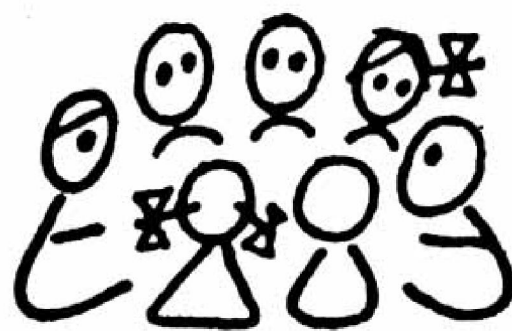
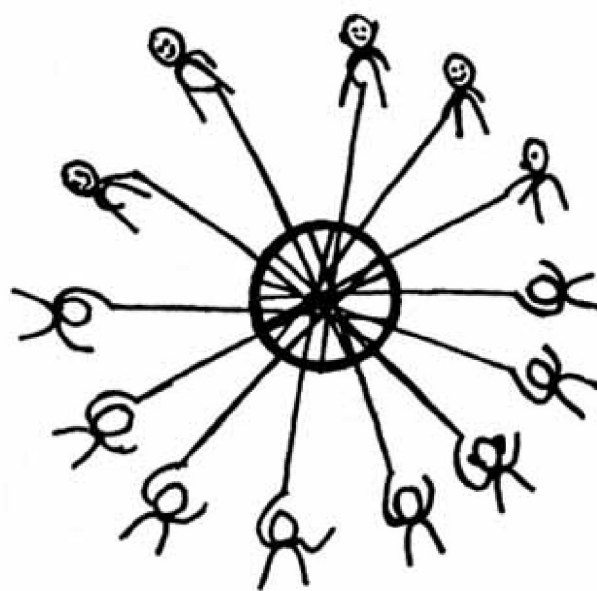


2014-2015

# Community Health Learning Programme

*A Report on the Community Health Learning  
Experience*

Juliet Angel Shangrit



**SOPHEA**



**socha**  
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Title: life changes in  
community health program

## **Acknowledgement**

I express my sincere thanks to Sabu Ku for his constant guidance and support without which this work would not have been possible. I thank Rahul sir, Mohammed sir, Chander sir for their valuable support and suggestions on the report.

I thank the SOCHARA team who have contributed this fellowship programme and especially to Ma'am Thelma Narayan who gave this opportunity to us to traveled and learned new experience on community health and spend her valuable time whenever we needed.

**Mr. Sabu Ku**

**Dr. Thelma Narayan**

## **Story of my life**

I was born and brought up in small village in Meghalaya I spend my childhood as a village girl enjoying in the river, paddy field and forest with a simple and innocent life. I studied in a government Lower Primary School in my village till 4standard and continued to government higher secondary school in my own district after I completed 10 standards I moved to Shillong for higher studies. I have done my Master of Social Work from Martin Luther Christian University Shillong. I am a fresher after I completed Master of Social Work I came to know about Community Health Learning Program from my Head of Department Ma'am Melari she introduce me the CHLP and sent the detail about this program and I check the website of SOCHARA. I was excited and I want to join this program so at this moment I mailed to Ma'am Maria. At this time I haven't know anyone other than Ma'am Maria and I got a call from Chander sir for the date of interview. I was scared when I came for the interview as I was expected so much but when I entered into the room surrounded by interviewers I felt the confidence as I feel the belongingness that I got from the interviewers.

### **My Aim:**

- To explore and learn new things in different states

### **Objectives:**

- To learn about community health
- To work with the marginalized and vulnerable people

### **Why I want to join CHLP:**

I want to join CHLP because I want to work with the marginalized and vulnerable people. I have the passion in community since MSW I want to help the poor people, women and children I want to bring them up from the problem. I am interested to talk about women empowerment but I never realized about caste, class, gender how it affected the health of the women and children.

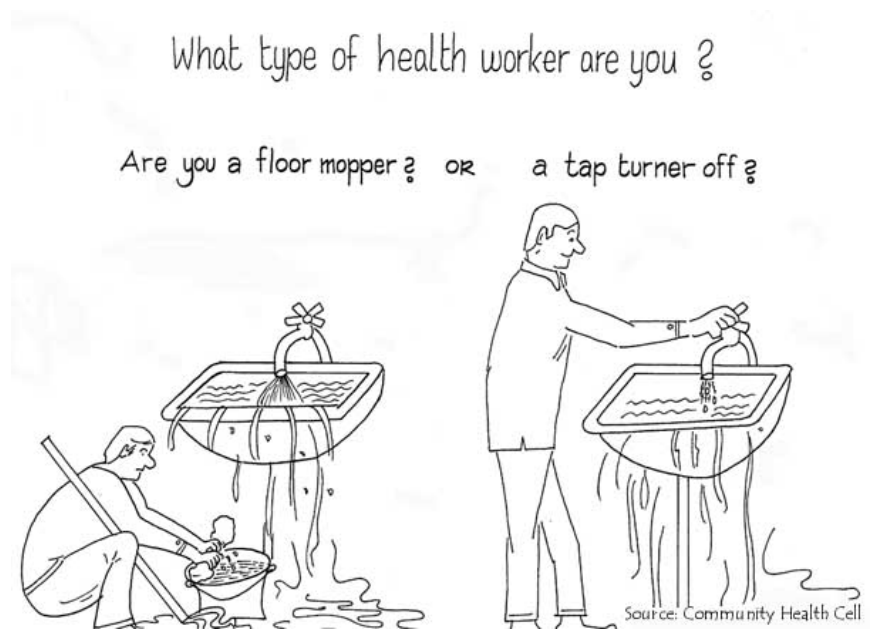
## Knowledge Changes in CHLP

Before I joined this fellowship I thought 'Health' is hospital, doctors, medicines, diagnosis but after the sessions that I had gone through I realized health is not medical. It is the water sanitation, caste class, gender, poverty, stigma discrimination and Social Determinants of Health (SDH). I was confused when I step into SOCHARA as I am not from medical background so its took a long time to catch and learn about primary health care and the ethics in health care. It's completely changes my knowledge and my attitude about health problem in our country the social determinant on health which I never realized, I never noticed about these entire problems.

### PARADIGM SHIFT:

|               |   |              |
|---------------|---|--------------|
| Medical model | ➔ | Social model |
| Individual    | ➔ | Community    |
| Patient       | ➔ | People       |
| Diseases      | ➔ | Health       |
| Providing     | ➔ | Enabling     |

Community health is the process of enabling people, to exercise collectively their responsibility to their own health and to demand health as their rights.



## **Health:**

According to World Health Organization “Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”

### **10 Axiom of community health:**

1. Community right and responsibility: demand their rights like food, shelter, water, sanitation and education. Responsibility the community had demand their rights so make used of it and take care of all these rights as a community as a whole.
2. Autonomy over health: autonomy means community should decide what they want. Community should give the final decision and control over.
3. Integrity health development: how can we bring together the community people to health?
4. Decentralization democracy: give responsibility to the community connected decision making. Give community the power to decide
5. Building equity and empowering:building equity (reaching the unreached) empowered community
6. Promoting and enhancing sense of community: bring value, sense of together, oneness
7. Confronting biomedical approach: biomedical is medicines, curative, preventive need in community health. Causes of most health problem are social, cultural, political and economic.
8. Confronting the super structure:
9. No professional package: no professional package in community health means find the root causes of the problem
10. Build a system to achieve health for all

These 10 Axioms is very important for the community health workers for the future references when we are working with the community we should implement these axioms to bring values to the community to enhance and improve their health

### **‘But how Social determinant play an important role in the community health’**

Social determinant means social, cultural, political, economic and environmental affected the health of the people. Caste, class, gender are the main issues in our country which affected the livelihood of the people which lead to poverty and the people started migrating to urban slum. Unemployment is one of the problems, water and sanitation which affected the health of the people. Political factors also divided people into different party which bring the differences in the community. So we can see how social determinant affect the health of the community.

Community health approach changes action from the community outwards and upwards challenging the various components of the existing structure of health services which include primary health center, dispensaries, sub-center, health program and health institution government or non- government.

### **Social exclusion**

Social exclusion is the process in which individuals or the entire communities of people are systematically blocked from various rights, opportunities and resources that are normally available to members of different group which are fundamental to social integration within the particular group eg. Housing, employment, healthcare

Economic perspective on social exclusion: Communities are socially excluded from the economic activities in the labor market, financial resources, and discrimination in skills development

Political perspective on social exclusion: Lack of participation in political activities, security voting rights, holding political leaders, lower caste can't participate in the community decision

Sociological perspective on social exclusion: In ability to participate in civil or cultural activities for example Dalit community cannot enter to the temple, cultural sphere in society are excluded.

Psychological perspective on social exclusion: If we are excluded from people in the community we feel isolated, low self- esteem. This feeling of excluded from the society its lead to misbehavior.



These four perspectives play an important role in the Dalit communities which they are excluded from all aspect. From the documentary that I have seen it depicts the example of social exclusion how they are excluded from the healthcare system. They could not access to healthcare for Antenatal care (ANC) Postnatal care (PNC) and for delivery. They always practiced home delivery and many children have died during delivery. The other is transportations they have to walk more than two to three hours to reach the primary health care so the people find difficult to go as they don't have proper transportation and they don't have proper drinking water the water is very dirty is not suitable for drinking but all the people using that water only. From the documentary the suffering of the people was so painful to me.

### **Gender:**

Biological bases gender means male and female. Women are reproductive, breast feeding and men are produce sperm but socially they differ by families, institution, religion, caste gender role. They are not equal they are divided and male are treated superior, head of the family and power but female are inferior doing all the work at home cooking, cleaning, eat the left food that their husband and their children left. This problem affect the health of women, mostly women are anemic because they prefer boy first than girl in any ways whether education, nutrition or care and affection

### **Social change:**

Social change refers to themodification in social order of a society. Social change may include changes in nature, social institutions, social behavior or social relations.

