constitution on *Panchayati Raj*. The efforts towards *communitisation* of child rights were more recent with many flagship programmes (ICDS - Integrated Child Development Scheme, SSA – *Sarva Shikha Abhiyan,* ICPS, NRHM) of various departments having a component of community monitoring. The community participation in ICDS is through Village Health and Nutrition Days (VHND), Early Childhood Care and Education (ECCE) day, *Anganwadi* Centre (AWC) monitoring and support groups. With the Right to Education (RTE) Act 2009 active community participation is to happen through the School Management Committee (SMC), Parent Teacher Association (PTA) and VLC which itself is a contradiction since there is an overlap between the functions of these committees. Child participation is facilitated through the children's parliament. The functioning of various committees is only on paper. These committees are advisory in nature with no power and with no higher order of participation. The challenges are to streamline the functioning of all the committees under the *Panchayati Raj* Institutions (PRIs) and flagship programmes- the committees should be sector wise. Further, there are no incentives for participation and there could be vested interests in selection. These committees, with exception of the Village Health and Sanitation Committee (VHSC) do not have financial powers. The members themselves do not know about the functioning of the committees and there is apathy on part of government staff.

Ms. Nidhi Shukla spoke about **'Implementation of CAH in Madhya Pradesh (MP)'** starting with the pilot phase between 2007-09 in 5 districts during which VHSCs monitored health services to prepare coloured rank cards, based on which community level discussions were initiated with representatives of health system and the community working together to find solutions to their problems. The process was then expanded to 313 blocks in all 51 districts of MP with formation of district and block level mentoring groups for community action (MGCA). At present 170 of 250 district MGCA members, and 356 of 939 block MGCA members have been trained. The district MGCA training is for five days, while the block MGCA training is for three days where the topics covered are about the ASHAs, maternal health and child health, VHND and immunization, nutrition, vector borne diseases, community participation, govt. schemes, G*ram Arogya Kendra* (village health centres), and the role of the MGCA. 2-3 districts are allocated each to members of MGCAs for visits and monitoring. She then explained about the composition and functioning of the district and block MGCA. Discussing the challenges faced she mentioned about districts and block MGCA not being properly formed; irregularities of MGCA meetings in districts and blocks; lack of planning by members for field visits; conflicts between district administration and MGCA members; conflicts between the ASHA, *Dai* (traditional midwife) and ANM (auxiliary nurse midwife or Junior Health Assistant); delay in payments of ASHA incentives; selection of illiterate ASHAs if 5th pass women is not available; attitude

of health officials towards ASHAs, MGCA and other community members; family planning targets for ASHAs; selection of ASHA *Sahayogini* if 10th pass women is not available, and most importantly the community part missing from the MGCA.

Dr. Thelma added that in Madhya Pradesh there are about 58,000 ASHAs, and 3000 ASHA *Sahayoginis*. She also mentioned about a recent meeting of the state MGCA in Madhya Pradesh where the issue of targets for ASHAs and relating their work to health outcomes was debated and contested. She referred to the recent strike by 35,000 contractual workers in the state public health system to highlight the complex and conflict ridden nature of health systems which also affect communitisation.

Mr. Basava Raju spoke about the ***'CAH experience in Karnataka'***. He started with a Kannada song from the *Jana Arogya Andolana* Karnataka (JAAK or People's Health Movement Karnataka) *Kala Jatha* handbook developed in the year 2000 CE, and shared his experiences of community participation in the National Literacy Mission through Village Education Committees and School Development Committees. He said that while in every programme community participation is given importance in policy and programme documents, this does not translate into meaningful action at the time of implementation. The School Management Committees membership has been reduced to those that take part in events, with no say in financial and management issues. The strengthening of VHSC's resulted in doctors issuing orders to volunteers involved to bring more patients to the primary health centres. He shared about the two phases of strengthening of VHSC's. During phase one each NGO was assigned one block and was to work in coverage areas of three PHC's. During this phase, village health plans were not prepared and it was observed that there was no connection between those working in the district and the state level committee. The implementation was dependent on bureaucrats with mixed experiences. During phase two, each NGO worked in a single district but there was no support from the government system. Training was conducted for VHSC members but there was no follow-up. In the last three to four years there is not much activity in the state. While attempts were made to prepare the state health plan based on inputs received from the village health plans, this did not succeed. For community participation to succeed, people should be interested, incentives should be given and participation should be promoted. In the case of education, children go to school and hence parents are more interested in its functioning, whereas, in health this attitude does not exist towards the functioning of health facilities. NGO's have to take a lead in strengthening communities and the health system, and should think beyond projects and make *communitisation* a movement.

Questions and comments from the audience included the need to move beyond participation to engagement with communities, methods of training, motivations, multiplicity of services and their effect on the *communitisation* process. The panelists responded by saying that different stakeholders had different motivations, which was a learning for those involved in implementation. At times those involved in implementation failed to think about the why different actors were supporting the *communitisation* process and what their motivations were. There is a need to come out with common approaches and forums for discussion since the motivations of the state do not match with that of the NGOs involved in implementation. Trainings need to be seen as activities for liberation and transformation. It has become a habit of the bureaucracy to blame lack of community participation for failure of programmes.

Dr. Thelma concluded the session by highlighting the need to strengthen and deepen community participation, and to undertake research on the same.

PARALLEL WORKSHOPS

1. The role of Panchayati Raj Institutions (PRIs or local bodies) in community health and development

Chairperson: Prof Shanmuga Velayutham

The session was attended by *panchayat* members and presidents, village sanitation committee members, SOCHARA fellows and staff, and others.

The process and challenges to create awareness, and implement changes were discussed. In the *Panchayati Raj Act*, there is a provision to implement health programmes. People need awareness about it. There is also need for ongoing capacity building. If community participation has to be successful, the

discussions should be understandable. The leadership plays a key role. With the introduction of the National Rural Health Mission (NRHM), the *gram sabha* meetings have received much more strength. Village sanitation meetings are used to mobilise people to attend *gram sabhas*.

At PHC's, the *panchayat* president has the authority to enquire about the status of health of the village. The PRI Act of the early 1990s has enabled them with authority. Through utilising the PRI Act and NRHM provisions, one *panchayat* president was able to get a separate ward for women, screens placed in between the beds, and regularly stock checks of medicines. The members believe that the *Panchayat* institution provides a platform to voice their issues and NRHM has mobilised community action.

However, corruption, government apathy, nexus between the politicians, bureaucrats, conflict of ideas and interests between the *panchayat* members and the secretary has created a gap in implementation of programmes.

Ultimately, the success of PRI is based on the government funding. Failure of which, has created an atmosphere of disbelief or cynicism regarding the PRIs among the villagers.

2. Role of ICT in community health

The workshop was chaired by Dr. Naveen Thomas. We started the workshop with a game to understand communication as energy. We had to address the person on our left with folded hands and say *'zip'* , person to the right with folded hands saying *'zap'* and any one in the circle with folded hands saying *'zoom'*. In reality people forgot which direction to say 'zip' and which to say 'zap'. For 'zoom' as the person was at a distance two adjacent people responded at once or no one responded for a while at all. It was a good ice-breaker.

We started the discussion, talking about role of technology in making communities far and wide more aware. Someone mentioned how technology was a big help to sensitise people on Patents during the patent regime in India. Dr. Naveen Thomas picked up the issue of Television advertisements being a strong tool in disseminating social messages. But clarity of information and mood of the advertisement is very important. Advertisements for Nirodh (*pyar hua , ikraar hua* - Raj Kapur, Nargis) was disapproved for lack of clarity. Recent advertisements for cancer due to tobacco were also scary and not appreciated. The baritone of the voice over in ads reflects lot of trust, for example Amitabh Bachan's voice

Sabyasachi Das presented on GPS (geographical positioning system) being used to monitor people in the field. He started by talking about disconnect of knowledge there was in earlier times in community due to caste and religion. Technology has helped reduce these gaps. Internet has made knowledge or information available to everyone. Conventional means of data collection in our field were that information was collected by ANM, ASHAs and community health workers. Data then had to be further analyzed manually or were fed to computers for further analysis. But the modern definition of data is more flexible and with more features. For example now for a DOTS (directly observed short course treatment for tuberculosis) programme, in a clinic serving 10,000 population, the data can be collected and analyzed before the person falls sick. The high risk patients can immediately be identified and administered drugs. So there is real time communication and intervention possible now.

Mapping of Community Health Workers is done with a Google fusion Table Data base. There are different color codes for different health workers. It removes any chance of overlap and mapping shows actual positioning of the worker. It is a very user friendly interface. The challenges are government implemented it without a comprehensive understanding. The other challenge is that government schemes are very vertical in nature like separate TB worker, separate malaria worker so there are huge chances of data getting duplicated.

Suresh from SOCHARA Chennai presented an experience regarding the use of SMS to develop a *Panchayat* Report Card for health. He started by saying communication is a cycle and has to be a two way process. He briefly described the Communitisation process in Tamilnadu where they worked with 446 village *panchayats* using SMS technology. The animators were trained to send SMS with colour codes for an answer. One hundred

animators were trained for the purpose, out of which fifty animators had no prior knowledge of using SMS facility. They were trained and within three days they started sending SMS without any errors

Animators used to send SMS which was received by a centralised server. For example if there are ten questions, the SMS may send something like ggggryyyrr, where the g is green , r is red and y is yellow. Like this a detailed data about the village was collected and a report card digitally generated for a Village called the *Panchayat* Card. Even real time communication was done on SMS. For example, whether the doctor is present or not in the PHC could be communicated by large number of health workers by ten o clock in the morning.

Then Suresh's team came up with the use of Photo Gallery / Photo Voices project through a COPASAH (community of practitioners for social action for health) initiative. They explained the innovative use of photo technology in three districts. The issues represented in the photo galleries were-

1. Poor maintenance of Village Latrines
2. Story of a Child with Special Needs – Nitish
3. Medical Mobile unit not being positioned in the centre of the village.

Digital cameras were provided by the trainers and photos were taken by community members. The members were trained and inputs given in respect to the quality and theme of the photos by the trainers. The initiative had a very good response and was equivalent to storytelling. It provided positive inputs in community mobilisation and dissemination of information.

There were challenges encountered: eg it was not possible to take a photo from top (bird's eye view). There were quick solutions from the community and the process speeded up, so, it was difficult to monitor. Sustaining the follow up was not easy. The spectators tend to be the same people every time. A limitation was the cost of the camera and need of an educated person to print the banners and set up the final presentation. The success of the project was that Nitish was enrolled in the primary school with government aid. The mobile unit was established in the centre of the village.

3. Has communitization addressed marginalization?

Dr. Rakhal Gaitonde, the chairperson opened the session stating that when the word community participation is used, the assumption is that we reduce inequality. There is some anecdotal evidence in favour of this, and thus, there is an expectation that changes in equity would take place. However, the question remains as to whether this is true? In the mainstream communitization process, do we define agendas? Who sets the agendas? Are people's voices heard? In Tamil Nadu, *a step ladder framework* is used when evaluating community participation

1. Coming to the meeting was a success
2. Sharing is a success
3. Action is a success
4. Different parameters are used to measure success

First speaker: Guru Raghavendra from Basic Needs India (BNI), India and Vasantham from Action for Disability and Development (ADD), India:

ADD India's operations are spread over 6 Indian states - Karnataka, Tamil Nadu, Kerala, Orissa, Chattisgarh and Maharashtra. Since 2 years in Karnataka and Tamil Nadu the team is directly involved in implementation. During the presentation, only Tamil Nadu experiences were shared with regard to Person's with Disability (PWD).

Activities included: sensitizing concerned government officials and people's representatives, using the Right to Information (RTI), documentation of related government organizations scheme's, press meets, networking and lobbying. Vasantha Federation of PWDs was active in the District Coordination Committees since 2013.

