

Community Health Learning Programme 2009

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Source: Community Health Cell

A Report on the Community Health Learning Experience

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COMMUNITY HEALTH CELL

Community Health Learning Programme

May 2009 to February 2010

Children
and
Community
Health

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Children and Community Health

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This report is dedicated to the
children, care takers and the team
at Nalam Child Development Center,
a rural initiative of Buds of
Christ

Acknowledgements

In my journey of learning community health, I would like to thank Community Health Cell for having opened the gates to a rich learning experience of many areas around health.

I would also like to express my sincere gratitude for the guidance provided by my mentor, Dr. Rakhal Gaitonde who supported my learning process at every stage.

I would also like to thank Dr. Sukanya, Dr. Ruth Vivek, and Mr. Premdas for their valuable inputs and suggestions during the learning programme.

Dr. Ravi Narayan and Dr. Thelma Narayan for their encouraging words

Dr. Regi and Dr. Lalitha of Tribal Health Initiative, Sittlingi and Mr. Krishnan and Ms. Anu Krishnan for sharing their valuable experiences and also providing opportunities to expose myself on community health and children in community health in tribal regions.

I am also thankful to administrative staff and librarian of CHC for patiently supporting us in our journey.

My learning was more enriching with the support of fellows in sharing their experiences in their area of interest which provided a wider area of learning.

I am extremely grateful to my family, especially Jpaul and John for enabling me to dedicate my time in this learning process.

Finally, my heartfelt thanks to the team of Nalam Child Development Center and children of Vetri Kootam in Namakkal for having shared their experiences which enabled me get a deeper understanding.

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Introduction

My journey into the community health learning programme of Community Health Cell, was thanks to the motivation I received from my husband Jeyapaul and my good friend Kousalya, the president of Positive Women's Network. The thoughts and ideas that my husband, who had just finished the same internship, had proposed with regards to a few initiatives in Chennai at a small level were completely new to me and resulted in a conflict of ideas between us. I was determined in pursuing focused interventions that would focus on addressing the treatment and information needs of individuals, while he talked of a more comprehensive approach. The differences made me inquisitive to know and learn what this community health approach really meant. Moreover this internship came at an appropriate time, because as a family we had decided to go and work in a rural settlement, in the district of Namakkal, where we had worked earlier.

This decision was further affirmed after a short visit to Namakkal early, in January to a village where we had worked with a group of children in 2003. We were shocked at what we found. The girls of the group were already married and had two children each. Out of the 12 girls in the community group, only 2 had been able to pursue higher education. While among the boys of the group even those who performed well in their studies were distracted by the economic pressures and had left schools and gone for work. Almost all of them had taken up jobs and were working as cleaners. These children were from the scheduled caste community and were exposed to a number of vulnerabilities as they were heading the household, as majority of their parents were working outside. Looking back at my earlier work I realised the futility of only focused interventions in complex situations like this.

Learning Objectives

At the beginning of the programme, my only thought was to learn about how to work with children, and especially those in the rural areas. The orientation programme provided a platform to look at my past experiences in a new light and unlearn much of what I had held on to over the years of study and work. . The programme helped me realize the various determinants to health; the various health programmes and policies, and gave the skills at analyzing the data and importantly reflecting on our own personal selves.

Having previously focused my work in the field of HIV and AIDS, my interest was to have a deeper understanding of issues affecting orphan and vulnerable children in the context of HIV and AIDS and also explore strategies to advocate for their issues, with their involvement. The initial list had almost 6 objectives, but later while meeting children in the community and having an interaction with the community, I understood that only if a good rapport is built with children, would children express the issues and concerns affecting them more freely. Subsequently I decided to focus on just two objectives.

These are presented below:

1. Understand the issues of orphan and vulnerable children in the context of HIV and AIDS in Namakkal district.
2. Learn how children and their issues have been approached in various community health programmes.

Notes on Methodology

To document my learning and reflection them better, I maintained a diary of my daily experiences and thoughts and doubts etc. This also facilitated me to write down my emotions when I was exposed to various situations and also helped me to resolve the situation more strategically. This process also enabled me to look at myself both in terms of work and at the personal level, the increased my ability to handle situations better.