Social may refer to the nation of social growth, the philosophical idea that society move forward by dialectical or evolutionary means. It may refer to model change in socio-economic structure. Shift away from feudalism and toward capitalism

### **Causes of social change:**

Effect characterizes aspect of society across the world. On micro scale shape all our major social institution, economic, politic, religion, family, education, science/technology, military and legal system, values, attitude, belief and behavior of human being to all over the world.

### **Globalizations how its effect health:**

Globalization is a word that has been purposely created to raise false hope among poor of the world, that the current processes in the global economy will allow them to approach the standard enjoyed by the rich countries of North America, Europe and Japan. While selling this false dream, these countries have riding a fresh offensive to lead upon the resources of poor countries.

In the name of globalization the rich countries demand that government should cut expenditure on health care, education and even food subsidies but at the same time government offering multinational lower taxes and subsidies such as reduce electric rates. The free market economy is not free at all it is controlled by rich to benefit only the rich at the cost of the poor.

Structural Adjustment Program was design to

- Cut in the welfare investment, leading to gradual pull apart of the public health service
- Introduction of service charges in public institution which has now making services inaccessible to the poor
- Handing over the responsibility of health services to the private sector

We can see how globalizations effect health services and people's health as this prescription were applied in India and the result have been predictable rising price, inflation, rising unemployment, changes in cropping pattern, loss of food security, withdrawal of subsidies on public welfare services such as public health, education and public distribution system.

### **Occupational health**

Occupational health problem occur at work place because of the kind of work we do. These problems can include, cut, broken bones, strains, loss of limbs, hearing problem cause by exposure of noise, diseases causes by breathing, touching or swallowing unsafe substance, illness caused by exposure to radiation. This is happened because of lack of safety measure practice in industries, mining place especially in poor country like India. The owner or the company did not provide safety measure and prevention for the workers who are exposed in any danger or unsafe which is affecting their health.

## Environmental health

Environmental health is the branch of public health that is concerned with all aspects of natural and build environment that may affect human health. The other terms referring to environmental health are environmental health protection. Environmental health and environmental health protection are very much related. Environment health is focused on natural and build environment for the benefit of human health, whereas environmental protection is concerned with protecting the natural environment for the benefit of human health and ecosystem

Environmental health addresses the entire physical, chemical and biological factor external to a person and all the factors impacting behaviors

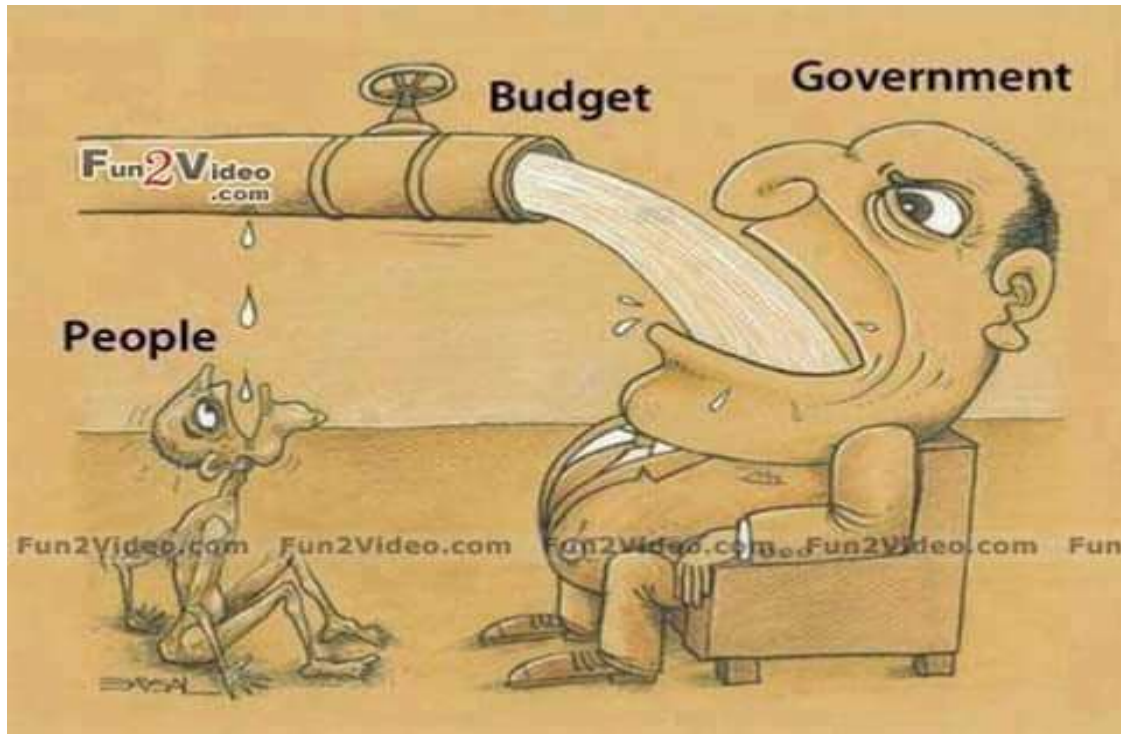
## Waste management:

Waste management is the generation prevention characterization, monitoring, treatment, handling, reused and residual disposition of solid wastes. There are various types of solid waste including municipal, agricultural and special. The term usually relates to materials produce by human activities and the process is generally undertaken to reduce their effect on health.

## Politic:



SHARE IF U AGREE



### **Primary health center:**

PHC means primary health center and there is different between primary health center and primary health care. Primary health care is about home remedies,NGO, traditional healer.

### **CPHC:**

Comprehensive primary health care, the most important principle in comprehensive health care are:

1. right to health
2. responsibility
3. equity
4. appropriate technology
5. inter-sectoral development

## 6. community participation

### **Health Management**

#### Multidimensional

1. Protecting people's health - outpatients should come down. We have to stop illness – idea is to decrease patients. Prevention is the goal of public health
2. Promoting people's health –
3. Restoring people's health
4. Improving people's health through collective and social action – This is part of community health. 1<sup>st</sup> 3 are public health.
5. Prevention programs
6. Health programs for needs of population as a whole
7. Reducing death, discomfort, disability
8. Promoting healthy life styles – exercise, diet – prevent disease
9. Creating supporting environments – environment around is telling them not to do certain things – media, marketing
10. Documenting, monitoring, evaluation, research and planning

#### Health System

A health system comprises all organizations, institutions and resources devoted to producing actions, whose primary intent is to improve health.

Should be aware of the whole system not just one sector or the other.

- Public - Government
- Private - For profit and non-profit (civil society)
- Traditional - AYUSH
- Informal – Dayi, traditional healers

Management as a system is a combination of managing all of these -

- Service – service provision
- Resources – management of time, materials etc
- Finances – management of finances

- Stewardship – Leadership

#### Primary Health Care 8 Elements

1. Food supply and proper nutrition
2. Safe water and basic sanitation
3. Treatment of common diseases and injuries
4. Women, children and adolescent care
5. Communicable and NCDs
6. Immunization and preventive care
7. Provision of essential drugs
8. Health Education and Promotion – These 3 are community health that are neglected by other medical personnel

#### **Values for Public Health Systems:**

Social goals or standards accepted by society

- Essential for setting national priorities
- Evaluating whether social arrangements are meeting population needs and expectations
- Moral anchor for policies and programs enacted in public interest

#### **6 values**

Equity – reaching out to the unreached different from equality. Reaching out – mobile clinics, outreach programs.

- Gender
- Right to Health
- Solidarity
- Integrity
- Quality

Community Health Approach – Different than regular health management

- Community – you have to create a community if you see that the community is not formed yet – increase understanding and connect them to each other
- Community involvement
- Community action
- Involvement

## Beyond and Public Health System Challenges

- Social responsibility/gender sensitivity
- Supportive environment - advocacy
- Inter-sectoral collaboration
- Medical pluralism
- Partnership for Health – Partner with community, other NGOs, government – Health for All and All for Health

## Framework for Public Health Management

Exploring plurality and diversity of the health problems in the region

1. Within the community
2. At the community level
3. At the intermediate level
4. At the district level

## **The Public Health Management Challenge**

A Multi-level Health System → Services at each level → Referral System

A Multi-member Health team → Roles of each member → Team building

A Plural Health System → Assessment

## **Skills required for Public Health Management**

- Make District/Taluk Diagnosis – social diagnosis, economic diagnosis etc
- Organize information system – record
- Evolving a plan
- Organize Epidemiology Surveillance
- Manage Epidemic/outbreak
- Manage Health Program
- Manage relationship with Government and PRI
- Manage HR
- Organize materials, drugs, equipment and facilities
- Monitor and evaluate
- Develop good leadership
- Advocate for health
- Promote sustain partnership

- Promote community participation

### **New Challenges to Health Management**

- Leadership – Authoritative leader  $\leftrightarrow$  Participatory leader; task-oriented leadership vs human-being oriented leadership
- Decentralized Governance
- Public Health Law and Ethics – eg. Surrogate mothers
- Research and Development – idea driven vs. evidence driven
- Innovation – new ideas (ASHA was an innovation)
  
- Crisis management skill
  - Rapid urbanization
  - Displacement of communities
  - Natural and man-made disaster
  - Large scale migration
  - Conflicts
  - Climate change
  - Economic downturn – global/local – agrarian distress – farmer suicide

### **Concepts of Prevention and Control:**

Inner learning – Upholding **dignity** – Maintain your dignity and that of the others. Any negative emotion will only hurt you – we are all not saints so we have the right to feel the emotions but we have to let them go.

Prevention – Stop it before occurring

Control – Manage after it happens

The goals of health care are to promote health, to preserve health, to restore health when it is impaired and to minimize distress and suffering.

These goals are embodied in the word “prevention.”



Actions aimed at eradicating, eliminating or minimizing the impact of disease and disability, or if none of these are feasible, retarding the progress of the disease and disability.