Achievements

1. Regular assessment of persons with speech and hearing impairment and issuing of disability identity (ID) cards, as an entitlement
2. Regular supply of psychiatric drugs for persons with mental illness (PWMI) at district and block hospitals
3. PWMI accessing disability ID cards, enabling entitlements

4. Home based support for children with intellectual and severe disabilties – *Sarva Shiksha Abhiyan* (SSA), mobile van
5. Accessible ramps and toilets for children with disabilities
6. Job cards for people with disabilities under MNREGA and 150 days of work
7. 3% allocation of budget for housing for PWDs
8. Separate train coach allocated for PWDs in Southern Railways; sometimes toilet is locked
9. Government order on allowing PWDs inside the temples with assisted devices
10. Vasantham federation in PWD committee, block committee and southern railway committee.

Significant decisions by the District Collector

1. One doctor is adequate to issue disability ID card - no need for medical board, no delay
2. Separate queue for PWDs in OPD at district government
3. Wheel chair facilitation for PWDs in all religious places/temples and public places
4. Marriage hall and cinema theatres –have ramps
5. Extra one hour in public exam for children with disabilities
6. Awareness on MI will be created among public through *pudhu.*
7. Monthly treatment camps for PWMI at block hospital.

Rakhal reflected on the long struggle to organize the disability sector and represent them in various committees. It is the result of over 10 years of work.

Second speaker: Sudha Nagavarapu

SPAD an NGO in Bengaluru worked with women's groups in slums before the National Urban Health Mission (NUHM). Now several of their field activists have become urban ASHAs. Looking through the experience of urban poor communities provides a different understanding of how systems work or don't work. For instance, when a woman from Tamil Nadu was taken to a BBMP (Bruhat Bengaluru Mahanagara Palike – Municipal Corporation) maternity home, they denied her service stating that she did not have the proper ID card. Instead, the woman had to be taken to the tertiary Vani Vilas Hospital, which comes under the Dept. of Medical Education. The ASHA programme comes under the Department of Urban Health and Family Welfare. The ASHA referring and accompanying the woman had to negotiate different rules of different departments.

This fragmentation doesn't work in favour of the urban poor in the local context/scenario. Bangalore experience – in urban slums, services are limited. Maternal homes are mainly focused on reproductive and child health. Urban Health and Family Welfare is focused on ANC and family planning and sends all the diagnostics to private facilities.

In Bangalore Medical College (BMC), a hysterectomy is free. However, bed charges, blood tests, X-ray etc amount to Rs. 40,000. This institution comes under the department of medical education. Below the poverty line (BPL) patients only get a 50% fee reduction.

Empowerment is different for different social groups – Muslim women, Dalit women etc. Ward Committee members, ASHA, municipal corporation – who is responsible? Municipal corporation – responsibility as a result of the Act. For government it is easy to dole out benefits. Healthcare is one of the biggest problems the urban poor have and communitization has helped, even though it has been in small numbers.

In the context of NUHM, the community is not brought together for planning: BBMP, ESI (Employee's State Insurance), BMC. Are the issues of the community brought out while planning?

Rakhal raised a concern – Are we domesticating dissent? We ask people to sit in a committee and we will build a ramp for you. What about the larger picture?

Third speaker: Francis from Community Action for Health – Tamil Nadu

Since 2007 after the Community Action for Health (CAH) initiative was launched we continue to work with Village Health and Sanitation Committees even now through other projects. However members of the Scheduled Caste (SC) community experience a difference. For instance,

1) In PHCs people are treated very badly

2) In health sub-centres (HSCs) - 99 in BCA camps and no other
3) Location of service, caste of doctor, home to stay - all of these are important

Members from the SCs community attend *gram panchayat* meetings, but will it lead to action?

Three main points arose from the discussions:

1. The first session brought about the topic of inclusion - showed actual results and policy changes
2. Fragmentation of public health services - can it adequately address the effects of marginalization?
3. *Are we focusing too much on the effects of marginalization, instead of focusing on the determinants of marginalization?*

3. Governance Indicators and Performance

The workshop was facilitated by CK Mathew, Public Affairs Centre.

It was suggested that we have our opinions about the governance in various states, which are biased and not based on evidence. It may be useful to look at official governmental statistics in each of the states in a composite way to get a more objective idea.

An index called the Public Affairs Index (PAI) has been developed by them, which includes various aspects of governance. Duty of government to balance the three things: economic efficiency, social justice and individual liberty = factors that determine quality of government.

The structure of the index:

- 10 themes cover the broad aspects that the government is involved in (which includes development, industry, security, and infrastructure among other things).
- 25 focus subjects (for instance, health comes under development) arise from the ten themes which lead to the 68 specific indicators (for instance, doctors or hospital beds per unit population)

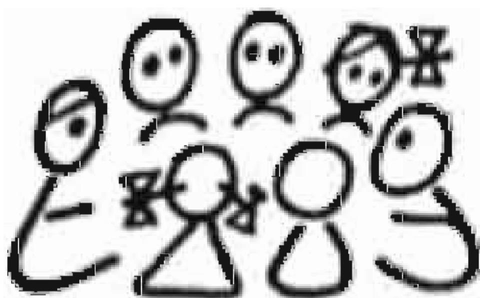
Data used is from public domain where the government has made it available for all citizens. Secondary data from past three years which is available in public domain is used, and this can tell about the progress made over the last three years. Each of the 68 indicators were assigned a weightage based on perceived importance (through deliberations by statisticians and economists). The PAI merged and integrated development outcomes and government processes; covers all representative aspects; new variables were discovered.

The audience appreciated the effort, and also critiqued some technical aspects of the index, including the validity of governmental data and the weightings awarded, the usefulness of averages, the possibility of smaller number of indicators etc.

CLOSING SESSION

Participants from various workshops reconvened to share their respective workshop experiences, and also shared their parting thoughts about the event.

Report prepared by: Rajeev BR, Suresh R, Shweta G, Uma C, Samantha L, Dwiji G, Anusha P, Rahul ASGR, Adithya P and edited by Thelma



Report of the SOCHARA Silver Jubilee Meetings in Bhopal 27- 28 April, 2016 (Madhya Pradesh, Chhattisgarh and Northern India Region)

By Azam Khan (Adv.), Nidhi Shukla, Sayyed Ali,

The Society for Community Health Awareness Research and Action (SOCHARA) is an independent, non-government organization registered under the Karnataka Societies Registration Act 17A (1960).

SOCHARA started its journey as the Community Health Cell (CHC) in 1984, and registered SOCHARA on 16th April, 1991. For over two decades, 1991 to 2016, SOCHARA persistently strengthened health movements across the county, participating with and supporting people, communities, professional bodies and governments for equitable health and development through a range of community and policy level interventions. SOCHARA believes in collective action with communities and Bhopal is not a new place for the organization. After the Bhopal Gas Tragedy in 1984, SOCHARA actively intervened with Medico-Friend Circle. Later the team with associates was involved with the MP Rajiv Gandhi Mission; two *Jan Swasthya Rakshak* evaluations; the MP Human Development Reports; and finally in 2009 initiated a public health resource centre in Bhopal called the MP CPHE (Centre for Public Health and Equity) which organized a Community Health Fellowship Programme (CHFP) in M.P. and engaged with grass-root level interventions in collaboration with other organizations. At this point SOCHARA celebrates its eventful community health journey with learning's and future challenges in two regions: for the South in Bengaluru and for the North in Bhopal.

First Day: Session -I

This two day northern region silver jubilee meeting was inaugurated by Dr. Mrs. Shashi Prabha Khare (wife of the late Dr. Ajay Khare), Mr. Daman Ahuja (from the AGCA secretariat), Mr. S.R. Azad (MP JSA and MPVS), Mr. As Mohammad (SOCHARA) by the traditional lamp lighting ceremony. Mr. As Mohammad welcomed all participants and guests, thanking all who support SOCHARA continuously in North. Ms. Sapna from Barwani sang a song "*Manviya Sanskriti Kranit, Bhartiya Sanskriti Kranti*" and people clapped with her. After self introductions Dr.Ravi D'souza outlined the two day silver jubilee programme.

The first session paid tribute to the Late Dr. Ajay Khare, through a photo presentation by Ms. Nidhi Shukla, a first batch Fellow of the MP community health fellowship programme and now an MP CPHE team member. She shared the inspiring and encouraging experience she had when working with him in Pathalkot through the MP *Vigyan Sabha* (MPVS). Dr. Ajay was a valued friend of SOCHARA. We worked together in the Jan Swasthya Abhiyan in organizing the 2nd *Jan Swasthya Sabha* (National Health Assembly) in Bhopal in 2007. Nidhi conveyed the message from Dr. Thelma about how Dr. Ajay Khare supported the setting up of MP CPHE in Bhopal of which he became an active Advisory Committee member. He helped in increasing our understanding and connecting us to the ground realities in MP. His sudden death in a road accident was a great loss to all of us and to the health movement.

Guests shared their experience with SOCHARA. In the first address Mr.S.R. Azad (M.P.Vigyan Sabha) said, "*First of all I congratulate SOCHARA on this occasion of happiness. We have a mature relationship with SOCHARA. We are working for people, through analyzing the health situation collectively and try to make their life easy trough rational thought and a communitization process. Health is not an independent issue, it is interconnected with other issues. In context of health care services our major problem is budget utilization and trained human resources in the public health system. Now it is time to raise our voice collectively to improve people's health.* "

Guests congratulated SOCHARA on the occasion of silver jubilee and shared memories of working together in the National Health Assembly at Bhopal in 2007, Bhopal Gas tragedy (1984) and community

base interventions in other pockets of Madhya Pradesh.

Session -II

After the inauguration Mr. As Mohammad greeted all on behalf of the Executive Committee and SOCHARA family. He presented the **25 year photo journey of SOCHARA** *"taking us 25 years back in time"* and covering the (a) Genesis and evolution, (b) Aim and objectives, (c) Interventions, (d) Regional, national; global alliances, (e) Achievements and challenges.

The pre-SOCHARA Community Health Cell (CHC) was based on a traditional Indian concept called *sarai* (an inn) where people stay for short periods, share, experience, reflect and move on as like fellow travelers on a journey. This component continues. SOCHARA later initiated active interventions to empower the community to achieve "health for all" such as community health training, life skill education, women's health empowerment training, community health fellowship programme etc. The organization was involved with policy level engagement (through the Karnataka task force, health policy, various commissions, evaluations), community action programmes, and was engaged actively locally, regionally and globally through People's Health Movement and other networks (see www.sochara.org for details under the archive section). Through active participation, a value-based approach and community support SOCHARA achieved many things and set new mile stones in these journeys. Based on the rich Indian traditional knowledge heritage in health and healing, they together with other organizations, successfully established the concept of a plural health system in the public domain also.

After the presentation in an **open forum** participants raised issues:

- *Challenges faced in Programmes (Fellowship)?* We have many challenges in programme (like maintaining the interest of fellows and partners) but through encouragement, communication and motivation we solve it.
- *Failures?* Our failures are our learning and we utilize it as per circumstance.
- *Establishment of issues in the public domain?* Our Partners, network alliances, supporters and fellows are our actual strength who directly involved with community affairs and our collective approach make it possible. The 73rd-74th amendment of the Indian Constitution strengthens the process of communitization initiated by the National Rural Health Mission in which we played an active role.

Session – III

Mr. Dhirendra Arya a first batch fellow from the MP CHFP and former team member of MP CPHE presented a **photo-journey of the two year Madhya Pradesh community health fellowship programme**, the concept of the fellowship, design and outcome. He spoke of the pleasant time spent in CPHE. Every photo revived lots of memories among participants of collective teaching sessions, cluster meetings and field work days. The group has formed a **'Fellows Collective'** covering 26 districts of Madhya Pradesh with more than 50 fellows in Madhya Pradesh. The Fellows-collective has a strong presence in the state, and now people recognize its efforts. Fellows-collective addresses key issues such as malnutrition, and supports initiatives of other networks, like the Maternal Health Right Campaign. The Fellows-collective have many questions and hope for further ongoing detailed discussions and engagement. He also shared memorable moments with mentors.