In addition to maintaining diary, a tabular format was developed to document the learning from the field. This writing down of learning in a matrix helped me observe issues keenly in the field and especially the feelings and concerns of the community I was working with.

The learning and the reflections that I have had throughout the nine month period has been varied and rich. During this period our own personal experience of setting up a child friendly center in a rural setting, working with children in reviewing the Orphan and Vulnerable Children's (OVC) framework, exposure visits to different community health programs, art-therapy sessions and projects with children in the community, helped me greatly to appreciate the intricacies of the community health approach as well as a community based approach to a problem.

I would like to present through this document the journey of learning and reflection as well as the many opportunities to understand the different dimensions that need to be addressed to improve the health of children in the community. In certain places I have used I which has been my personal thought and reflection and in places where I have denoted "we and our", it includes Jpaul and the team members in the reflection process.

Setting Up Child Friendly Center in Namakkal

After the orientation programme, my first exposure to working with a community was during the setting up of our own child development center in Namakkal. We decided to name the center using a locally appropriate name instead of the registered name and hence the center is known as 'Nalam Child Development Center'. Nalam is the Tamil word for well being.

Though our initial work was to work with children affected by HIV and AIDS and also children vulnerable to HIV, we did not want the name of our organization to be linked in any way to HIV and AIDS. For identification of children affected by HIV and their organization into a group, the local networks of people living with HIV (with whom we had worked earlier) were approached. Through their contact two volunteers (women living with HIV) were identified for support in the work with children. Engaging the affected women, proved very supportive, especially in meeting families affected by HIV and AIDS and even establishing rapport with the family members. Further a list from the medical officer of the Government ART center was obtained in identifying children between the age group of 12-16 years, living with HIV. Obtaining list is not an easy task for people who are completely new to the district. There are lots of procedures to it. The process was easy for us as we knew the medical officer since 2003 and had had initial discussions before settling down in Namakkal, which helped in establishing a trust between the medical officer and us.

Having obtained the list, home visits were made to have personal interactions with children, while the other children (children who are not from Tiruchengode block as two groups were formed, one in Namakkal and one in Tiruchengode taluk) listed were contacted by the volunteers of the center. It was only while meeting the families, personally in their homes, that the issues of caste and gender were appreciated by us. We also realised how access to services was also limited by these factors. The visits revealed that young adolescent girls who have attained puberty were not allowed to go hospital for treatment, unless accompanied by an adult, thus severely constraining their access to quality care.

Two girls shared that when they had symptoms like fever or headache and wanted to visit the hospital, they had to check about the availability of the adult in the household to accompany them before being able to access the services.

Thus often there is a delay in accessing the appropriate medical service.

This experience was a truly shocking one. This was especially so my having been brought up in a family and environment where neither gender nor caste had any influence. The learning that was stressed during the orientation helped me realize how these factors can affect the health of the individual.

Following this, in order to set up the child friendly center, as truly child friendly, we believed that children should be consulted and that listening to them would truly help us achieve our objective of making the center child friendly. So when we made visits we used to recall with the children the experiences of the children's center of which I was in charge five years ago in the same district. Almost all the children expressed the need to come together in groups, as that facilitated them to share the concerns and fears more

openly with each other, as most of them had no trusted friends outside the support group. But after the project they had not been able find such support systems in the district. Hearing this from the children motivated us very much but at the same time some children expressed concern over the name of the institution and the name board identifying them as HIV affected, to which we assured them that no such terms would be used.

Two children expressed another set of fears that they had experienced when using the earlier center, which was that the charts about HIV and AIDS which were displayed within the office building could give away the true identity of the institution even if the name was not linked with HIV/AIDS. This made us also realize, how we missed the finer details of the design etc. of the institution, but to the children everything matters. As alternatives to these posters children suggested display of charts that conveys messages on positive living, nutrition, child rights etc. Listening to children helped us realize how much vital information children have and in order to truly help them how important it was to listen to the children's voices.

So the center we developed does not have any charts on HIV and AIDS and all the teaching materials we use on HIV and AIDS in workshops on treatment adherence etc. has been filed and not pasted on the walls of the office.