Eradication – permanent – small pox, polio

Eliminating – temporary

Three levels of prevention – primary, secondary, tertiary and primordial

### **Determinants of prevention**

- A knowledge of causation
- Dynamics of transmission
- Identification of risk factors and risk groups – endemic (consistently present in that area – malaria endemic areas), epidemic and pandemic (crosses geographical boundaries)
- Availability of prophylactic or early detection and treatment measures
- An organization for applying these measures to appropriate persons or groups
- Continuous evaluation of and development of procedures applied

### **Preventable Causes of Disease**

**B** – Biological factors and Behavioral Factors

**E** – Environmental factors

**I** - Immunological

**N** - Nutrition

**G** - Geographical

**S** – Services, Social, Spiritual

### **Leavell's Levels of Prevention**

Pre-disease – Primary prevention – health promotion and specific protection

Latent disease – secondary prevention – pre-symptomatic diagnosis and treatment

Symptomatic Disease – Tertiary prevention –

**Primordial prevention (socio-economic-cultural determinants of health):**

- Consists of actions and measures that inhibit the emergence of risk factors in the form of environmental, economic, social and behavioral conditions and cultural patterns of living etc.
- Main intervention is through mass education

**This is community health approach! – keep environment clean, water hygienic**

**Primary prevention**

- Action taken prior to the onset of disease, which removes the possibility that the disease will ever occur
- Intervention in the pre-pathogenesis phase of the disease
- Specific protection and health promotion

**This is public health approach – immunization, bed nets, repellants**

**Secondary prevention**

- Defined as action which halts the progress of a disease at its incipient stage and prevents complications
- Specific interventions are early diagnosis (screening tests and case finding programs[TB]) and adequate treatment.

**Tertiary prevention**

- It is used when the disease process has advanced beyond its early stages
- It is defined as “all the measures available to reduce or limit impairments, disabilities and adjusts patients to irreversible conditions”
- Intervention – disability limitation and rehabilitation

**Learning form collective teaching**

The collective session started by providing the basic definition of health, but with the growth of the discussions the multi-dimensional aspect of health, which is beyond just ‘physical health ‘for the very first time, was introduced to me in such clear manner. The sessions gave me a deeper understanding as how other determinants such as class, caste, gender, language and other artificial barriers cause a hindrance to good health.

From all the session that I attended it is very helpful for me to build up my professional work in future to understand more about the community health and equity. The session that I had attended that give me the clear concept on community health and give lots of inspiration by Dr.Ravi Narayan when he shared with us his experience with the Malur health cooperative that was setup in Malurwith the help of St. John's medical college in the 70s. This center was initially successful and a lot of people were able to access health care at the cooperative hospital, which succeeded in connecting some of the societal inequalities also. After a few years this milk cooperative has stop due to certain problem. His work gives us more motivation to work for the people who really needs in their daily life. all the session is very important for us to practice in our future when we working with the people in the community. Like the session on caste, class and gender which is the major problem in our country that affect the health of the people especially the women's health. Social exclusion is also one of the issues that affect the health of tribal people because they are lagging behind in many ways as they are excluded from health system, education, transportations, water and sanitation.

### **Learning and reflection on field visit**

The overall reflection and learning that I have visited to the organization such as Snehadan,FRLHT, Seva-in-action,Karunashraya, APD and protest program that we attend such as Bhopal tragedy, GSM food, Bangalore Blind work, women's voice extra which was a good experience that I had and made me understand more about this issues which effected the poor and poorest in our country. Through the field visit I had a good experience and learned more about the problem that the people in our country are facing and how these organization are function and link with people networking with government and other organization so it's really helpful for our future professional when we start working in any NGOS. This kind of visit motivate and inspires us to work for the people's health because through these we learned more about the problem link with health services in different states of our country.

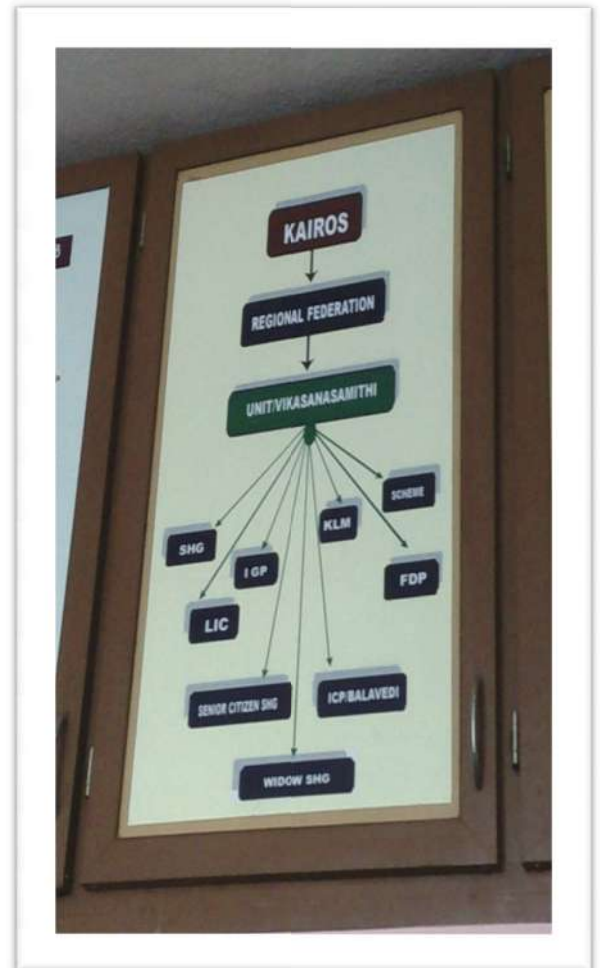
So we need more visit and programs like workshop and protest that will make us feel the needs of the people if we could see and heard the sound of the people crying their help and to get the idea how the organization are functioning and how the administration are formed to improve our future plan how to work and form our own organization.

**Reflection on trip to kerala:**

Trip to kerela was a good experienced that I ever had. The best that I had was the visit to the Palliative Care. This organisation was working for the cancer patients, old age and psychiatric. They are working through the SHG -panchayat and only the terminal ill will selected from the community. They had volunteers for home visit. These volunteers had to observed and look to the family condition and support them both physical and mental through counseling. The volunteers didn't receive any salary but they work as a voluntary for the people. So this was a good example to motivate others to work for the people who are suffered and vulnerable.



This kind of NGO I never been this is the first time I visited and it is a good example to have people like this who working for people's health with all their heart and soul. Good participation both government, community Base Organisation



### **My First experience in Tamil Nadu**

The first placemesnt in DAS-CBR Organization in Tamil Nadu was the best experiences that I have. I moved from Bangalore with my friend Saraswathi by bus on the way full of imagination what would happened when I reach in Tamil nadu how can I interact with the people I don't

know Tamil language. I was visited two villages Mastrapalli and Kodyur I found that there is a big different between this two villages. When I step into the state I felt the different as I can't understand the language I want to come back to Bangalore but I have a faith that I should not give up and God always with me in everything I do.

**Understanding community:**

When I started to go to the village I am not confident at all I was confuse but after two three days I fell that the people are very nice good and friendly. Whenever I went to the field, the people always offered food, drink and I realized if the outsiders come to our state did the people do the same as they did for me I was not sure. The important point that I have found in these villages are about health of the people. All the people are aware about health system and the schemes in the PHC and its make me very surprise even if they are illiterate but they all know about health services. When I compared to my own state we are lacking behind with everything regarding health system. In Tamil Nadu even in remote areas Village Health Nurse (VHN), Anganwadi workers have a good responsibility in the village for ANC and PNC and SHC and PHC accessible in the villages. And I had a lot of experiences on health service in Tamil Nadu and the infrastructure the transportation even in the remote area the transport is good and better but when I look back to my own state Its really touch my heart many women died during delivery because of transportation the road is bad no vehicle available and some village vehicle is available but due to the road condition the women delivered the baby on the way or she died on the way before they reach to the hospital that is the condition in our state.

## Interaction with people in the community in Tamilnadu



### **Problem in the community**

**Water problem:** In this village the people facing water problem especially in this season there is only two mini tanks only one is working and OHT also is not working. People frequently used to fight for water and we have seen with own eyes when we go to the field in the morning. One day at night time the water came from panchayat some people they get more some get less of water then they start fighting each other and they broke the water pipe also and this continues till morning we have seen some people repairing the pipes. But in such situation no one from panchayat come to make them understand or to solve this problem. This is the main problem in the community the people said that during rainy season is not a problem for them because they have one pond but this season is dry no water in rainy season the water came from one river to this pond so people get water from this pond its serve the whole village.

This is called water scarcity and this problem it's happened in all over India because of lack of sufficient available water resources to meet the demands of water usage with in a state. Water

scarcity involves water stress, water shortage and water crisis. Shortage of water is caused by climate change such as altered weather pattern including drought or flood, increase pollution and increase of human demand and overuse of water. So we need to make the people aware all of this and the most important is to make the people aware is in of population, global warming, urbanization and deforestation is the main effect to water problem.

**No unity in the community:** the people in the community don't have unity that why they are lacking behind. The panchayat are planning to build the anganwadi in the community but people are not ready to give space or land some of the people are ready but some are confusing so they can build that anganwadi. In this community there is only one caste but lack of understanding each other. Even for water there is only 30 households but they can't maintain for this problem they used to fight each other if they have a broad mind I don't think that they will fight.

**Opinion of the people about drainage and sanitation:**

The people said that from the panchayat no one will come and clean the village the people they clean only in their own compound but if we look at the surrounding in the village they didn't maintain hygiene lot of waste, plastics and no proper drainage. When we asked from the villagers they said this is not our land this space is belonging to some other family in the village so we don't want to clean that area. But that place is near by their home only but that space is belong to some family but their children used to play in this place the people didn't aware from this waste their children will get diseases and if not effect also if the villagers maintain hygiene to the surrounding it look beautiful and the other people also will take the example from them.