Session -IV

Dr. Ravi D'souza presented an overview **of the work of the Centre for Public Health and Equity** (CPHE) Bhopal describing the present status, operations etc covering the following themes : (a) Mentoring fellows from the Bengaluru CHLP and students on placement (b) Networking with other organizations and alliances, (c) Training for NGO's, (d) Interventions in slums through Anganwadi's (in two urban poor localities : Mira Nagar and Indra Nagar), (e) Evaluations.

After lunch Ms. Sapna and Ms.Archana sang a movement song *"Tum Mujhko Vishwas do, Main tumko Vishwas du"* with everybody clapping and singing along.

Session V

An **open session based on Fellows sharing of experience** before and after the fellowship programme was chaired by Ms. Aarti Pandey from the MP National Health Mission, Ms.Sudeepa Das from Samvedna, Mr.S.R. Azad from MPVS. Mr.Jitendra Prajapati from the second batch presented his experience and present interventions on Malaria, and Village Health and Nutrition Days (VHND) through his organization in Betul. Smriti, Archana, Sapna, Prabhu Sharan, Irshad, Ajit and Rahul spoke of their experiences. Dhirendra raised questions. Fellows expressed that their confidence, sensitivity, awareness and technical knowledge on health increased after the fellowship. They described the challenges faced in the community. The summary of the discussion was that "we are all different individuals and we work with different organizations, but the common thing in all of us is the SOCHARA vision and approach. The approach makes us special." Mr. Azad felt that certification after the Fellowship would be helpful for the participants. While SOCHARA does give a Certificate it was felt that accreditation could be considered.

Sudeepa Das commented on the need for knowledge updation in the age of knowledge and information. Fellows were urged to use and create knowledge collectively, through an information centre on community health. Fellows can develop manuals in the interest of the community. "The community and supporters observe us through our actions, not plans."

Mr. Azad had observations and suggestions, "Change is a continuous process, but now-a-days people shift from one place to another within a short time span, and it is bad for us and the community also. Without a political understanding we cannot achieve "health for all". Plan everything carefully before an intervention (time, place, stay) if you want to see the change in community through your efforts. I am happy to see SOCHARA fellows in our MPVS campus."

Ms. Aarti Pandey said, "First utilize your knowledge and skill as per circumstances, and second choose your partner and work happily."

Session -VI

Dr. Ravi D'souza analysed the child and maternal health situation in MP as per data in the National Family Health Survey (NFHS) 4 in comparison with NFHS-3.

- Maternal and child health has improved in comparison with NFHS-3 but not satisfactorily.
- Anemia is still high.
- In the context of adult nutrition, obesity and overweight has increased.
- Number of institutional deliveries have increased, but the Caesarian rates are high.
- Total Fertility Rate (TFR) decrease and decrease in sex ration rapidly (961 =>948).
- Burden of Non-Communicable Disease (NCD) is high.

The open forum discussed sample size, social determinants, anemia and malnutrition.

Second Day

Ms. Nidhi Shukla welcomed participants, and Ms.Sapna Kanera an alumnus from the first MP CHFP batch sang the Fellows favourite song ,"*Maa Reva Tharo Pani Nirmal*" the song people sing in the *Narmada Bachao Andolan*. A recap and reflections on the previous day sessions was held.

Session -I

Dr.Sunil Nandeshwar, Head of Dept. of Community Medicine from the government Sagar Medical College, in the Bundelkand region of MP spoke on the Millennium Development Goals (MDG's) and Social Development Goals (SDG) and their importance. MDG's address the limited issues like: poverty, water and sanitation, malnutrition, education; under 5 years child mortality etc. The target period was 15 years (from 2000-2015). Before the MDG's development issues were addressed without timelines. The MDGs had 8 goals, 18 targets; 48 indicators with a monitoring mechanism. However the goals were not achieved by 2015 and the UN set new development goals through the SDGs which have 17 goals and a timeline from 2016 to 2030. The MDGs adopted a target driven vertical programme approach, while SDGs are horizontal, more comprehensive, with

a holistic approach to address development issues, including a focus on environment and gender equity. It can be said that the SDG's are based on a structured communitization process with partnership among the state, public, and other stakeholders. It can change the development scene universally.

Open forum: Participants raised issues of partnership, participation, accountability, transparency and responsibility among the entire stakeholder group. Mr. Mohammad thanked Dr.Sunil and concluded with a reflection that development is a continuous process, and without active participation by the community, we cannot achieve our goals.

Session -II

Mr.Kedar (MHRC) and Mr.Ajay (Centre for Health and Social Justice) spoke of the Maternal Health Right Campaign's (MHRC) State Level *Jan-Samvad* (Public Dialogue) to be held on April 29, 2016 at Bhopal. MHRC is working since three years in 22 districts of Madhya Pradesh as a non-funded initiative, in which some community health alumni participate. Under MHRC they spread information, create awareness, monitor and advocate maternal health issues in the state.

The MHRC's secretariat is in Bhopal and most of the members of campaign are representatives of grass-root level organizations. They have a co-ordination committee. Community Based Monitoring (CBM) is the key component of the campaign where they train community members to monitor the health care system and measure the services as per Standards and community opinion.

Session – III started with the video message from Dr.Mohan Isaac, President –SOCHARA.

The session on Future Action was moderated by Mr. Prasanna Saligrama. After a video on the SOCHARA Community Health Learning Programme he mapped the initial stages of SOCHARAs involvement in MP. He highlighted the active presence of over 100 people in MP who carry the thoughts of SOCHARA. The 100 include three sets of people in the audience –SOCHARA team + Fellows + Mentor organisations in the 51 districts. The larger influence as integral members of the health for all movement in the state through ASHAs, NGOs etc is part of the larger context. For framing a future plan of action, expectations and suggestions of fellows, mentor organizations and SOCHARA is important. Participants were divided into groups to discuss about: a) Expectations; b) Suggestions; c) Work Plans and d) Next Steps and the points raised were as follows:

- Mr.Prabhu Sharan Masih shared points from the '*community health fellow's alumni group*'. They wanted continuous technical knowledge support; support from Bhopal office (space, library access); alliance with other organizations. The Fellows Collective needs a concrete action plan and support for the same which was discussed in the meeting that evening.
- Mr.Chetan (Spandan) from the '*mentor organization's group*' shared the opinion that our alliance is very nice, and through your fellows we exchange knowledge and experience, but we need a more active connection with SOCHARA. It is the right time to review the programme (Mr.Arun Tyagi). The Padhar Hospital, Betul was ready to provide training on mental health. SOCHARA was considered to be a reliable partner for the group.
- Mr.Sayyed from the '*SOCHARA mentor's group*' shared his group's view that we need a strong and active alliance, with support from partners and fellows; and develop further as a state level resource centre and research centre.

In conclusion Mr.As Mohammad said, "on behalf of SOCHARA I accept all the suggestions. We are all equal and we work collectively. If you have anything to share please share it with us. We need strong collective action to address social problems. And the Silver Jubilee of SOCHARA is the right time to assess our action and improve according to the situation."

After lunch, Nidhi specially remembered and thanked people in the administration who work tirelessly behind the scenes and who play an important role. Dr.Tripathi sang "*Chalo Geet Gao,Chalo Geet Gao, Gagake Duniya Ko Sar Pe Uthao*". After his energetic song the next session on Communitisation of the health system started.

Session – IV Community Action for Health (CAH)

The presentation by Mr.Daman Ahuja (from the Secretariat team for the NHM Advisory Group on Community Action - AGCA) and Mr.Narendra Jaiswal's (MP State Program Manager, CAH) was based on three points:

a) Background of AGCA; b) Film; and c) Stage of communitization with Govt.

At first Mr.Daman explored the background, functioning and accountability framework of Community Action for Health (CAH) developed through the AGCA. He screened a film "*Jan-Swasthy ke Badhte Kadam*" and in the third part, both speakers briefed participants about community monitoring mechanisms and utilization of information in policy making.

Under the National Rural Health Mission (NRHM) from 2005-2012 and the National Health Mission (NHM) since 2013, Community Action for Health is most important component and through AGCA's advise, feedback and module development we educate and create awareness in society, share information with on community monitoring with various stakeholders and initiate public dialogue. Under the Accountability Framework the first step is external survey, second routine programme monitoring (HIMS) and third is community based monitoring and planning (CBMP) which assures participation of communities. Documentation is necessary for advocating the issue and AGCA uses feedback, monitoring data in planning and evaluation also. The *Rogi Kalyan Samiti* and *Swasthya Gram Samiti* (Village Health Sanitation and Nutrition Committee) are micro-level committees that can be very effective if members are trained and pay their role. Mr. Ahuja spoke of the Pilot Phase in 9 states, including MP. He also mentioned that in MP CAH is now being run by the state government in 5 districts in an intensive way (where the earlier pilot had taken place) and the ground is being prepared in the rest of the districts with orientation and training of health department staff. A state level training had taken place in February 2016 and *Jan Samvad's* are being planned. They suggested that all participants could be actively involved with these committees and see the change over time. Diversified composition is the specialty of every committee. Dr.Thelma Narayan is a member of the AGCA which is a Standing Committee of the NHM and supports activities promoting communitization of the health system.

Session – V Public Private Partnerships in Health

Mr.Amulyanidhi from the MP unit of *Jan Swasthya Abhiyan* (JSA) shared his experience on privatization of the public health care system being undertaken in the name of partnerships, based on the experience of an ongoing public private partnership in Alirajpur district. Madhya Pradesh is very unique state in India where experiments are implemented in the tribal belt (like Jhabua, Mandla, Alirajpur). In the name of a partnership, an MOU was signed between the Rajya Swasthya Samiti (State Health Society) and Deepak Foundation which is the Corporate Social Responsibility initiative of the Gujarat based Deepak group of companies to conduct all training programmes for ASHAs and VHSCs. The MOU does not mention the financial aspect in the public domain. While an attractive picture of the PPP is portrayed, there is a dark side. The public health system gets weakened. The JSA has a campaign in this regard. Similarly a knowledge partnership programme was initiated with Bhandari Hospital in Indore, but through interventions by civil society, doctors and nursing association's they could not execute this in Indore. Before intervening in the issue of privatization of health care services in the tribal belt JSA requested Vikas Samvad to conduct a study on IMR-MMR of the area and utilized the study in a PIL and now the matter is pending before the Indore High Court. Regional language newspapers such as Indore Patrika and Naiduniya support the raising of public interest issues. Together with JSA the process has now been stopped by the department. JSA works on two levels - first organize people, study the issue, and intervene legally. In conclusion if we want to intervene on a policy level we should unite and intervene at every level.

Session –VI Fellows collective

Mr.Sayyed Ali briefed about the Fellows Collective's Nutrition Programme in Madhya Pradesh covering: a) Causes of malnutrition; b) Stakeholders; c) Intervention areas; d) Plan of action and c)

Collaboration with others. Under the programme they intervene in 2 slums of Bhopal (Miranagar; Indiranagar) and cover 300 children in collaboration of NGO's and the Women and Child Department through a community based approach. They share the status with community and Department, develop and conduct training programmes for community members and Anganwadi and NGO staff; and mentor community health fellows. Jitendra does similar work in Betul. Other alumni have also shown interest.

In Conclusion

Mr.As Mohammad expressed pleasure about the presence of participants and members, appreciated presentations which were full of facts and information, and give us new directions for future.

He recognize that we need more information and Knowledge and in next coming days we will exchange our knowledge, studies; information with our fellows and mentor organizations through different mode of communications.

Mr.As Mohammad thanked all those including the Fellows collective, Mentor Organizations, Administration Staff, and Other participants who made the silver jubilee programme memorable one in Bhopal.