Drainage: the people said they don't have space to give for drainage construction and they said that its will smell if they construct drainage. We asked if no drainage the flies will come in that stagnant water those come from their home they said no flies will not come this is a dry area we make used of it since 15 or 14 years and it does not infect anything to us. And they said that they are expected road and water from the government but they won't say anything about toilet facilities the most needed for daily used they are not interest for toilet they have a habits of open defecation. And the people said that from the panchayat also they don't have any scheme for toilet.



## **Health Care Practices**

The views of the people in Matrapalli village about health like joint pain, fracture, snake bite and home remedy. The people in Matrapalli village when they get sick they went to private hospital because they said is near by their village and give good services. When fellows interact with them about joint pain, fracture they said

- For joint pain and fracture the people they will go to Tripattur government hospital for the treatment because in private hospital they don't have treatment for fracture if they have also the service is not a good services. The people said that there are some people they go to Tannerpanthal village for traditional treatment for fracture.
- For snake bite the people will go to another district for sidda treatment
- For coughing the people said that they used to give ginger decoction to their children
- For diarrheal people in this village they said that they used to go to traditional healer for treatment.

This is the people said when fellow interaction with people about health treatment. Mostly people are aware about the health and the scheme of the PHC so people always consider government hospital and the other thing is because of VHN the people get a lots of information and aware of all the program and services of government hospital. **Primary Health Centre**

### **Government schemes (NRHM) in Primary health center**

**Meal for pregnancy women:** Under this scheme, pregnant women will be given free lunch at PHCs during their weekly checkups on Tuesdays. The women will be scanned at least once during their pregnancy to ascertain the health of the baby in the womb. Also, when the pregnant women came for delivery, they would be provided with meals thrice a day for three days. This would ensure they received adequate care

**JananiShishusurakshaKaryakram (JSSK):** This scheme was launch by the government on 1<sup>st</sup> –June- 2011 which entitles all pregnant women delivery in public health institutions for free no expense delivery including caesarean section, free drug and consumables, free essential

diagnostics like blood, urine test etc, free diet during stay in the PHC up to three days for normal delivery, free transport from home to institution and drop back from Institution to home.

**JananiSurakshaYojana:** This scheme is being implemented with the objective of reducing maternal and neonatal mortality by promoting institutional delivery among pregnant women. This scheme encourages pregnant women to undergo at least four antenatal check-ups and to deliver in an institution rather than at home by providing cash assistance. The scheme was launched under NRHM.

**Financial assistance under JSY:** Pregnant women who deliver in a government hospital or accredited private health facility are entitled to Rs.1400 in rural areas and Rs.1000-in urban areas of low performing states. In high performing states, pregnant women are entitled for a sum of Rs.700 in rural areas and Rs.600 in urban areas.

**Scheme for promotion of menstrual hygiene among adolescent girls in Rural India:** The Ministry of Health and Family Welfare has introduced the scheme for promotion of menstrual hygiene. This scheme aim at ensuring that adolescent girls in the target group have adequate knowledge and information about menstrual hygiene and the used of sanitary napkins are save product and easily available for to them. The sanitary napkins are provided under NRHM's brand freely these napkins are being sold to adolescent's girls at the rate of Rs.6 per pack by Accredited Social Health Activists (ASHAs) and Tamil Nadu they used to get from Anganwadi.

**Muthulakshmi Reddy-maternity benefit scheme:** This scheme was launch in the year 1987 by Tamil Nadu government in the beginning they provide only Rs.300 for Antenatal mother (ANM).At present they provide 12000 to ANM for eradicate or control the mother and child mortality rate by the malnutrition, anemia and child marriage.

#### **Eligible age for this scheme**

- The pregnant mother should at the age of 19 year or above
- The women should be Below Poverty Line families
- Only for women those who are take treatment in PHC or government hospital or government medical hospital in Tamil Nadu with delivery also.

- She should completed immunization such as DPT, pentavalent, Hepatitis B and polio

This scheme they divided into three installments for four thousand rupees in each installment

- During the seven month ANM should visit PHC for TT immunization, Blood grouping and hemoglobin, weight, height, scan and testing HIV every visit this test should be completed
- In second installment- delivery should be in government hospital or PHC
- Third installment- the mother should completed 3 dose DPT, Hepatitis B, polio, Pentavalent for child in the time schedules

All this programs are implemented in parampatta PHC and it is helpful for the people in the community but one thing from Matrapalli to this PHC is very far so people cannot effort for transport and the waste of time also. That why the people in this village mostly they prefer to go to private hospital it's nearer to them.

### **About Voices**

The procedure of this project is more or less the same with the community health and action. Under this voices they have researcher, facilitator, DAS-CBR and 3 PHC. The DAS-CBR are given training through the VHWSC

### **Process of VHWSC**

Mr.Palanisamy the co-coordinator of DAS-CBR explain about this process the main theme of this project is to monitoring and research .The facilitators will go to and meet the people in the panchayat and they covered 17 panchayat. They will give orientation about NRHM and VHWSC they will select volunteers as members through this meeting and will continue till 3<sup>rd</sup> weeks of April.

### **First committee meeting:**

In 4<sup>th</sup> week of April they conduct first meeting of Village Health Committee in that meeting they will select leaders, members and secretary

**Gram sabha:**

In gram sabha meeting this committee will approve by people and gram sabha with resolution and this copy will send to Medical Department and government.

**PHC federation:**

They will select members from each village committee totally 15 or 18 to 20 members will be in this committee.

**Block federation:**

Five members selected from 3PHC federation totally 15 people will be in this block federation.

**District monitoring committee:**

Six members selected from the Block Federation Committee, this members will share and discuss about village health problem to Deputy Director of Health Service.

**Criteria of VHWSC:**

Mr.Ameer khan he spoke about this criteria he said that in the community formation the people who are involve in the committee are president as a leader, secretary VHN she should live in the village itself.

**Membership:** Approximately 15% of members should be in this committee all people should select from panchayat with different caste should involve like ST, SC.

**Group:** one member should be from SHG and youth group

**Participation:** In this committee one third of the elected members should participate like president, secretary and counselor.50% should be women in the community to participate in the meeting.

**Leader of committee:** leader should select from this committee and to lead the committee should select from women group.

**Monitoring:** the member of this group should monitor the water and sanitation in the community like cleaning water head tank and the cleanliness in the villages, and they have to monitor the PHC available of medicines, available of doctors, the water and cleanliness the quality of services.

**Anganwadi:**

The anganwadicentre provides a good service to the women, children as well as adolescence. Anganwadi worker give a good work for the children every day to make them sleep, provide them food and also practice hand washing to children this is a good habit for them. Fellows many time used to visit the Anganwadi to observe and playing with children. Compared to other state like Meghalaya this is the best job that they are doing in Meghalaya I never found like this kind of services as I have visited some Anganwadicentre. Anganwadi worker she taker the children like her own child. VHN has a good responsibility in the villages with the help of Anganwadi worker.

This VHN they got one and half year training in government hospital and if we compare with ASHA they have a good training and knowledge they can provide injection plus with immunization but ASHA what I found is only pulse polio and refer the pregnancy women to PHC. When fellows interact with students they said that sometime she comes only once in a year not once in 6months and they did not get any nutritional food from Anganwadi also for the adolescence in the villages as the Anganwadi worker told us.

**City of lake**

This is my placement in Bhopal District, Madhya Pradesh. Bhopal was called a city of lake for it various natural as well as artificial lakes and is also one of the greenest city in India. Bhopal is a nice place when I reached in CPHE office I was observed the office it's very nice and calm place it suited for study reading books so clean and systematic.

**About the organization**

Sathiya welfare society was started in the year 2003 and it was registered in the year 2006 under the society Registration. Sathiya is working for the welfare of excluded and marginalized

communities for the past 8 years with a special focus on the development and empowerment of women and children. Sathiya's focus areas are mainly developing and capacity building, providing training on livelihood skills enhancements, developing strategic and short term planning of the organizations. The aim of the organization is to build the community confidence through creating communalization processes in reality and help them to be self-dependence through developing their skills in various trades which are in demand in today's market. Sathiya are working with child and mother health and works both with men and boys on gender issues. Sathiya are working for strengthening the local health facilities providers and for the community.

### **Vision**

Access Rights for all by ensuring active participation of women and men for the marginalized sections of society by involving them in a process of decision making on the basis of informed choices and strengthening local self-governance system in reality

### **Aims**

- To strengthen the community about their basic rights and land rights
- To empower the women and men and increase their participation in decision making and community activities
- To work for the overall development of children with special emphasis on their health, education and nutrition
- To promote sustainable income generation activities

### **Objectives**

- Initiating a public debate on the priority issues of the disadvantaged group
- Building capacity of women, men and marginalized groups so that they realize their rights
- Building a pressure group for influencing policy makers
- Raising awareness and sensitizing the community and alliances on the issues of disadvantaged

Marginalized groups

## **Projects and activities of the organization:**

**Strengthening women's political leadership in local governance in India:** in this project they are working with in 10 panchayats of Ichhawar block of Sehore District of Madhya Pradesh. This project is run with the partnership with 'The Hunger Project'. In this project they are strengthening and bring out leadership capacity of elected women representatives(EWRs) by providing training, exposures, close guidance and handholding support provisions.

Promoting education with the help of education films: the main goal is to reduce the dropout rate among school going children by generating motivation and interest so that they would complete their higher education in future by continuing the school education. This work are preventive approach so that dropout of children would reduce at maximum extends and children would realized the importance of education in their life and know how to contribute for the development of the society once they become capable to perform their parts once they become highly educated.

Action for reducing under nourishment among children: they are working in 15 panchayats of Ichhwar block of Sehore District of Madhya Pradesh.they facilitate, provide information, training as needed and promote the Anganwadi workers, member of Village Health Committee, EWRs and community to identify the under nourished children in their panchayat and deal with community level or take them to Health Centers as per the situation of children.

**Awareness generation general health among community in slum of Bhopal city for:**sathiya welfare society is working in two slums of Bhopal City of Madhya Pradesh. They are focusing on the maternal health, adolescent health and status of nutrition among children under 6years of age in the community.

**Forming of farmer clubs under NABARD:** Farmer clubs are organized as informal forum in villages at grass roots level with financial assistance of NABARD. The purpose of the programs is to co-ordinate with banks to ensure credit flow among its members and create better bank borrower relationship. For the better functioning of the program they organize minimum one

meeting per month or even two or three meetings per month as per the needs. For non-member can also be invited to attend the meeting for enhancing information and knowledge skills of farmers. The professor of the Agriculture Universities and member of Development Departments and other related agencies are called in those meeting for up gradation of technical knowledge of farmers.

**SHG promotion under NABARD:** SWS are working close association with NABARD where helping the rural villagers particularly the women to form their own self-help group. Formation of SHG is like building clock where community organized on the basis of money management. Once the community realized the importance of gathering forming groups they would automatically understand their power. At regular interval SWS provide them information, knowledge, and skills about the services available for them. It helps them empowered to use those services for their own overall development.

**Key learning:**

Within this two weeks I have learn the activities and project of the organization and through the Logical Framework Analysis it will help me in future if I work in any project to frame the activities and the action plan so this is the good ideas that the field mentor assign me to do and through the school dropout I have observed this is the good way for them because they get a chance to share their problem like personal problem and family problem. And this is the first time that I attend this kind of programs for school dropout.

**Goutamnagar slum:**

Goutamnagar slum is a small slum situated in Bhopal district Madhya Pradesh. This slum is a un- notified slum it consist of 900 populations. The people who stay here are migrated from Maharashtra, Rajasthan and Indoor. The people here they used to celebrate the festival like Diwali, Rakhi, durga puja and Rakshabandhan. The type of family that they are follow is the join family the oldest family the people are living here more than 40 to 50 years in this slum and they don't want to go back to their villages even the place are congested and they stay in a small room



with 5 or 10 people but they are happy to lives in this slum. The main occupation of the people is construction workers, some are engaged in their own small shops and women are domestic workers sweeping, dusting and washing in the household of the rich people.

The common diseases in this slum are malaria, flu, join pain, diarrhea and chikungunya and the people in the slum when they get sick they used to go to the government hospital they never go to private hospital because its expensive even the people in the government hospital they are very rude to them and it take 7km from the goutamnagar slum to this hospital. For the immunization they can get from the Anganwadi center and for the polio they ANM and USHA they used to do home visit for two or three days. For the delivery case they used to go to district hospital.

**Sanitation and facilities:**

The people in the slum they never used toilet they practice open defecation but there are some family who used their own toilet. Water is easily available from the government and the waste they used to through in one place and the truck used to come and collect this waste. So this is un-notified slum but the all the facilities like electric current, water supply and Anganwadi center.

**Social problem:**

The main social problem in this slum are alcohol the husbands they used to drink and gambling without working their wives take the responsibilities to their children and the financial in the family also so the women has a big burden in her arms even the domestic violence is very high in this slums their husband after they drink they beat them event they don't event go to work.

**Observation:**

- The Guatamnagar slum when compared to other slum is much better they maintain the hygiene and keep the surrounding clean and the people also are more educate and understand and it difficult to speak with them also because their lifestyle is improve so they are not friendly and open.

- The drainage system is there and water is running the whole day but in other slums they have water problem
- The social issues is less compared to other slum

### **Reflection:**

When I started to go to the slum I was confused how I will start to work and I was new here and the slum is small and I don't have so much to do because the slum is developed and no issues so I discussed with the field mentor so she suggest me when I do the HIV/AIDS I should covered the three slum Meerenagar, Indira nagar and gautamnagar so that my work will be effectively so I was satisfy when she suggest me to do like this.s

### **Gauravi center**

Indian's first one stop crisis centre name Gaauravi launch in Bhopal on 16<sup>th</sup> June 2014 by Bollywood actor Amir khan. This is the first centre in India working for women who are victim of violence. It will provide help and assistance to rape survivors and victim of dawry harassment, domestic violence and atrocities for women. The one stop crisis center will provide legal advice, medical aid and police assistance. Victim can call the helpline number or visit the facilities centre for the assistance. And it also provides assistance in filling FIRs, providing security rehabilitation for the victim and support.

JP hospital provides basic infrastructure two rooms, tables, chairs, bed, curtains and basic kid. The location is near the emergency department which is easily accessible for women. They have two senior doctors who interested working on the issues and is akin to the head of the department, two social workers, two nurses for part time, two lawyers and police officers appointed by respective departments.

The Centre provides from 24x7 emergencies admission services for women facing violence. At present they have file FIR 300 cases and the most cases are domestic violence and rape cases if they are ready to file cases they will file but if they are not ready not file. They give free medical checkup for the victims who are injured.

The information that we get from this Centre are 40% are reported 30% are not reported according to the victims that they came to this Centre. The age group that they are accepting is 10 to 75 years old.

### **Helpline center**

In this Centre they give counseling through phone and they received 200 calls in a week from the adolescent boys and girls. The most issues that they received is related with study, relationship, family problem and peers pressure. We asked about suicidal tendency the counselor said that in this generation the youth have change their mindset is not like previous anything happened to them they want to end their life but now they know how to find the way to get rid from that problem. So this center is really helpful for the adolescent in these modern days as they face different kind of problem related with their age. This is the age that the people find difficult to cope up with the problem and this is the age that they have to build a good character if they mislead their life will spoil so I was appreciate this helpline center i wish it could be in our state also. In this helpline the client can come to the Centre also or they can counsel through phone.

### **Primary school:**

In this week I have visit the government primary school meeranagar. This school was started in the year 2007 from class 1 to class 5 the total number of student are 48 in this school they don't have any facilities no toilet no water and in office also there is only tables and chairs, fan is donate by SBI bank but no electricity .

They provide mid-day meal every day and they gave different type food everyday .the food is ready made food supply by Nandy Foundation. In this school no USHA no ANM visit this school but there is school health camp twice in a year.

They have parents meeting but no one used to come in this parent meeting also this is the big problem for the teacher in this school because the parents they don't have the responsibility to their children for education.

They used to conduct a program to the student like storytelling, poetry writing, and drawing

Student dropout is very high as the parent they don't have interest to send them to school and the environment also was not good, the compound was dirty the surrounding covered with garbage that the slum people used to throw, class rooms no bench or desk the student sit on the floor only books they get free from the government. The student they get scholarship for ST, SC and construction workers scholarship.

When I asked about the behavior of the students the Head Master told that they don't have any respect they come to school whatever they want there is no punctuality and sometime the student after lunch they run away from school if the teacher talk to their parents the parents told no need to send them to school again better to send them to work. They never understand the important of education and they don't have any responsibility to their children. The HM told that their father asked their children to go and steal the shoes from the house of people and the wire they cut and sell and the money that they get they give to their father and the father go to drink with that money. In this slum father never go to work, he only drinks, beats their wife and assaulted their children.

#### **Interaction with adolescent girls:**

I had meeting with adolescent girls in Merenagar I was planning to discuss about HIV but they don't even know about this diseases and not event heart about it so I just talk about their problem and health and hygiene because they are still young aged 10-13years old so I don't want to talk about the HIV/AIDS. The problem that they shared is that the gender discrimination in their family as they consider more to boys than girls one girl I wish I could be a boy because in family parents are strict so much and boy are so free they go and do whatever they want. But for girl not even talk to someone especially with boys and there is some sexual abuse also by their father but she didn't come out because she scared to her father one of her friend shared about this. I discussed with the field staff try to get a chance to talk with her but their family never let her talk with stranger or to anyone may be there is some reason behind but we don't know. Only in school she gets a chance to share with her friends and to get out but at home never let her out. So this is one of the problems that the small girls faced in this slum.

**Observation:**

The overall observation about the center that I visited is very systematic in their work the room also was good and they have separate room for counseling and they separate room for legal room for the lawyer. The counselor in this center are very active and enthusiasms to their work especially from the Guaravi center.

The school was not good the environment but the teachers is good they give full time work but the student they don't have respect when we went there the student are shouting running here and there they don't listen to the teacher also.

**Reflection:**

When I went to visit the Gauravi center I fell that this kind of center should be in Meghalaya also and I wish that it will be there because in our state domestic violence is very high even though in Meghalaya is matrilineal system the women empowerment is improve but the rape case and domestic violence is increase day by day and so many case they are not reported especially in the interior part of the state

In this week we have a sharing about the one month fieldwork that we have so far in the present of Kumar sir, Ravi sir and CPHE staffs. In this day all of the fellows who are here in MP are coming to present our work that we have done so far and through this sharing it will help us to improve and correct our mistake and we get lots of feedback and suggestion so personally I'm so happy to get this kind of sharing and suggestion.

We went to the slum along with Kumar sir and we do the transect walk in all the slums meeranagar, gautamnagar and indranagar. We went and visit the anganwadi in three slums along with Kumar sir we are so happy to get a chance to go together with the facilitator in the field it's inspired us if we don't know much the language.

In this week I have started my areas of interest in the slum actually I did not get to interact with the people living with HIV/AIDS but I want to know the knowledge and attitude of people about HIV/AIDS. As we know this is one of the deathly diseases that taken many life of people in our country and it spread silently to many people and many people they don't know about this

diseases some they don't want to share about this to anyone as they feel that this diseases is a curse not a diseases. Ignorance and lack of awareness this diseases is increases in our country some are reporter but others are not reported.