Silver Jubilee Reflections - The Faded Pants Experiment

By Dr. Suresh, CHLP – Flexi fellow - (Batch 12)

I was told at a very young age that people will judge you by how you dress and accessorize. In a way this is true. The people of our world who are rooted in material things, judge themselves and others by their externalities and will judge you by how you dress, how you accessorize and how you look to others. They will behave according to how you are dressed and the titles you or your relatives own, it is a reassurance to attach your ego directly or indirectly to anything that "looks good" without reflecting if beauty is skin deep or more. I was told before an international meeting that I helped organize with a group in Chennai in 2014 *"dress so that people will know who you are"*. Who am I? I have wondered ever since is this the way to garner love and respect? By dressing well? Is this the matter of priority and relevance to the world- How you dress? So I decided to conduct an experiment. At the SOCHARA Silver Jubilee Meeting, on the first day when we would meet and interact with many new people for the first time, I wore my most faded and torn pants and made sure that they didn't go well with the colour of my shirt or with my dusty *chappals*. Also, I drove to St.John's in a very old beat up second hand car that was scratched and dented all around.

What I learnt is that true friends and new friends do not care about whether your pants are faded or torn nor are they concerned with the car you choose to drive, true friends and new friends are more concerned with how you feel and how you make them feel, how authentic, engaged and connected you are. New acquaintances feel more comfortable talking to you when you don't dress "*up*", They reveal their true selves to you and trust you more freely and willingly. I never once felt anyone at this national level meeting respected me less or loved me less on the first day. My friends and I sang songs to the gathering in my faded torn pants and never once did I feel anyone was judging me by my clothes. The warmth of the community did not fade with the colour of my pants. Nobody noticed nor cared if they did. In fact for the evening song before the *Kala Jatha* performance, Kumar and two strangers, professionals who I have never met before agreed to come and sing along with the fellows when I invited them though I was wearing faded and torn pants. On the road while I was driving back people didn't compete for space around the car like they would with a nicer car. Dressing *up* and driving *up* garners attention and fosters competition with other people who like to dress up and drive up. It *does not* foster love, trust or respect. If it does, it garners the respect of the kind of people you don't want in your life and the wrong kind of respect.

I also think about the people who judge others exclusively by the clothes, the titles and behaviour shift the value they have for themselves to these

external things. They commodify not just others, but end up commodifying themselves. The less stuff you have, the more confident you are because you have nothing to attach your ego to but Your Authentic Self. When the ego is attached to your Authentic Self, you engage in right action and it makes no difference if you have nothing or you have everything.

Respect and Appreciation are not on the same tracks as Love and Satisfaction. You can have all the respect and appreciation in the world, but have no love and satisfaction in your life. But the same doesn't hold true for processes which begin in love and end in satisfaction. Those who are successful and get appreciated while working within an organization be it private, government or NGO need not do much work. Those who are interested in respect and appreciation just need to pretend to work within the system, suck up to the "seniors" and kick down the rest. They will always be surrounded by a codependent group of yes men or women who don't really like them but don't want a kick. Those who are in it to work for works sake will have the satisfaction of the fruits of their labours and the informal support and appreciations of the true friends who they make beyond lifetimes on their journey wearing faded pants in dented cars and clap for themselves while the glory hounds glow in the credit of their efforts. They probably don't mind this because they know there will always be a lot of appreciation and love for them from themselves and others whether they are acknowledged or not even long after they are gone.s

"Mental Health, Care and Rights" A report of the Medico Friend Circle Annual Meet

By Anusha Purushotham[1], Manisha Shastri[1], Pooja Venkatesh[1] and Janelle de Sa Fernandes[2]

The 41[st]Medico Friend Circle (MFC) Annual Meet was held from 20th to 22nd February 2015 at the SM Joshi Socialist Foundation, Pune and was organised by MASUM (Manisha Gupte and Ramesh Awasthi). The meet brought together biomedical, community and legal perspectives on "Mental Health, Care and Rights" and served as a platform for dialogue between different stakeholders.

SOCHARA was represented by a few current fellows from the Community Health Learning Programme (CHLP) - Anusha Purushotham, Bharti Sahu, Ashma Jahan (CHLP Batch 11), Manisha Shastri, Pooja V. (CHLP Batch 12) as well as SOCHARA staff (Janelle de Sa Fernandes), CHLP alumni (Shelly, Satyashree Goswami, Anant Bhan and Syed Touseef Hussain) and SOCHARA members/ associates Dr. Mani Kalliath, among others.

Background papers were circulated for discussion in the months leading up to the meet. These included papers ranging in focus from mental health survivor stories and perspectives to institutional psychiatry; policy and law.

Day1:

The meet was opened by Manisha Gupte with a round of introductions by all participants followed by two keynote sessions.

Keynote Session 1:

The first keynote was delivered by **Bhargavi V Davar (Bapu Trust);** a mental health survivor and activist. She raised the following questions through a discussion of her paper on, **"The Discriminatory Standards of Constructing 'Patienthood' of the 'Mentally Ill' within Public Health".**

- Is mental 'illness' really worth being included in a public health discourse?
- Who is a 'patient' of mental disorders?
- Are we buying into medical interventions as being the sole answer?
- Is there a specific class of psychosocial interventions that can be plugged into context based interventions?

1 SOCHARA Community Health Fellows.
2 SOCHARA Team Member.

Some comments and questions raised by participants included:

"The crux of the problem lies in social control – people over the centuries have always been reigned in to conform. Back then, there was a feudal society and now, under the name of capitalism, a secular business model is built around the issue of mental health."

"We can see how DSM 5 colonises the human spirit. But at the same time we cannot ignore the fact that many people do not have access to much needed therapy. Thus, the 'moral outrage' against having no access to psychotropic medicines should be justified – we need those drugs"

"Mental health in the 'West' went through a whole process – from incarceration to abandonment and now, over-diagnosis. In India however, we skipped a step. Users are protected but are not productive. They are being flushed out and are brought to doctors who are ill prepared or even clueless about the facts. It is just as we have skipped the landline age where most of India never owned a landline but now 90% of the population have mobile phones."

"In India we do not even have our own data for support. There is a lack of exposure of doctors to mental health during MBBS. We have a weak taskforce."

"There are certain conditions that are genetic where medication can help like bipolar etc. Isn't it important not to devalue the role of drugs in such illnesses? What can psychiatrists, as service providers who have limited time, do to help patients out of their sphere of expertise? It is easier and more practical to prescribe drugs to patients than to fight social structures. How do we set up support systems?"

"How is the issue of mental health different from other public health issues?"

"Physicians use mental health as a dumping ground for anything that is "problematic" i.e not well understood and has no pathological evidence.

It is far easier to blame larger constructs of capitalistic agenda, pharmacology and other larger forces. Instead, we should clarify the causes of the issue"

"We need to look at the preventive and promotive areas and not just the curative. Counselling is an overused concept – much damage done by unqualified 'professionals'. This needs to be considered along a spectrum, not just the illness end of it. The issue is much more complicated: Suicide is not always a diagnosable event, but how do we include a more holistic understanding of it?"

Bhargavi responded, "We (users/survivors) are not saying we do not need any support. Is mental disorder really an illness? It can actually be described as a distress, a disturbance or a social disability." She asked, "Is it only medical care that is needed? Traditional healers, arts based therapists, yoga practitioners and other alternative health professionals are not recognised and not addressed at the level of regulation. They are all brushed under the umbrella of quackery."

She continued, "Why isn't women's social status a health problem? If we believe in a social model of health and social determinants, where are social sciences in mental health? Are there any tools being developed for psycho-social indicators? Why is there no funding for social science research? Why is it only a medical model? According to Phillip Thomas, we need to get people back on their own path to recovery."

Bhargavi concluded the session with the following points:

- All public health problems, including mental health, have a common ground – they all stem from social inequity. We need to tackle the problem at its root.
- Presently, our public health system is designed to combat only infectious diseases. This model is highly flawed and thus, it is failing. We have to change our methods of engagement.
- We need strategies, specifically empowerment strategies. What happened to nutrition, balanced diet, etc? Need to focus on building community resilience, need to focus on localised problems and stop palming them off as medical problems. Community work is a requirement and cannot be outsourced to doctors.
- The real solution is social change – although it is a daunting task, there is no other way.

Keynote Session 2:

In this session on **"Law, Mental Health and Human Rights"**, **Amita Dhanda** reflected upon the various aspects of law in the realm of mental health and the rights of people with mental illnesses. The following are a few salient points from the discussion:

- Although a lot of questions raised in regard to mental health, are common and relevant for many other public health issues, the difference lies in how legal interventions are implemented. There is a need to address mental health law and rights.
- It is not just a problem of 'social control'. For our general beneficence and for the larger good of others, does help need to be externally organised and can users be coerced into it because generally they would not have capacity to know what is good for them? We need an alternative law/ legal scheme to question present social structures. Law is not a panacea, but we need to reassess our relationship with the law.
- How does law look at force in the context of mental health and how is it different from force looked at in general? Does law make a distinction in the 'type' of mental illness? What should be the role of law in mental health?
- The writing of a 'Will' and consent is central to treatment but this is taken away in mental illness. Before the disabilities rights movement came into picture, the model was, "disempower and help" where the voices of the patients are lost. The medicalisation leads to disempowerment of people rather than enabling them to make decisions when they are empowered. The voice of the patient is lost in the process.
- Is compulsion in mental health care in consonance with human rights? India has ratified the UN Convention on the Rights of Persons with Disabilities (CRPD) and thus, the national laws should be changed accordingly, such that doctors can 'persuade' but not 'force'. Currently, CRPD offers a gamut of human rights without ousting force. But we need to oust force to really allow for choice.
- Not only does our law compel treatment, it also compels a particular type of treatment – 'Institutionalisation.'
- The choice at present is in between 'institutionalised care' or 'no care (caring for ourselves).' What about the 'in-betweens' like peer-to-peer support groups and alternative therapies other than allopathic / AYUSH? Users are not speaking up for the kind of support needed. There is a need for care and support determined by people's own voices and their own choices.
- There is a necessity to critique 'exploding diagnosis' which impacts people's lives in entirety. When you add the force of state and the role of law behind knowledge (in science and social science), you freeze the state of knowledge.
- It is important to talk about those who have committed suicide due to psychiatric care because others took control of their lives. But it is also important to focus on those for whom psychiatric care was unavailable.
- Lunacy is a term used mainly in law. Mental illness used as means to address marital problems and as grounds for seeking divorce. How the laws are in conflict with one another.
- The present law 'medicalises' social problems, putting the onus on the individual rather than his/her social context.
- Laws pertaining to mental health are in isolation from principles of social justice and equality.
- Does law have a role to play in mental health?
  - o Yes, legal wounds need legal salve
  - o Need to enact mental health legislations which
    - Recognize the autonomy and choice of people with psychosocial disabilities
    - Oust the use of force
    - Mandate a bouquet of services
    - Regulate their provision
- Such proactive effort has a greater chance of reversing the legacy of force prompted jurisprudence.

A few key concerns rose among the audience:

- There is already a bouquet of services for PWMI, but there is no humanity when rendering these services. Instead of increasing the number of services, focus should be on 'how' these services are delivered.
- The context of disempowerment became very clear after this presentation. The law needs to be on the side of the disempowered. It is ok to question the existing services. Psychiatrists need not be gatekeepers to the medical establishment. Regulation of other alternative therapies is essential because such evidence-based practices are also beneficial for PWMI.
- Who evaluates the legal capacity – the decision-making power of PWMI? Amita stated that "PWMI do not have to justify their capacity. If you ask these questions to PWMI, you should ask everyone else too. One should be careful in creating a hierarchical communication as this is the sort of discrimination PWMI are fighting against.

After the hour-long discussion, Amita closed the session with the following remarks, "One cannot medicalise a social problem in order to exonerate/ bail out the government or society. We cannot emphasize only the individual responsibility and ignore the social context of psychosocial disability. There is very less clarity regarding biological markers and thus, we cannot and should not consider these problems in isolation. The law needs to align with the disempowered person and not align with the forces against empowerment.

The keynote sessions set the tone for the rest of the conference. The discussions that followed were thematically divided six sessions based on the background papers that were circulated prior to the meet.