### **Discussion with youth (boys) on HIV/AIDS:**

I have an open discussion with the youth group (boys) along with the sathiya staffs about HIV/AIDS in this discussion we asked them about these diseases they heard about AIDS but they don't know much about these diseases and we explained to them how it spread and about the prevention. They asked so many questions when we explain even the person living with HIV/AIDS they live for 40 to 50 years with proper treatment, exercises and nutritious food. One boy he asked how long did they live without treatment? So we told him that may be 10 to 15 years they can live. We explain also about the PPTCT and ICTC, ART and they asked can we get free for this treatment. We told them that this is for free in the government hospital like J.P Hospital and Hamidia hospital. The other question that we got is through mosquito did HIV/AIDS can be spread or not we told them that no it would not spread because mosquito suck blood from our body not that he give blood to us.

We have talk about the high risk group also like the sex workers, migration, drug users, truck drivers and the army is prone to this diseases. We got one question that if the truck drivers used condom they will not infect with this diseases? We told that yes but as we know that condom is not 100% sure so there are some cases that it will infect. As we know that if the people using condom they have to check properly because there are some cases it leak so that why is not sure.

Before we start the discussion I was scared because this is sensitive topic may be they don't like or they are not open but it not like that they are all open and we got a good response they asked many question I was so happy is like we give some knowledge to the people in the slum mostly are migrate and smarginalized to the society no one care about them. And this disease is increases day by day but the people are not aware some of them they don't even know about this diseases. For the next planning I want to interact with the women, youth girls in three slumMeeranagar, Indranagar and Guatamnagar.

We have given information to the women and adolescent girls about the Guaravi center is very important that the people should know about this center because it is working with domestic violence, rape, sexual abuse and harassment. So these issues is very prevalent in these slum especially domestic violence every interaction that we have they always mention about her husband beating her he used to drink every day , he never work he just drink and create problem in the family. We have gone through one issues that one adolescent girl she told the story about her friend who had beensexualyl abused by her father and this girl she never get a chance to go out because her parent never allow her to go out so only in school she get a chance to shared her problem and the other reason is there are many suicide in this slum last two month before we come to the slum one case happened in his slum one man hang himself for the small reason. This is all because of alcoholism all men are drunk and become addicted they can survive without drinking so if their wives ask something to them they take themselves in risky behavior like suicide, beat their wives so many thing they create a problem. So this Gauravi center is very helpful for the women.

**Attending classes with school dropout:**

On these days we attend the NGO activities the classes in the slum with school dropout in this day they explain about the culture, caste system, child marriage, prostitutes, and kidnap how these issues effect in our society put the people in danger and scared. This issue is very prevalence in our society and its increases day by day. So it is good to educate the people and make them aware all these issues to protect them from all these issues.

**Observation:**

The people in the slum are very open if we talk about the social issues and if we talk about the diseases like HIV this is sensitive issues but when we talk they are open and response very well. When I look to their house and the compound surrounding I feel how can they live and how can they survive is very congested, crowded. The houses are very small with number of people in one room. And in raining season the house they cover with plastic, kutcha house all are leaky they can sleep at night also they have to stay awake at night also because of the rain. If it is hot they can sleep because no fan and the room are congested they sleep 10 or 8 people in one small room that why they infect different kind of diseases and the water that they drink is not good to drink the surrounding is smell and lots of mosquito.

### **Reflection**

In this month we find difficult regarding with the fieldwork because the staffs are busy with their work in the field so we can interact with the people without their help because of language problem so our work are still pending. And one think this time is rainy season so it difficult to go to the field the people are busy with their work and they want to rest because they can't sleep properly. And when I ask about AIDS even the student they don't know about this so what about the illiterate people how will they know and aware about this disease and I don't know why the people think that this disease is a sin.

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violence, rape, sexual abuse and harassment. So these issues is very prevalent in these slum especially domestic violence every interaction that we have they always mention about her husband beating her he used to drink every day , he never work he just drink and create problem in the family. We have gone through one issues that one adolescent girl she told the story about her friend that she has sexual abused by her father and this girl she never get a chance to go out because her parent never allow her to go out so only in school she get a chance to shared her problem and the other reason is there are many suicide in this slum last two month before we come to the slum one case happened in his slum one man hang himself only for the small reason. This is all because of alcoholism all men are drunk and become addicted they can survive without drinking so if their wives ask something to them they take themselves in risky behavior like suicide, beat their wives so many thing they are create a problem.so this Gauravi center is very helpful for the women.

#### **Attending classes with school dropout:**

On these days we attend the NGO activities the classes in the slum with school dropout in this day they explain about the culture, caste system, child marriage, prostitutes, and kidnap how these issues effect in our society put the people in danger and scared. This issue is very prevalence in our society and its increases day by day. So it is good to educate the people and make them aware all these issues to protect them from all these issues.

#### **Observation:**

The people in the slum they are very open if we talk about the social issues and if we talk about the diseases like HIV this is sensitive issues but when we talk they are open and response very well. When I look to their house and the compound surrounding I feel how can they live and how can they survive is very congested, crowded. The houses are very small with number of people in one room. And in raining season the house they cover with plastic, kutchra house all are leak they can sleep at night also they have to stay awake at night also because of the rain. If it is hot they can sleep because no fan and the room are congested they sleep 10 or 8 people in one small room that why they infect different kind of diseases and the water that they drink is not good to drink the surrounding is smell and lots of mosquito.

## **Reflection**

In this month we find difficult regarding with the fieldwork because the staffs are busy with their work in the field so we can interact with the people without their help because of language problem so our work are still pending. And one think this time is rainy season so it difficult to go to the field the people are busy with their work and they want to rest because they can't sleep properly. And when I ask about AIDS even the student they don't know about this so what about the illiterate people how will they know and aware about this disease and I don't know why the people think that this disease is a sin.

## Research

*Title of the study:*

**“A study on the factors related with nutritional practices among HIV infected women and the response of civil society organizations to it”**

*Name: Juliat Angel Shangrit*

*SOCHARA Supervisors: Mr. Sabu Ku*



**sochara**

***Title of the study:***

“A study on the factors related with nutritional practices among HIV infected women and the response of civil society organizations to it”

**Primary investigator:**

Juliat Angel Shangrit

**Supervisor:**

Mr.Sabu (SOCHARA), Mr. Chander (SOCHARA) and Miss Rebina (SHAMAKAMI)

**Duration:**

Two months 18<sup>th</sup> September to 18<sup>th</sup> November

**Associations:**

Research proposal arranged as part of the Community Health Learning Program (CHLP) at SOCHARA (Society for Community Health Awareness, Research and Action), Bangalore in collaboration with the SHAMAKAMI-Lamjingshai Meghalaya

**1. Background:**

According to the WHO, *“nutritional support is an integral part of a comprehensive response to HIV/AIDS. There is evidence that nutrient intake can improve Anti-retroviral absorption and tolerance. Receiving appropriate nutrition can help improve the health and quality of life of HIV infected individuals and helping to maintain the immune system and sustain the healthy levels of physical activity. Individuals who received anti-retroviral therapy with appropriate nutrition are more likely to regain weight and more likely to follow to their medication”*. (1)

Many parts of the world most severely affected by HIV have long been tormented by system and chronic food insecurity and there is a complex interrelationship between AIDS and food insecurity. The emergency plan has a clear responsibility to prevent, treat and care for people with greatest burden of these diseases concentrated in developing countries. The countries of Sub-Sahara Africa and the Caribbean are approximately 30 million people living with



HIV/AIDS, more than 40 million people living with HIV throughout the world; 5 million are newly infected in 2005. According to UNAIDS over 25 million have lost their lives to the diseases leaving behind orphaned children and ravaged communities. (2)

It has estimated that 3.9 million people are living with HIV in India (UNAIDS, 2002) which is a higher than of any country a side from South Africa. Around 8% of HIV transmission in India is injected drug users, another 8% of cases have arisen through HIV infected blood used in transfusion, 80% of HIV transmission in India is through sexual more specifically heterosexual contact, commercial sex workers are the largest group of HIV infected individual in India today.

(3) According to the report from Meghalaya Aids Control Society in Meghalaya have detected 151 positive cases within 5months between April and August 2011 a total 2,616 persons are examined for HIV virus out of which 121 were faced be positive cases, a. Pre-natal test on 5,635 pregnant mothers also confirm presence of virus in 30 of them. There are 344 people living with the virus in Meghalaya 170 men, 162 women and 12 children. (4)

## **2. Rationale**

Meghalaya is one of the tribal states of India which is poor in infrastructural. This poor development in tribal dominant areas have been the main reason contributing to the inability of health programs in reaching to the Tribal people which is includes the National Aids Control program. The Tribal people in India are being particularly vulnerable to HIV/AIDS. The study was chosen by the researcher because the people in this region are illiterate and have poor access to media so they are vulnerable to HIV/AIDS. The awareness regarding services for treatment, care and counseling are very low in the state. So the knowledge on nutritional is very low they don't get any information about the importance of nutrition among the HIV infected. The reason is lack of awareness and the others is health facilities are not available. Insufficient treatment available with counseling the people living with HIV/AIDs makes them more vulnerable. (5) (Source-center for social research 2006). Women are more vulnerable to HIV/AIDS because of the commercial sexual activity at an early age

### **3. General objective:**

To assess the factors related with nutritional practiced among HIV infected women and the system response to it

### **Specific objectives:**

1. To identify the nutritional practices among HIV infected women
2. To identify the socio-economic factors influencing the nutritional practices among HIV infected women
3. To assess the knowledge of HIV infected women on their nutrition requirement
4. To assess the systemic response to the nutritional practices of HIV infected women

### **5. Key Research Question**

#### **Type of study**

This study will be descriptive study using in-depth interviews. The study population must be the HIV infected women and the staffs of community based NGOs. The participants will be known using the following inclusion criteria –

- a) Must be a resident of shillong East Khasi Hills District.
- b) Must be women living with HIV/AIDS
- c) Must be the staffs of community based NGOs, public health field staff working with HIV/AIDS

A Snowball sampling will be implemented to get the participants easily and to get the several view point on nutritional practices by HIV infected women

#### **Method of Data Collection:**

Qualitative method- the interview will conduct in the place where the respondent feels comfortable in shillong city. Interviews will supported by using only one local language- khasi and the semi structure interviews will followed by using checklist in khasi local language. The detail of the study will explain in khasi language which the respondents can understand and the

inform consent will sign with their agreement the interviews will conduct with the respondents consent. The in-depth interview, Focus Group Discussion and semi structure interview will be used topic guideline or checklist.

- In-depth interview
- Focus group discussion
- Semi structure interview

|                          | HIV infected women | Staffs of the CBOs who are working with HIV/AIDS | <b>Total</b> |
|--------------------------|--------------------|--|--------------|
| In-depth Interview       | <b>6</b>           | Nil  |              |
| Focus Group Discussion   | <b>1</b>           | Nil  |              |
| Semi-structure interview | Nil                | <b>6</b>   |              |

**Tools and technique:**

- Observation
- Recorder
- Semi-structured questionnaire

**Ethical issues:**

The participants will be provided with the information sheet which mention about the study purposes objectives and the rights of the participant as a voluntary respondents. The audio recording will be using with mobile and if the interviewee fail to recorded hand-written will continue and access with without harm by the Researcher.

Confidentiality should be maintain by the researcher and the staffs of the Shamakami-Lamjingshais organization the name of the participants should not reveal in the data and if they are not ready to participate should be respect to them and the research should conduct in a manner that respect the dignity, safety and rights of the participants.

Risk will be minimize in this study both by preventing possible harm and minimize the negative impact. The risk should not be affecting the participant status nor family neither society.

### **Indemnity issues:**

No financial recompense is given to the participant's contribution in the study. The study include the in depth interview and focus group discussion in the place where the participants feel comfortable. The study is sensitive but I would keep confidentiality no risk wills expected so insurant is not necessary.

### **Analyses:**

## **1. Nutritional practices by HIV infected women**

### **1.1 Type of dietary**

Food habits of the participants varied widely. The respondents from the poor family consumed rice, mustard leave, pumpkin, green vegetables which they picked up from the forest; they could buy rice and dal, potatoes, mustard, sometime meat rice, milk occasionally. Both day time and night time they could take rice, vegetables pumpkin, dal, green vegetables that they could collect from forest. 35 year old labor woman said:

*“Breakfast rice, lunch rice and dinner also rice”*

On the other hand, some of the participants could afford more supplementary food such as; chapatti, paratha, dal, vegetables, soup, meat, milk, fruits with cornflake, oats, Bread, cake, meat, green vegetables and different kind of fruits and dinner same rice, meat and vegetables. 34 year old employed woman said:

*“For breakfast I eat chapatti, paratha and sometime bread and for lunch I eat rice, dal I never miss, vegetables and soup I used to have and meat, for dinner I have the same thing that I used to eat for lunch”*

The participants that belong to the poor family have poor nutrition. This is because of the financial problem and the main reason is that after they got infected their husband left them so they have to support themselves and take care to their own children and they have to go to

domestic work. Some of the participants they don't get any job whether it is labor work or domestic work so unemployment is one of the problems. No one would support them from the family to maintain their nutritional status they can't afford to take treatment also because of financial problem so mostly they felt sick they can't go to work. They face the discrimination in their family also and that why mostly the participant never reveal their status with the family member or within the community. But the participants who could afford more supplementary food they have many choice and they don't need to be in the Anti-Retroviral because they could afford good supplementary food and more support from the family.

### **1.2 Maintaining CD4 COUNT within safe level**

Mostly they want to keep the CD4 count in safe level they tried to eat well and some of them are not at ART center because their immune system is very high. And they are aware that if they undergo stress or tension the CD4 drop down so they tried to make themselves in a happy mode. In some cases, though the participants did not get sufficient support from the family due to the death of the family members and the stigma associated with the HIV, they tried to keep themselves happy as they were aware of the risk of stress and its association with CD4 count.

21 year old women said: *'I have to eat properly and eat good food like nutritious food and proper sleep is very important, I always make myself happy'*

Some of the participant mentions that treatment also is very important as the only nutritional food can't maintain the CD4 count. Regular treatment also is needed to improve immune system. Some of the participants are aware the risk association of lowering CD4 counts so they tried to eat properly as they identify that their body develops weak. 54 year old women said:

*"When I came to know my CD4 is low I tried to eat well"*

Some of the participants can't keep the CD4 count within safe level they tried to make themselves happy but the CD4 count dropdown for some of them because of the poor nutrition they can't maintain the CD4 count. 32 year old employed woman said:

*"I can't sometimes I'm in a very good mood happy mood CD4 count just drop down"*

### **1.3 Changes of food pattern after infected**

The supplementary food that the participants added after they are infected is juice, soup, bread, jam, butter, milk, cornflake, oats and fruits.

Some of the participants changed the food pattern after they are infected because they are aware the risk related of lowering CD4 count and the other reason is that they are engaged in government job, NGO extra so they are secured they don't have financial problem they get a good support from their family also even though their husband have left them, they have a security job so they are not in big problem they can add more supplementary food. 32 year old employed woman said:

*"I tried to change my dietary by taking juice, soup then bread with ghee or jam or butter, now I ate peanut butter, cheese, sweet, daily product which made with milk"*

There are some participants who cannot change the food pattern they want to change but they have multiple problems regarding with the financial problem. They are aware the relationship of nutrition and CD4 count but they have no other choice they have to cope up with the entire problem and the body energy also is less because of less nutrition, low immunity system so simply they would felt sick. They are aware about the important of nutrition as they have attend many workshop and program conducted by the NGO(Meghalaya state network positive).34 old women said:

*"If I get I will change but what to do I can't afford If I feel healthy I could go to any kind of domestic work but I feel very weak I don't feel like doing any work"*

### **1.4 Nutritional management along with children to improve immune system**

Most of the participants can't manage the nutrition because there are some problems related to nutrition. One is the discrimination from the family they did not support to them, financial problem, the other reason is they have many children and some of the participants have to support alone for the children their husband left them. 45 year old daily wage woman said:

*‘For that how can I say I always tension about that no one support me even the food I can’t get properly I eat whatever I get’*

### **1.5 Spending for food per month**

| No of participants | Work engaging    | Amount |
|--------------------|------------------|--------|
| 2                  | Daily wages      | 200    |
| 4                  | Domestic workers | 2000   |
| 1                  | Outreach worker  | 8000   |
| 1                  | Peers counselor  | 5000   |
| 1                  | Ward girl        | 4000   |
| 1                  | Business         | 5000   |

## **2. Socio economic factors influencing the nutritional practices of HIV infected women**

### **2.1 Occupation**

Some of the participants are engaged in labor work, daily wages, domestic work and some of the participants are engaged in government job, peer counselor, outreach worker and business. Majority of the participants are domestic workers as they are single parents. They have to take care by themselves to their children without any support from others and their husband also left them after they know that are positive.

### **2.2 Family support**

Mostly all of the family members of the participants are not supported whether in financial support or physical support. When they are sick they can’t go to their work so they face financial difficulties for raising their children as well as for themselves. Instead of helping them they looking down and insult to them. So they have to work hard by themselves for their health and for the nutrition to live a better life. And some of the participant doesn’t need any support but treat them normally not to look down on them even though they are positive. 27 years old young women said:

*“No one support me, my relative are very rich they look down on me even though they don’t know my status if they know what they would do. We have a small family i has only one sister so that why no one is there to support me”*

34 years old women:

*“No they just say are you ok, they never say that ok I will give you 1000 buck every month for the nutrition and they never let me down. I don’t want them to treat me as abnormal not as an physically disable I want them to treat me normally”*

### **2.3 Family response**

The participants had a good response from their family members they just said that is unlucky the reason is mostly the participants are infected from their husband so it is not the false of the women to be positive so the family felt sad about this because of their husband they suffered so much. But there are some family who are insulted to them they spoke badly they give a very bad response but they are not listened to them. There are some participants who are not disclosing their status with their family. 34 years old women said:

*“They insult me but I never listen to them”*

### **2.4 Family discrimination**

The discrimination among the participants is less yet there is discriminate in the family as the feel scared that it will get infected to them also as they are lack of awareness so they need lots of awareness in the family so that they will understand how to prevent and reduce discrimination for the people living with HIV/AIDS. Some of the participant before they disclose their status they talk about HIV in the family it is a kind of awareness to the family that kind of idea they tried to bring in and it is a very good thought they had taken. Some of the participant are scared to disclose their status because of discrimination and stigma that the people is having that why mostly they are not open about their status. Discrimination in the family is very danger it bring lots of tend to the victim it affect their mentality and emotionally so awareness is very important especially to the family members. 34 years old women said:



*“Earlier there is lots of discrimination at home they feel scared of me, first I told to one of my brother and he spread to whole family. After that without my consent my name and photo it came out in the newspaper during this time I already work in MSNP then my family wanted to cut the relationship so my parent want me to move out from here to Kerala to stay away for some time from here but what I feel is this issues it never go even if I go anywhere. And all my uncles, aunt came together to cut off the relationship with me I haven’t seen them before so I fell very happy because of me they all came together my mother introduced me and she said that they want to cut off the relationship with you and I said its ok because when I am sick or when I have a problem I never seen them coming like this and it became one of the family get together. I am very happy my mother was accepted me during this time I feel like I become mad but now I can manage”*

## **2.5 Community reaction**

The participants mostly never disclosed about the status to the people only to the person that they are trusted. But there are some people they suspected but they are not sure. The participant don’t want to disclose because they feel scared if they know they will insult them and disclose their status to others. 40 years old women said:

*“No they don’t know about my status only my family knows about my status”*

## **2.6 Co-workers reaction**

Mostly the participants feeling scared to disclose their status to their co-workers because of discrimination they might be leave them alone if they know their status and look down on them. only those participant who are working in NGO are disclosed to the co-workers and they feel free to open about their problem and speak out to people also they open up they give testimony in the public place they don’t feel hesitate to tell their own status is like a motivation to others people who have the same problem to come out and speak their own status so that discrimination will be less and the spread of HIV/AIDS will reduce. 35 year old women (outreach worker) said:

*“I like them because they more like my family they understand about my needs. If I feel stress tens I came to the office why? Because here I can share my problem they understand about*

*HIV/AIDS but at home sometime I don't get to share or if I share my problem they mention their own problem instead of sharing I have listen their problem but if I came here the more I shared the more I relax “*

## **2.7 Changes after infected**

The participants are feeling the different after infected whether in physical or mental. They feel bad and feel low after they get these diseases as they feel shy to their friends, neighbor and family. Mostly mentally affected because they are confused and fear about their life how long they can live and how they could live and worry about their children about their future so they can't eat properly it will affect their health both mentally and physically. They are very tensed they live in fear and they see the differences in the family some of them they are not healthy after getting infected. Some of the participants change in habit before they are rude and never listened to their parents but after they realized parents is the most important whether they are in sickness or happiness what they did before is wrong so they started to live a new life with the family with a good habit. 27 years old young lady said:

*“No, I just feel low I think about my future how many days and years I live, what about my children what would I do so I feel tension and worry. There are changes in my habit also before I was very rude and never listen to my parent after I realize the important of my parents”*

## **2.8 Contraction of diseases**

Mostly participants are infected from their husband and mostly they came to know about their status when they conceive a baby and when for a test. So it is a shocking result for the entire participant as they did not expected and one of the participants said:

*“I was shock that I got this disease as am not a sex worker or use multiple partners. First I got diarrhea more than two weeks I went so many checkup and test but it does not work after that one of my friend suggest me to go for HIV test my result came positive I feel sad”*

The people think that only the prostitutes are infected by HIV/AIDS they never realized we are all vulnerable to this diseases and this is because of stigma that the people believe that why discrimination are not reduce. The participants are much worry after they are infected as mostly their husband left them and they have to take responsibility to their children and for themselves. That's why they face financial problem they can't afford good food, good nutrition as per their needs. They face discrimination in the health care system when they go for delivery or checkup they are not happy whenever they go they always face a problem.

### **3. Knowledge of HIV infected women on nutritional requirement**

#### **3. NGO responses**

These NGO is Christian base so they are linkage with the churches in north east. They went to different churches in north east to give awareness program about HIV/AIDS and they speak to the pastors, priest about the important of awareness on HIV/AIDS that they are the right person that the people in the community are trust and worthy. They used to have a special program on HIV/AIDS in the church to make the people understand about these diseases. They have workshop, picknic with the children living with HIV is like a get together to know each other. One pastor said:

*“We have a program in the church about HIV/AID once in a week and in the month of August every year we have a program only on HIV/AID and all the people who are coming in this church are aware about HIV/AID and they don't have any negative thinking on this issues”*

They provid nutritional food to the children living with HIV/AIDS for 27 children they select the children according to family background who are facing financial problem, parent are left or died these are the children is really need support. And there are many children who are disappeared they come only once but they are not coming again the reason is the parents are feeling scared to come because they scared if their friends came to know about the status of their children and the

other reason is they stay in the village so its difficult to them to come back and their parent they never take a good responsibility that why they disappeared. One of the staff said:

*“I feel very pity for them if the parents are not responsible about their own children like some of them they disappeared from the church without informing why they are not coming to take the nutrition that we provide”*

The NGO mostly provide nutrition only for children and they provide good nutrition every month plus with money to support for education. This will help the children to live healthy and improve their immune system and they can't go to work they have to depend on others so that why they consider only for children. They are not providing to women even though they are vulnerable because they can't engage to any kind of work or job they are not depend on others. And this nutrition is goes to the whole family the kid who get this he have to share to the family he live together. So is like they provide the whole family.

*“We gave different kind of nutrition which is helpful for them not like Maggie, biscuit this is not nutritious food which give energy to the body we have a list for different kind of food very good and helpful for them”*

#### Discrimination in Meghalaya

The participants mostly said that discrimination is very high in Meghalaya because of stigma that the people had. Mostly the people who are infected they are not coming out to speak about their status and they are vulnerable as they fear to the society and lack of awareness. There are some victim who want to revenge after they are infected and some of them they re-married and the sex workers are continues their work without prevention. And the society is believed that these diseases are given by God for their sin because they did a dirty job which is against the Biblical values. That why this NGO are working with the churches to make the people understand if we still living in a narrow minded then these diseases will increases day by day so we should start a

new ways of thinking to fight against the stigma and discrimination on PLHIV in Shillong. One of the staff said:

*“Meghalaya from bad become to worse as compared to other state HIV/AIDS has decrease and in Meghalaya increasing day by day. This is because of stigma and discrimination the PLHIV feel ashamed to come out as people think that this is not a disease this is a sin, revenge given by God. If they are not change the mindset this issues would not decrease”*

The participant (pastor of Nepali church) mention that they are working on HIV/AIDS because it's get worse day by day yet there are some people talking about us because in the church it should not speak about this issues but what they think is good because the priests are the people who are more trusted by the community if they speak or give awareness in the church people are more attention and respect so if they could that then this issues will decrease that why more NGO are link with different kind of churches so that it easy for them to convince the people in the community.

### **Discussion**

Women are more aware about the nutrition which is needed for them as the people living with HIV/AIDS but due to poverty, single parent, lack of support from the family they are suffer so much and CD4 count is low. All the participants are aware about the immune system and the nutrition if they eat good nutrition then their immune system will increase and they are healthy. If they had a good nutrition they can live a better life and longer life. All these information they get when they are attended the workshop that the Meghalaya state network positive conducted. The women who registered in this NGO they understand and they are very positive about HIV/AIDS. They live happy and peacefully as they received many counseling. As we know that people who infected by HIV/AIDS they need counseling because they are fear and scared about their life and the society, because of the stigma and discrimination in family and community. So we need more awareness programs to make the people understand about this issue.

I really appreciate about the churches that are accepted this issues to speak to the people about HIV/AIDS which is a big issue in Meghalaya. Some people are really come out and speak about their status in public so this is a good example that the people have done that the other who infected are not fear to come out and disclose their status to people so that the stigma and discrimination will decrease and people will think positive about this diseases.

**References:**

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3. Meghalaya AIDS Control Society Report
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*Participation information sheet*

My name is Juliat Angel Shangrit . I am a student of the Community Health Learning Programme in an NGO called SOCHARA (Society for Community Health Awareness, Research and Action) in Bangalore. As part of this programme, I am conducting a research study along with the SHAMAKAMI-Lamjingshai in your area to understand more about people living with HIV and AIDS. I would like to kindly request your permission to participate in this study.

This note provides an explanation of the nature of the research. This sheet may contain words that you do not understand. If there is anything you need clarity on, please feel free to ask me. At the end of this information sheet you will find my contact details.

Communicable diseases (CDs) like HIV/AIDS have increased over day by day. People with these diseases face many problems in managing their care because of several reasons. One such reason is the facilities are not available and the people are not aware about this disease the important of the nutrition who are infected of HIV so I want to know what is the gab that the people are not aware that nutrition is one of the component

I would like to ask you a few questions about the history of your disease, your past and current experiences about the nutrition practices and your opinions about the NGOs who are working with you. Your answers will be very important in helping us understand the reasons why people are not responsible about the nutrition.

Some of the questions are very personal and if you do not feel comfortable to answer you can refuse to answer them. Your participation in this study is voluntary and you can withdraw at any time you do not need to give any reasons for not answering the question

The interview will be around 15-20 minute along with your permission; I will record the interview on a mobile. If you not comfortable with this please let me know I will write instead of recording and with your consent your words will be copied exact for the purpose of creating a report. I assure you that everything will be confidential and your identity will be protected. All confidential data will be handling only by me and the mentors of SHAMAKAMI-Lamjingshai. All the information are used only for research purpose.

You are not receive any resource of benefit for participating in this study but the information that you provide might help us to give you suggestion maintain healthy life.

For more information or clarification please contact us:

Juliat angel shangrit - phone no.9615337479

Rebinasubba – phone no.9863065255

Thank you for your time. This sheet is for you

### *Participant Consent Form*

**Title:** “A study on the factors related with nutritional practices among HIV infected women and the response of civil society organizations to it”

I have read and understood the participation information sheet (or it has been read to me). I understand that it includes me for taking part in an interview. I have been explained the purpose and way of the study. I have been informed that there will be no direct benefits for me. I understand that the information I will provide is confidential and will not be disclosed to any other party or in any reports that could lead to my identification. I also have been informed that the data from study can be used for preparing reports and that reports will not contain my name or identification characteristics. I have been provided with the name and contact details of the



researcher whom I can contact. All my questions have been answered to my satisfaction. I had enough time to decide whether I am going to participate or not. I know that I am participating as a volunteer and I can step out of the program whenever I want and it is not necessary to give an explanation. I know that research team will see my details. I give consent for my details to be used for the research purposes mentioned in this form. All information regarding consent and purpose of the study has been explained to me in the language I understand. I provide consent to the following-

- Participation in the in-depth interview: Yes  No
- Audio-recording of the in-depth interview: Yes  No
- Publishing of words/sentences spoken in interview verbatim: Yes  No

.....  
.....

Name of the Research Participant

Name of the Researcher

.....  
.....

Signature of the Research Participant

Signature of the Researcher

\_\_\_\_\_

\_\_\_\_\_

Date

Date

**WITHDRAWAL OF CONSENT**

I hereby wish to **WITHDRAW** my consent to participate in the study described above and understand that such withdrawal **WILL NOT** endanger my relationship with the Institute of Public Health.

**Signature of participant**

**Name**

**Date**

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