1. Philosophies of Survival:

This session was significant in that it completely comprised of the perspectives of the community of PWMI.

'Psychiatry' came into existence after the establishment of institutions (asylums) unlike other branches of medicine, where the institutions arose after the development of the medical science. Colonial perceptions led to institutional psychiatry and thus, there are 'user-survivors' of psychiatry who still continue to demand sensitive care. In countries like Thailand and Nepal which have no history of colonization, the landscape is bereft of oppressive institutions.

The user-survivor movement arose towards the end of the 20th century and PWMI who became a part or forced into the system of psychiatry began to identify themselves as 'users' or 'survivors' of psychiatry. Three papers by the survivors of psychiatry were discussed in this session.

In the first paper, *'Power to Label: The Social Construction of Madness,'* the author highlights the need to question the dominant biomedical psychiatric approach and seek alternative context-specific models of recovery. The author argues that psychology was meant to study the soul but instead became more scientific by creating categories and leading to exploitation. She raises the role of labels and language in creating identities and safe spaces for PWMI. She also recommends a process of construction, deconstruction and consolidation of the present as a therapeutic process. In conclusion, the, the author questions whether more people are willing to look at the alternative therapies like music therapy, art therapy, social psychology, language, family studies as alternative paths to recovery.

The paper, *'Healing as the Archaeology of the Self'*, describes the author's 'psychotic experience's and how the answer to healing someone from 'mental illness' can be found within the 'psychosis' itself.

'Childhood Sexual Abuse and its Relation to Mental Illness' discusses the lack of understanding about the victims distress and experience, problems of disclosure, the implications of abuse and the lack of linking it up to mental distress. The author states the 3 Ps, *'Patriarchy, Power and Penetration'*, make it harder for children to cope and disclose.

There is a need for recognizing the '*power of testimony*' and acknowledge individual narratives as authentic and understand trauma. Finally, the author emphasises that several mental health issues are

matters of social justice and equity rather than purely medical in nature.

2. Biomedical Psychiatry in India

'*Mental Illness: Diverse Perspectives, Partial Truths and Imperfect Solutions*', discusses how psychiatry's complete disengagement with psychosocial factors is ultimately more harmful than useful. The paper brings the Diagnostic and Statistical Manual (DSM) into focus by questioning its relevance in the Indian context and draws attention to the limitations of such biomedical classifications that fail to capture the multiple dimensions of mental illness.

The paper, '*Does community mental health really engage the community?*' looks at the relationship between local and global healing practices in mental health. The paper highlights how in India, healing shrines are being colonised by psychiatry, although at an international level, healing shrines are being considered as prospective models for community-based mental health action. The paper further emphasises the dearth of people-based movements in mental health which could escalate the mediatisation of mental distress.

The second day of the MFC meet brought community mental health, the youth and society into focus.

3. Community mental health

Medicine is very paternalistic in nature. The perspective of the doctor is always seen as more important than that of the patient. To address this, the biomedical model was replaced with the biopsychosocial model. However this model is more praised and seldom practiced. It is not just enough to highlight the limitations of this model but imperative to provide alternatives. It is not enough or helpful to only criticize the current model.

The paper, '*Coping and Recovery from a Community Perspective*' focuses on the alternative '*Recovery model*'. Different people seek different pathways to care, be it through culture, beliefs, or values. Recovery is a very personal process. The recovery model focuses on staying in control rather than the illusion of returning to pre-morbid function. Recovery model serves as a means of self-discovery and looks beyond survival and existence. The model emphasises recovery, support, connectedness and resilience; and enables people to lead hopeful and meaningful lives despite institutional remnants.

Community mental health was further discussed based on the experiences of organisations like Basics Needs India, The ANT, and Emmanuel Hospital Association (EHA).The following were their key learnings:

- Social inclusion, employment and psychosocial interventions are more durable than psychiatric interventions alone.
- Healing is much more than just giving medicines. Although handing the power to the people requires more effort, it is more effective.
- Support PWMD to access relevant government entitlements and medical care.
- Advocate for essential medicines.
- Conscious efforts to record life stories, record files and the journey of each patient
- Mobilise access to the government system through advocacy and maintenance of good data systems.
- Awareness building on existing laws, sensitising and engaging with local self governing bodies (panchayats).
- Build mental health resilience knowledge and skills among communities.
- Capacity building at different levels of government and community through training of ANMs, ASHAs, panchayat members, family care-givers and patients themselves.
- Focus on empowering PWMI to rehabilitate and integrate themselves into society. Equipping them with skills that enable them to become economically productive, self-sustainable and even run their own organisations.
- Describe and disseminate information about alternatives
- Collaborating with local traditional healers who treat a lot of mental illnesses and disorders to understand their view on mental health and encourage cross referrals. Previous experiences, especially by The ANT, in such collaborations have shown positive results.

- Since there are more cases of mental distress observed amongst women, there is a need for gender-sensitive interventions, perhaps, by bringing in female volunteers.
- The process of community consultation can be adopted by considering, "What can you do? What can the community do? What can the patient do?"

4. Mental Health of the Youth

Young people have to deal with rapid transitions in relationships, educational and early careers decisions that may make them vulnerable to depression, anxiety and risky behaviours. Mental health problems among the youth are widely underestimated as a normal part of adolescence and hence, the need for support mechanisms to cope with their vulnerabilities is ignored. The discussion of the papers, *'Personal Resilience: The missing link in improving wellbeing among youth,'* and *'Youth Suicides in Colleges,'* illuminated the following points:

- Building resilience and skill enhancement as techniques to promote well-being among the youth.
- The need to create 'empowered' and safe spaces where youth from both genders can work together to solve their own problems.
- We need an organised way to deal with suicides through counselling services in educational institutions and peer support groups.
- In addressing the number suicides that occur in educational institutions, rather than questioning individual students and their capabilities, the responsibility of the institution should be to reconsider its academic and social structures.

5. Psychiatry and Society

During this session, the medicalisation of distress, effects of alcoholism, pathologisation of the LGBTQ community, and disasters in the context of mental health.

The discussion drew attention to the fact that good practices in psychiatry emerge with non-technical aspects which focus on healing in every dimension of life. Unfortunately, medicalisation has kept these aspects in the dark.

In addressing alcoholism for instance, the question that was raised: 'Is Alcoholic Anonymous (AA) really central to the de-addiction needs of society?' It was argued that AA groups may be more damaging than useful as they may cause problems of self-esteem in individuals struggling with abstinence when seeing others in the group being successful at it.

Matters of sexual orientation are not only limited to religious discourses but also find their way into medical settings. In attempting to explain its origin, psychiatry had earlier classified 'abnormal' sexual preferences like homosexuality as a disorder. Though the classification has been completely removed from the DSM, the Indian Psychiatric Association and Medical Council of India continues to use it.

"**Ego-dystonic sexual orientation** is a mental disorder where the individual has a great discomfort with his/her sexual orientation and feels/expresses a strong desire to change. In contrast to this **Ego-syntonic homosexuality** is a state where the individual is absolutely comfortable with his/her sexual orientation," as explained in the paper, *'LGBTQIA & Mental Health'* and further points out that, "This classification is a big laugh at the lives of homosexual people, with the kind of stigma, hatred and taboo a queer person is put to live with.... most queer people would be in a state of confusion and dilemma in the initial days..., would this be considered as ego-dystonic homosexuality?" The author stresses that these notions are framed by heteronormative outlooks and challenges the views that any mental distress experienced by the LGBTQ community is intrinsic to their sexual preference rather than the societal stigma attached to their status.

The discussion on the role of mental health services in disasters underscored the lack of psychological first-aid in disaster situations and the excessive focus on medicalising normal reactions amidst grossly abnormal environments. As part of disaster management, the need for addressing psychosocial aspects by mobilising long-term local and cultural support was emphasised.

6. Policy and Budget

This session explored the relationship between mental health, policy and budget. The first paper, *'The Role*

of Caregivers in Mental Health Discourse,' called for the inclusion of 'carers' needs in policy decisions. Due to the high cost of care-giving and lack of trained human resource available for PWMI, 70-80% of care-givers are family members, as opposed to institutional and community care-givers.

This aspect of care is least visible, primarily because of stigma and the Government has ignored this major group of stakeholders. Care-givers need professional help and support, in terms of emotional, financial and psychological care. They also need information and guidance. In summary, the paper focuses on the need for mental health professionals and policymakers to work with care-givers and take their rights into account.

The existing National Mental Health Bill of 2013 introduces the 'right to mental health.' It increases access and availability of psychiatric services from primary health care to the highest level in mental health care. However, there is no mention that the 'right to mental' health goes hand-in-hand with 'right to social equality.' In addition, the draft National Mental Health Policy of 2015 reportedly has no mention of psychosocial aspects of mental health. Therefore, it was argued that the current policies focus on treatment of mental distress with pharmacological agents, which in turn leads to commodification and marketisation of distress. The underlying issues like education, labour, justice, transport, environment and housing should be brought to the forefront in the health policy making process.

Concluding thoughts:

The MFC meet served as a platform for not only the medical fraternity concerned with mental health, but also as a common space for survivors, activists and other health and social professionals to come together to exchange thoughts and experiences on mental health, rights and care.

The three-day meet drew to a close with many participants having broadened their own network base that would enable taking various issues in mental health forward at different levels of community, health system, policy and rights.

For us as novices in community health, attending the meet helped us broaden our understanding of mental health, the widely practiced bias towards the biomedical model and the need for social perspectives in addressing mental health within the wider context of achieving health for all.

The role of biomedical psychiatry in mental health: Lessons from the 41st Annual Meet of the Medico Friends Circle

By Anusha Purushotham, Community Health Fellow, Batch – 11

The Medico Friends Circle (MFC) is a 'thought-current' that was formally established in 1974. It brings together diverse groups of pro-people, pro-poor individuals with a common goal – "*to critically analyze the existing health system and evolve an appropriate approach towards health care which is humane and which can meet the needs of the vast majority of the people in our country.*"[1]

Since its inception, MFC has held annual-meets every year with a focal theme to encourage members to gather and generate discourse about pressing health issues. The theme for the 41st meet was 'Mental Health, Rights and Care' and was organized in Pune, between February 20th – 22nd, 2015.

As a first-time attendee with an immense admiration for the MFC and a keen interest in mental health, I was extremely impressed with the scope and extent of the topics that were discussed in the annual-meet. However, what was most intriguing to me was, despite the heated debates and wide-ranging viewpoints on various aspects of mental health, there was an overwhelming consensus on one issue. All participants who comprised of, not only activists and user-survivors of psychiatry, but also mainstream mental health professionals agreed that the present-day dominant approach to mental health - biomedical psychiatry - is insufficient and incomplete.

One of the papers presented during the meet, **"Mental illness: Diverse perspectives, partial truths and imperfect solutions,"** effectively and succinctly

encapsulates the essence of this concept. It is unique in that the limitations of conventional psychiatry are discussed and acknowledged by its author, Dr. KS Jacob, who himself is a renowned psychiatrist from CMC Vellore, with over 30 years of experience and the lone psychiatrist amongst other health professionals, researchers, lawyers and journalists who attended the mid-annual meet at Pune. This article attempts to understand the role of biomedical psychiatry and builds primarily on Dr. Jacob's paper[2] along with references to other relevant literature, discussions that ensued in the MFC annual-meet and my reflections.

History of Biomedical Psychiatry

In his paper[2], Dr. Jacob takes us back to his journey as a young psychiatrist who was awestruck by the promises made by new discoveries in the field of biomedical psychiatry. During the early 1980s the Diagnostic and Statistical Manual III (DSM) and new scientific publications identifying genetic pathways to common mental illnesses brought a sense of confidence among young professionals like him. They were believed to simplify the discipline into precise operational categories of diagnoses and disease etiologies. Thus, psychotropic drugs were lauded as the answer to every form of mental illness.

With the sudden increase of newer anti-psychotic drugs and marketing strategies by pharmaceutical industries the world over, the focus on biological model of mental illness increased and social factors were grossly neglected. These new drugs purported to have fewer side-effects than before and psychiatrists found it easier to prescribe these 'wonder-drugs', which claimed to improve the mood of patients regardless of their circumstances. Therefore, the common attitude was that there is little or no use in resorting to time-consuming psychological interventions like psychotherapy to tackle other causative agents like inept stress coping mechanisms or behavioral problems in patients.[2]

Psychiatric Classification

The next three decades, however, saw multiple revisions of the DSM (III, IIIR, IV, IV-TR, 5 and VI) and International Classification of Disease (ICD 9, 10 and 10 for Primary Care). These revisions raised a lot of questions regarding the nature of mental disorders and validity of these classifications.[3]

DSM was developed in the 1970s, a time when psychiatry comprised of 'unproven' etiologies for mental illness and poor diagnostic agreement among psychiatrists.[4] It introduced operational criteria that focused on inter-rater reliability and symptom counting sans context, and soon became the gold-standard.[4] Although these classifications help people find the terms to express their distress to their family and mental health professionals, they also group people with heterogenous syndromes under the same umbrella.[3]

This could be a result of DSM's complete disregard for context and environmental stressors in favor of inter-rater reliability.[4] Even within circles of mainstream psychiatry, it is slowly being accepted that "*current diagnostic systems for mental disorders do not adequately reflect relevant genetic, neurobiological and behavioral systems - impeding not only research on etiology and pathophysiology but also the development of new treatments.*"[3]

Due to the sheer complexity of identifying specific brain processes that lead to mental illnesses, there is a lack of laboratory tests for diagnosing mental disorders. This is further complicated by any current research efforts being hindered as they rely on poor psychiatric classifications and thus, are not entirely accurate. Therefore, psychiatrists have to depend solely upon clinical features and the DSM symptom checklists that are employed in isolation of context.[4] Such categorizations, therefore, run the risk of medicalizing many normal human experiences.

Population and Primary Care

In the 1990s, DSM-IV for Primary Care and ICD-10 for Primary Care were introduced. However, the ground realities of treating mental disorders in the primary care setting were starkly different from that of psychiatric facilities.[2] Primary care physicians saw milder forms of mental distress and more often than not, attributed their cause to psychosocial adversity.[4] They were more likely to label these conditions as 'distress' rather than 'disease' or 'disorder' because these conditions were frequently associated with psychosocial stressors, spontaneously remit, respond

to placebos and have limited response to psychotropic drugs.[3,4] Therefore, this challenged biomedical psychiatry's popular framework of using drugs as the sole form of therapy.

Non-biological determinants of mental health

Poverty, unemployment and low education have been linked to depression, anxiety and other common mental disorders.[4] Insecurity and hopelessness about the future, and risk of violence or physical illness associated with poverty are thought to be contributing factors for such conditions. Social exclusion, gender injustice, religious/cultural conflicts are examples of the many social determinants of mental health. [4] In addition to the social, economic and cultural determinants, there are larger structural and political players that precipitate the issue. Medicalization of distress, rise in the number of new psychiatric diseases and consequent increase in the number of new pharmaceutical drugs entering the market are characteristic of the neoliberal capitalistic agenda that seeks monetary gains by expanding its business interests, even in the domain of human distress.[4]

Alternative Approaches

The current state of biomedical psychiatry is in dire need of a paradigm shift. However, it is important to not only acknowledge the limitations of the present model, but also suggest alternatives. Thus, the concept of ***the biopsychosocial model*** emerged.

The presence of interconnected biological, psychological, social, cultural, economic and political determinants of mental health necessitates multifaceted, interdisciplinary approaches. Interventions at every level - individual, family, community and population are essential.

The heterogeneous nature of mental distress mandates 'person-centered' care at the individual level.[2] The biopsychosocial model does not disregard the use of psychotropic medications altogether. They are beneficial in severe forms of mental disorders and thus, have their own place in the treatment spectrum.[4] However, milder forms of mental distress can be effectively resolved without the use of medications by psychotherapy or other various non-traditional treatment options like social therapy, art therapy, music therapy, yoga, language, family studies and alternative health traditions.[5]

At the community and population level, measures that address the social determinants of mental health must be adopted. The focus should be on empowerment strategies, community resilience building, social exclusion reduction, and ensuring social security schemes that ensure equitable access to nutrition, education, housing, water, sanitation, employment and healthcare services.[4,7]

Political will is usually entangled with economic interests and the more profitable curative individual treatments are favored over long-term, population-based social interventions.[4] Medicalization of psychosocial distress serves two purposes: i) it garners profits for stake holders like pharmaceutical industries and ii) transfers the responsibility from the government to individuals by focusing on disease pathology and genetics instead of socioeconomic inequities that lie at the root of distress.[4] Therefore, divorcing economic interests from health is of utmost importance and this can occur by organization of strong people movements, advocacy for social justice and generation of systematic evidence to persuade policy change.

There is also a need to challenge the paternalistic nature of the doctor-patient relationship in the biomedical model, which overemphasizes the perspective of the doctor while neglecting that of the patient. Patients' understanding of their own illness is influenced by various contextual cultural and social beliefs. Sometimes, they simultaneously hold multiple and contradictory explanations for their illness and these explanations are helpful in coping with challenging symptoms and deficits. For instance a person might attribute their illness to black magic and seek help from a faith healer in addition to visiting the hospital and seeking conventional psychiatric treatment.[2]

When patient narratives are excluded, a lot of information about their beliefs, culture, concepts and local reality is lost, and their path to recovery might be affected.[2] This calls for a ***shared and negotiated model of treatment***, where the doctor-patient relationship is viewed as a partnership and an acceptable treatment plan is negotiated between the

doctor and the patient, thus, protecting the patient's autonomy to choose their own course of treatment. In the case of diverse contradictory explanation models of disease held by the patients, it is important to not belittle their local cultural beliefs and force a biomedical model of illness upon them.[2] Instead, the approach must be to "educate, match, negotiate and integrate psychiatric and psychological frameworks and interventions."[2]

Similarly, understanding cultural influences on stress response and coping mechanisms in the context of mental health led to the ***Recovery model.***[6] Coping mechanisms (or pathways to care) are dependent on culture, beliefs, values, gender, class, caste and social support systems. Therefore, different people seek different pathways to care.

Recovery is a very personal process and the recovery model focuses on staying in control rather the illusion of returning to pre-morbid function.[6] It is described as 'healing with scarring' or 'cure with defect.' Recovery is seen as an outlook or process with a strong belief that it is possible for people with mental illness to regain a meaningful life, despite persistent symptoms.[2] It looks beyond survival and relies on connectedness, hope, identity and empowerment as the *mantra's* for recovery.[6]

Conclusions

Psychiatry came into existence after the establishment of institutions (asylums) unlike other branches of medicine, where the institutions arose after the development of the science. The brain is an incredibly complex organ and its functions are dependent on highly dynamic interplays of the environment and biological predispositions (genes). It is relatively inaccessible for pathological advancements and thus, the principles of physical illnesses cannot be applied to mental illness.[3] The current state of knowledge and research in psychiatry is lagging behind all other forms of medicine and the poor classification of mental conditions by DSM has impeded identification of specific biomarkers (if any) for major psychiatric illnesses.[3]

Therefore, the discipline needs to acknowledge its knowledge-gaps and incorporate a more inclusive and holistic approach to treating mental distress. The biopsychosocial model should replace the traditional biomedical views. Players in all realms that affect health - biomedicine, psychology, social sciences, economics, law, and politics – should be involved. Larger forces that push forth agendas that medicalize normal human experience, ignore the social context of psychological distress and exonerate of the government/society in favor of capitalist gains must be stopped.

Concerted action of individuals affected with mental distress, their families, communities, health professionals and the larger society is paramount. Social change coupled with biomedical progress, although more daunting than just prescribing a pill, is the only route to a equitable, mentally and physically healthy society.

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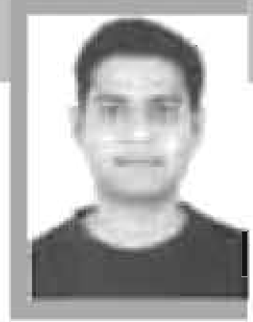
My Cycle Diary of Community Health



Dr. Rajeev Basapathy, CHLP Fellow, Batch 12

Last October, I pedaled for a social cause on a fund raising venture. The week long ride was more than a fun or leisure ride; it was a great learning experience. We stopped over at organizations involved in various approaches to community development. What was supposed to be an adventure filled joy ride, turned out to be a moving experience. I learnt a great deal of community health. Every place I visited had an interesting tale to narrate. Everyone, I met had a story to tell. Every event that unfolded bewildered me and awakened me to different realities.

I cycled nearly 400 kms from Bangalore to Gudalur in the Lower Nilgiris on my mountain terrain bike. The ride would start off early morning by 6 am passing through the countryside, enjoying the green waves made by the wind as it cuddled the blades of paddy, ragi and sugarcane and the forests of rural Karnataka and Tamil Nadu. The ride would finish for the day by noon at a school or a not for profit organisation involved in activities such as rural employment, youth development, revival of traditional economies, alternative education, community health programme, tribal development, women empowerment, etc. The cycle ride was unique in many ways. First of all, it was not a race and participants could cycle at their pace. If it was difficult, one could load the bike on the truck behind and relax in it. The ride was a fund raising event. All the money raised would go into various development activities of Gudalur *adivasis*. Most importantly, the ride passed through the beautiful countryside of India and offered a chance to meet interesting people and know about their inspiring work.

As we biked past Bangalore's deafening traffic and chaos on Mysore road, the overwhelming stench from the drainage running alongside the road was strong enough to make me clip my nose tightly with my fingers, and I rode as quickly as possible to avoid any more assault on my olfactory sense. The huge stream of Bangalore city's drainage that we cycled past was once upon a time a river, called Vrishabhavathi. Now the water is replaced with nitrate and phosphate rich sewage. What was once a life supporting river, is now dead, and carries the litter of urban civilisation. It reflects poor governance, and passive participation of the civil society. I felt helpless, and held myself responsible too for being a passive part of governance.

We passed through the first green patch as we moved away from the city. The board read "*Kumbalgodu forest*". I couldn't see any variety of flora. Neither shady humongous trees nor wet forest floor! It was a perfect parade of an infantry of eucalyptus trees. What a disappointment! I felt angry at what mankind has done to nature, which has given us surplus, and yet the greed doesn't subside.

The rest of the ride was through the scrub and arid deciduous forest of *Saavanadurga* with its huge monolith hill and ruined forts on top in the backdrop. We met young architects of a rural architectural firm called Andagere architects. They were reviving traditional rural economies like blacksmithery, country tile making, and using the products in their work, thus creating livelihoods.

We stayed at *Hosa Jeevana Haadi* (New path in life) in Melukote on the second day. It was founded by Sri Surendra Koulagi and Smt. Girija Koulagi, a couple inspired by Mahatma Gandhi and Jayaprakash Narayan. The Trust has been striving to create a non-violent and egalitarian order of society. Its core area of work is welfare, education, rural industry, environment and agriculture.

Surendra Koulagi, now a nonagenarian, whose age doesn't seem to mellow his zeal. We met his son, Suresh Koulagi, a pleasant looking man who manages the activities of the trust. Mr Suresh's spoke about his life journey, that took many interesting turns. He said, "*I once read One Straw Revolution by Masanobu Fukuoka after graduating as an engineer. That book changed my life. I decided to come back to my village and work here*". According to him, the greatest problem the country is facing today is that the youth of the nation are feeling disempowered and diffident, and the misconception that urban area

provides more happiness is widespread. His tone expressed apprehension about today's education system leading to individualism. He added, "*Youth want to earn more money by quick means without much effort. Most of them want a comfortable air conditioned room, but none want to till the land, sow grains, reap yields. The capitalistic market based economy is luring away the creative minds of the country. Very few are interested in handicrafts and skilled work like sericulture, carpentry, weaving*".

The next day we headed towards Mysore - the cultural capital city of Karnataka. A small stretch of the route, about 10 kms, was on the mound of the left bank canal of Krishna Raja Sagar Dam. It was by far the most picturesque landscape. A quiet flowing canal on one side, with bright green carpet of paddy fields on the other side. The air smelt of the water filled with algae and fresh foggy soil. Few small and yet quaint villages dotted the otherwise emerald fields. The scene was very romantic, reminding me of poems of the Kannada poets Kuvempu, Da Ra Bendre and English poet Wordsworth, etc. This lustful decor has to be enjoyed and words fall short in describing the countryside grace.

A grand welcome at Mysore by the Green Hotel staff just added merriment to the wonderful day. Garlands, lemon drizzle cake, *samosa,* tender coconuts kept coming in.

Green Hotel at Mysore is one of the best social business initiatives. The Green Hotel initiative is based on the model of sustainable tourism started by Dame Hilary Blume. The profits of the hotel are used for economic and environmental issues in and around Mysore. Their pragmatic solutions have helped thousands of people through their eco-friendly business - charity model. That evening we visited *Dhwani*, a slum dweller women's federation. The women self-help groups have made tremendous progress in housing, community development, education and health. One woman in her forties trained as a midwife told us that she has delivered more than 250 babies successfully. Each one has been through their own ordeals and their cheerful smiling faces gave me hope. Their success story narration was filled with emotions, hardships, toil and sweat.

After a day's break and relaxation, we visited another organisation outside Mysore called Rural Health and Literacy Programme. We celebrated *Dasara* with the children of *Ashadeepa* and *Ashakirana*. These two homes for children for both boys and girls are alternative schools aiming at providing vocational training alongside education. Children sang, danced and shared their innovative experiences on recycling garbage from the kitchen. The guava fruits from the farm grown by the children were sweet and tasty.

We were already four days past and deeply involved in the journey. The ride got more absorbing. We passed by meadows, hills, shrub forests, dried lakes, canals, ruins, etc. Train of milkmen carrying churns on their motorcycle backs, migratory birds enjoying the tropical heat, perplexed villagers faces became our norm. Dawns were chill with roosters crowing almost everywhere. Men hurrying into their fields, women folk sweeping muddy floors and the perfect protein and carbohydrate diet breakfasts were a big hit. As the day faded, the gloaming golden sky was idyllic. The Indian countryside is diverse and offers more than one can imagine.

On the way to Sargur, we broke for breakfast under a Tamarind tree at Puttegowda's farm. Puttegowda was growing Okra, Tomatoes, and *Avarekaayi* (Hyacinth beans) in only two acres of his four-acre plot. He complained about water shortage and hence couldn't grow in the rest of the farm. This was shocking to me as we passed through the KRS (Krishna Raja Sagar) reservoir which was about 30 kms away. What was supposed to be an irrigation project hasn't served its purpose and that fact baffled me. With monsoons with less than the average rainfall this year, agrarian distress could escalate. As predicted, the monsoons failed and resulted in heavy economic loss which had its repercussions felt long afterwards too. Farmers committed suicide and this caused uproar in the legislative sessions. Agrarian distress can be devastating on the families and it is rightly stated that, *"Indian agriculture is a gamble with monsoons*". That made sense to me. Sympathising with Puttegowda's plight, I felt heavy hearted.

It was a joy ride from Sargur to Chikkayalchatti. The first half was around the Berambadi state forest and the later half through the plains before we entered

the Bandipur Tiger Reseve. As we were passing the last village and the patches of fields along the *kutcha* road, I spotted women standing still in the fields with an expression of disgust, nervousness and anxiety. My involuntary smiling face wasn't received well. I sensed some discomfort from these women because of our presence. A little away about 10 meters, a woman in her early 20's stood up quickly in shock. She was near the edge of the field. I also spotted a pitcher next to her and that was the clue. All these women were attending to nature's call. I felt embarrassed. Their loathing faces were strongly repulsive. It must be awful to them. Open defecation, sanitation and safe drinking water is a big public health problem in India. I recalled Prahlad's view, an environmentalist working on sanitation at SOCHARA. He opines that, women go out to defecate because many do not have toilets at their houses, but also because it is the only time they get to venture out their fortified houses, gossip on mundane things with the other women folk. The *kutcha* road turned into a terrain soon afterward and my focus shifted to the safety while balancing the bike on the gravel road. The distant Nilgiri hills were visible. The blue hue of the mountains created a mirage. The day was welcoming the dusk with warmth. The eerie silence, green meadows, chirping birds, blue mountains and the early night sky was like taking a short ride into a beautiful medieval painting.

Chikkayalchetti is a small charming village of only five houses. The village headman, also the priest at the only temple in the middle of the village around which houses are located, hosted us and his family cooked the Mysore style food. Ragi (finger millet) balls with coconut chutney, rice with *sambar* was served while we sat in rows on the floor. The villagers were very warm and kind. The bon fire under a huge Banyan tree was perfect for the chilly night. All of us sat around the fire and the topic of the chit chat became horror stories. David's horror comedy jittered everyone and all of us laughed at ourselves. I retired to the sleeping bag around the fire and stared at the starry sky. I hadn't seen a twinkling night in years and was trying to recall the last time I was amazed to such an incredible wonder. I slowly passed into slumber.

Next day was to the final destination- Gudalur. The entire stretch was in the forest. First, Bandipur and then Mudumalai. It was a complete uphill and total highway ride. We had to be extra cautious of the reckless motorcycle and car drivers. The forest road was laid with tarmac with potholes the size of a small crater at frequent intervals. At one point, I spotted two forest officials on either side of the road handpicking plastic litter and loading it into their sacks hanging from their waists. They looked like tea pickers on the higher hills. I couldn't stop admiring them and applauding their effort. Environmental pollution has become universal in India even in protected areas. *Swachh Bharath Abhiyan* doesn't seem to have any effect so far. We further passed though Bamboo forests and finally made it to Gudalur after seven days of cycling through Indian countryside.

Thighs aching, joints biting, spirit dying, but, I made it to the final destination. It had seemed impossible in the beginning, but the team spirit and the wonderful support team helped me reach my goal. Most importantly, the people we met made a remarkable impact. Learning from everyone's experiences and listening to their tales brought goose bumps over my skin.

Community health is the outcome of every action done towards well being of an individual, family and the community. The farmers complained about the lake which was dried, and they say, they have never seen the lake bed in their lifetime. Climate change is here for sure. How will the farmer be happy when there is no water to grow crops? The mental agony of the elderly when all their younger ones want the comforts of the urban spaces. How do we address the problem of open defecation when the problem is not with the ability to afford toilets but rather the complex social construct driven by paternalism and oppression of the weak?

A hive of activities always engage the village folk throughout the year. Women, young, old, everyone is involved. Men fight over lands and their heads held high egotistically. There are all sorts of things happening. There is much more bonding and community relations are stronger. India lives in her villages. As I start to think seriously, I understand the concept of rural self-governance without any unequivocal note. Mahatma Gandhi talks about village life in Harijan, "*My idea of village Swaraj*

is that it is a complete republic, independent of its neighbours for its own vital wants, and yet interdependent for many others in which dependence is a necessity" (Harijan, 26-7-1942; 76:308-9). I agree with Mahatma Gandhi's statement without ambiguity. Village life contradicts capitalism, but sadly the market economy has invaded rural life and has shaken the foundations of the solidarity.

On a travel note, this has been my favourite travel journey so far in my life. I have been asked quite often about my favourite destination and now I proudly announce it as rural India. I want to visit again and again to know more. The whole ride was organised with great care. Responsible tourism is what I believe in and this ride truly lives by it. Before the ride, I was a cocky nonchalant person with a 'know it all' attitude. I admit now, I know little as much as a tiny shred of a cotton fiber of a warp in the vast textile that is made rich with intertwined weft weaved by, of and for mankind.

There sprouts wisdom once in a lifetime or perhaps twice to get out of the self-made cocoon and to see the world as it is. To see it without prejudice and premonition. In that journey, everything appears natural with no fancy sparkling notions attached. The world is a stark truth. Things that we often tend to oversee because of ignorance, become apparent. People and places appear more connected and that wisdom helps us to see the reality of what they are made up of and what it takes to be there.

A report on the Community Health Learning Experience

By Dr. Suresh Raghunath, CHLP Flexi Fellow, Batch 12

The CHLP is a one of a kind program with an equitous approach to community health education and sensitization to the Social Determinants of Health which reaches out to a broad audience of students ranging from masters students in mainstream universities to experienced professionals from a wide spectrum of disciplines and backgrounds who embark on a transformative journey together in a quest to understanding health better and delivering better health for all. The students of our batch came from diverse backgrounds from various states in India and formed a well-represented cross section of Indian Society. Just sitting in a CHLP session and observing our fellow travelers can open one's world view to our country and to the borderless potentials of humanity.

The program immerses students in the realities of health and healthcare through classroom learning's, experienced mentors, resources, videos, articles, theater, songs, poetry, real stories, experiences, simulations, games, interviews, symposia, meetings, workshops, and a broad array of field visits and real world responses and scenarios which allows each student to visualize, implement and understand the effects of the learning's and training in the classroom in the context of the real world and to reflect on the new learning's from each experience before bringing them back to the classroom and to practice. It also exposes students to the on the ground realities of working in various organizations across India and brings students face to face with people working for decades to bring about change from the ground up who provide invaluable guidance and sharing during the journey.

While the process brings out the potentials and capabilities of the students through a transformative journey, the mentors and well-travelled travelers who have already walked the walk and done the journey before, refine and develop the skills and attitudes that emerge through the process and reorient attitudes to better fit the relevance and needs of each scenario.

At the end of each one's journey we share our experiences and learning's with our fellow travelers and learn so much from each other that no write up or document will ever be able to do justice to. I shed a tear as I glance through the pictures and writings as the memories of the experiences remind me of how priceless the 5 months were and how I have not been able to do justice to the learning's and experiences with my report.

Swasthya Swaraj, Orissa - Learnings and Reflections

Our trip to Orissa opened my eyes to the realities of rural and tribal parts of Malaria Endemic Orissa. The gravity of the word inequity stared us in the face as we came out of our CHLP classrooms to examine and experience first hand one of the most gross examples in the world in our own country.

At the TB clinic we learnt that giving medications and explaining them well isn't enough and there is a need to follow up hospital treatments with a social worker to check for treatment adherence in the community regularly. Adherence is extremely poor in these areas even if people come to clinics. In a study conducted by a community health fellow traveller only 1 in 8 people he surveyed had complied to treatment.

My experience with Swasthya Swaraj oriented me on what it is to run outreach programs in remote areas, who are the key people to coordinate, how to account for medicines and equipment, and how to follow up with the implementers in the team. We also got a first hand view of the consequences of not following through with responsible people and how important discipline is in a team in order for each day of the program to be successful.

We learnt how to conduct outreach programs and Under 5 Clinics about the checklists required while conducting programs and the importance of regular follow up before the days of the program with the health workers responsible for execution of the program. We learnt how to account for medication after each day of clinic, how to prepare dispensing pouches with old newspapers but most importantly I had my first experience of a Focus Group Discussion on Health seeking behaviours of people in the region and this served me well as a primer to the Qualitative Analysis Workshop I attended soon after our return from Orissa.

Bare Necessities:

I learnt that life can be extremely pleasurable and fullfilling with the bare necessities and that all we need to live is a good purpose, a shelter, a clean source of drinking water, some food and good company.

Abandoned Buildings make for Great Clinics and Overnight Resthouses:

The final Under-5 clinic of the week was conducted in Kandhelguda and was conducted in an abandoned school since the highest educated person in the village was a 3rd standard dropout and there was nobody available with the skills to teach the school lies abandoned and works as a makeshift hospital. We slept in the classrooms and conducted the clinic in the corridors. Schools have been a recurring theme in my journey and abandoned schools are capable of serving as good a purpose as a normal functional school.

Swasthya Swaraj - Malaria and Under-5 Clinic in Kandhelguda, Rampura Taluk

Problems with Accessibility:

There are problems with accessibility not just with regards to access to healthcare but also with access to benefits being handed out by the government to the poor. There are difficulties with accessibility not just to patients but also to the doctors, nurses and health workers. Along with 4x4 Jeeps, talented drivers are needed to navigate the terrain. Equipment and passengers have to disembark on particularly difficult sections and vehicles have to be changed at sections inaccessible by 2x4 vehicles.

Cinema in Kalahandi: Curiosity and Flexibility of thePeople

There was a screening of a health awareness video on the Malaria Mosquito. This was the first time I saw people from an entire bunch of villages around where a camp was conducted gather around a projector, the

only source of light at night so happily to watch a rather dated visual experience of Malaria in English though they didn't understand a word. *Are there no movies in Odiya about Malaria?*

Kalahandi: A Window Into Understanding Poverty

Our trip to unreached villages in Kalahandi, Orissa with a group of friends from CHLP made me think about poverty. What is poverty? Can we limit it to exclusion through the scarcity of the quantifiable materials and services or should it include exclusion through absence of the unquantifiable, love, care, trust, respect, peace, hope and human values?

If you or I were to live neglected and forgotten lives in the darkness of a drought hit Kalahandi, in the rubble of a crumbled public education and health system, with little food, barely clothed, alien to the concept of electricity, ventilation or a world where open defecation isn't the norm, where the most enjoyable luxury is sometimes but not always one clean source of drinking water that the entire village has to share, deprived of the right to read or write because you were deprived of the right to learn, deprived of the right to know that the money being allocated to your survival is dwindling or pilfered while people outside your world are being made to believe you are being helped, wouldn't you be satisfied with the prospect of dying to malaria while you are sipping a bottle of *mahua* because you have nothing to lose?

Once a month, 35 kilograms of rice is supposed to be handed out through PDS, even if we assume PDS is implemented perfectly, after distributing to the family, does the nutritional value break even with the nutritional losses of walking 30 to 40 kilometers barefoot on hot unpaved paths strewn with stones

under the searing sun, crossing at least a few rivers, some with no bridges, standing in line and then walking back carrying 35 kilograms of rice on the head across impossible terrain for the family? What is the energy and strength keeping these people alive if they don't have enough to eat? Is it a physical energy or beyond?

Malaria and Malnutrition were rampant. Of the 80 children who came to the clinic in just two villages, *Silet* and *Kadhelguda*- 62 had malaria. Not just the human beings, even the goats, cows, dogs and chickens in the villages looked underfed. Hunger prevails here to the extent that every time we stood or sat outside the homes or abandoned schools where the clinics were conducted, to serve food to the people in the village or to eat our lunch or dinner, we would always be accompanied and surrounded by hungry animals and they would sometimes fight with each other in the irritability of hunger.

I leave Orissa wondering what gives the people here the energy to carry their loved ones on their shoulders dying of a serious disease or going into labour for hours on paths across rough terrain and rivers, come sun, rain or darkness, what gives them the energy to walk back and face their families when they die on their shoulder?

This article is a tribute to Dr. Aquinas and the team of dedicated nurses and health workers of Swasthya Swaraj who have selflessly and tirelessly sacrificed their lives and comforts to quietly and persistently, through their passionate commitment spread their message of love, care, trust and hope through health and care to the unreached villages in Orissa.

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HEALTH AND SAFETY OF SANITATION WORKERS – APILOT STUDY

By Ms. Vipparthi Uma Chaitanya, SOCHARA, CHLP fellow, Batch 12, 2015-2016

Acknowledgement:

This pilot study was conducted as part of the Community Health Learning Programme of SOCHARA –SOPHEA during the first field placement at the Dr. T. M. Samuel Memorial Medical and Dental Center, Kodur. It was a part of community understanding and analysis. I am grateful to Dr. Abraham Thomas and Ms. Sheeba Simon from the field placement organisation for helping and supporting me to initiate this study, and to all the workers who willingly took part in this study. Dr. Abraham and Sheeba want to take this study forward through further enquiry and action.

The title of the pilot study was " **To assess the living and working conditions of *Panchayat* sanitation workers of railway Kodur, Andhra Pradesh, INDIA** "

Aim: The pilot study aimed to assess the living and working conditions of *panchayat* sanitation workers of railway Kodur; with a focus on work related health issues; with the objective of providing a framework for development of best practices in town waste management, inculcating occupational health, safety and dignity of work, with public awareness and participation.

Adolescents working instead of parents

Introduction:

This study was conducted among sanitation workers of Kodur *panchayat* (elected local body), covering an area of 60 sq km and a population of 32,725 (2011 census). The study sample included a total of 48 sanitation workers (23 men and 25 women) of which all 48 (100%) participated. Disposal of waste in Kodur includes six tractor loads of solid waste per day, including street sweepings, waste from households, shops, hotels, and *panchayat* dust bins.

The Objectives of the study were to assess and analyse the living and working conditions of sanitation workers; with a focus on their work-related (occupational) health issues; and provide evidence for policy recommendations towards occupational health safeguards and a dignified working environment; in an effort to create a proper town solid waste management plan through policy implementation and public sensitisation.

Methods:

The study was conducted among all the sanitation workers (48) of Kodur panchayat of which 43 were contract based workers with no job security or Provident Fund, even though some of them had 10 to 20 years of work experience in the same job. Only five were permanent workers. The work includes sweeping streets and roads, collecting and transferring waste into tractors, collecting waste from households, clearing clogged drains, clearing pools filled with stagnant water and waste, using

disinfectants. They work eight hours a day in two shifts- from 5 to 10 am and 2 to 5 pm.

Data collection was by direct interviews using a structured questionnaire which included questions about education, housing and sanitation, working conditions, with a focus on health hazards, socio-economic conditions and awareness. Home visits and site visits were also made for in-depth discussion. Problems and solutions were discussed in detail. Interview data and participant observations were recorded, tabulated and analysed.

Sanitation worker, Kodur, AP

Findings:

i. Work is carried out without any protective gear, even during the rains. Sweeping, collecting, and transferring waste is done without use of any safety measures; Workers step into clogged drains barefoot for cleaning; and soon after clearing the blockage people again throw solid waste into the drains. They clear pools filled with stagnant water and waste. They physically carry dust bins to the vehicles for dumping the waste and load the containers manually.

ii. There is no segregation of waste. Infectious medical waste is also not segregated from the domestic waste and injuries with needles were observed to occur commonly.

iii. Work related health issues were prevalent; Exposure to exhaust fumes and dust resulted in eye diseases. Carrying loads resulted in excessive exertion resulting in increased incidence of musculoskeletal problems. Frequent handling of bleaching powder is leading to skin problems. Working on empty stomach resulted in higher risk of gastrointestinal disorders. Burn injuries have occurred while burning the waste in the open places.

Working in an environment with health risks

iv. No protective or preventive health measures were undertaken by the *panchayat*. Workers were not vaccinated for tetanus, hepatitis A, hepatitis B, polio or typhoid. There is no regular health monitoring or medical checkups.

v. Housing, hygienic practices and sanitation: Housing conditions were poor with no access to sanitation facilities. A side effect of solid waste handling is that the filthy nature of the work demotivates people about self hygiene. Women reported preparing meals immediately after returning home from work without changing clothes. Alcoholism and chewing pan along with tobacco was found to be high; many of them developed this habit exclusively after joining this work.

vi. Poor socio-economic conditions: There was very little awareness about the need for girl child education. Boys were discontinuing their studies between 17 to 20 years of age. Parents were unable to provide nutritious food for their children. Many incurred debts for medical expenses (71.42%). These people face discrimination in society because of their work.

vii. Deaths before retirement were reported to be 7. The workers were not ready to access care from the government health care system due to lack of reliability/credibility, lack of proper equipment and services and lack of accountability among the hospital staff.

(Details are in the Final Report of Ms Uma Chaitanya)

Vemana, The Poet, speaks to us

By Dr. Abraham Thomas
Dr. TM Samuel Memorial Medical and Dental Centre, Kodur, Andhra Pradesh (Batch 1 CH Fellow 2003)

Maha Yogi Vemana was a commoner who questioned society, individuals and the elite in equal quantum through his concise Telugu poetry in both simple and meaningful ways. He is described as a *"people's poet"*, and rightly so. In the times that he lived (1652 – 1730), people had lost sight of peace, wisdom, justice, spirituality and freedom. People in his era had embraced meaningless idolatry, quest for material wealth, and a caste based hierarchy that was unjust. Kingdoms had lost sight of people and their needs and were dwelling in conquering lands from neighbours.

This great saint and poet is relevant today since society is following a similar pattern, though the context is very different. Individuals are beginning to move away from the collective conscience to self justification, opinions are fractured, and violence is building up deep within the soul of society.

C. P. Brown (Charles Philip Brown), a civil servant under the British empire, was probably the only reason why we have Vemana's poems still being recited. His contribution to Telugu literature is well recognised. As another example of humanity needing each other for a better world, it is said that Brown, at times, even borrowed money to complete his work of restoring Vemana's glorious poems.

In one of his most powerful and simple poetry he talks of human greed, lack of generosity, and cowardliness.

"Bhoominaadiyanina bhoomi phakkuna navvu
Daanaheenu joochi dhanamu navvu
Kadanabheethu joochi kaalundu navvunu
Viswadaabhiraama vinura vema!"

The earth laughs at those who believe they own it,
Wealth laughs at the miser,
And the God of death, Yama, laughs at those who run away from the frontlines of war.
Listen oh bounteous of knowledge, listen Vema.

When the society is at war with the earth, nature,
and when wealth is being concentrated in fewer hands,
it is for us to be brave and understand that it is certainly worth changing.

In another of my favorite poems, Vemana says

"Shanthame Jayamunundhinchu
Shanthamulana guruvuni jaada theliyunun,
Shantha bhaava mahima charchinchalemaya
Viswadaabhiraama vinura vema!"

This says peace will bring success among people,

Peace shows the path of the great saints (wisdom),
The mystical magic of peace is so holy
that it cannot be brought by discussion.
Peace is practiced.

Vemana has lent us his thoughts, but it is for us to bring its relevance to the fore of our lives, in our ethic, work, and our life's philosophy.

RAINBOW

A poem by Samar, Gwalior, CH Fellow, Batch 12

I am a rainbow

You are a rainbow

We are a rainbow

Sands and thorns all over shattered

People crawling in desert, no one bothered

For bleeding knees and glint eyes

We are a rainbow.

When rain of notion fell upon

We threw our umbrellas and ran along

All black and white washed

We are a rainbow.

Dead rivers are alive again

Flowing through eyes, carrying pain

Behind the dark clouds

We are a rainbow

Let's make it green, red, yellow

Building blocks of health, we the fellow

Let's lead to HEALTH FOR ALL, Make people follow

We are a rainbow

Dream of Health will crow

Nothing last forever, pain or rue

We will bring Indigo, Orange, violet and blue

We are a rainbow

Fellows of CHLP – Batch 12, visiting an Anganwadi at Tamia, Madhya Pradesh

Fellows interacting at a Health Facility, Bhopal

Fellows visit to FRLHT, Bengaluru

The Kalajatha troop who performed at our Silver Jubilee event, at St. Johns Amphitheatre, Bengaluru

Swasthya Swaraj - Anthropometry in Under-5 Clinics, Kalahandi, Orissa

PUBLISHED BY:

Society for Community Health Awareness Research and Action (SOCHARA)
359, Srinivasa Nilaya, 1st Main, 1st Block, Koramangala, Bangalore – 560 034
Email: chc@sochara.org; cphe@sochara.org; Website: www.sochara.org

This issue has been supported by the International Development Research Centre (IDRC), Canada.

Printed by
National Printing Press, Bangalore - Tel: 080-25710658