One child expressed openly during our second meeting that though we assured everyone would not be linked with HIV /AIDS and there would be not material either inside or outside that could be linked, he found it difficult to believe, so he told us that he had in fact come earlier that day and visited the center to confirm that there no identifies. Only after checking out for himself did he feel secure to attend the meetings.

At present the member of the group have become great supporters by encouraging each other to ensure treatment adherence. They have also become educators for other children during their individual visits to Namakkal government hospital on the importance to treatment adherence.

The other learning that, I could recognize during my visits in the community that I understood during the learning programme were the determinants of health. These include availability of food, support to access the health service, education, economic condition of the family etc. I found that these issues play a major role in the lives of the children.

The following case study illustrates this very well:

Thangadurai, 15 yrs old is living with HIV. He is looked after by his mother, who is also living with HIV. His father left them when he was very small. They stay in a small rented house that is costing them Rs. 600 per month. There is no support from relatives of either side due to their HIV status. His mother earns an income selling greens. Through this she earns about Rs. 1200 /month. She has not accessed the Positive people's scheme as her house owner does not know her status, and she does not want to reveal it to him. She is currently on ARV treatment. Their food is mostly rice and an onion or tomato chutney. Sometimes she adds greens in the diet, if there is balance from the sales of that day. They buy rice in the open

market which costs them about 25 /kg. They try and consume less than they need to be able to manage for the whole month. Rice available through the Public Distribution System is not used as they find it hard to eat.

From the above case I learnt that it is not only the HIV status that influences his condition. In another instance he shared how he had read from his school text book that HIV was a killer disease with an incubation period of 6 months to 6 years. Not able to understand the meaning of incubation period, and not having anyone to turn to, he presumed that he had only 6 years to live. This led to a lot of stress, though he failed to realise that he was born with HIV and was presently 15 years old and that thus what he was thinking was wrong. This shows how even the education system / the textbooks etc. need to be sensitive to the diverse groups who will be using it. The choice of food influenced by their dire economic condition also is a determinant of the health status of Thangadurai. Such in-depth understanding helped me personally to look differently at every child that we have reached and acutely appreciated the need for a network, knowledge about the government schemes and how to access them, and learning more about other schemes (adolescent health by VHN, general health programmes of the government) that can enable a better health status for children affected by HIV.

The children and their care takers felt the center as a second home and said so on a number of occasions. They said that they felt this way because of its ambience and that they could associate the thatched roof setting to their own house. The center was established due to initial budget restrictions, but as the children and their care takers felt the center was more approachable thanks to its appearance, the center has been further furnished along those lines with only basic lights and mats on the floor in response to the positive response of the community we work with.

Exploring issues with children affected by HIV/AIDS

In addition to setting up the center, deeper understanding of issues of children was done through observation and field visits. First in understanding the issues, I had listed few organizations, one was CHES that worked among children affected by HIV and AIDS, then met with Grace Project-a community project of World vision, then the networks in Namakkal district. Visits to the government hospital were also made, where doctors and counselors of ART center and ICTC center were met. These visits helped me to understand the adult perception of issues and the estimates on how many people were affected.

As a family when we wanted to establish the center, understanding the issues of children with children was found essential especially when we are looking at them as active participants. Firstly from the list obtained from the government hospital home visits were planned with support from volunteers of the network (People living with HIV) as support from an already established person will enable an easier introduction. Following this, children were formed into groups and monthly meetings were organized. To gain a deeper understanding on specific areas like disclosure, treatment issues, interpersonal relationships a tabular column was developed as shown below:

Knowledge I am starting out with	What I want to know more about / explore.	Areas that are new, that have emerged from children and caretakers and that I need to explore.
The key findings made during the discussions and visits are:		
Children on disclosure		
<ul style="list-style-type: none">❖ Children said that parents should disclose their status when children begin to raise questions to them regarding why they were being taken to hospital and why they have to take medicines etc.❖ The children did not define any age group, but instead they said that disclosure should be when they come to an age of understanding. This age was defined as the age when they started asking questions about their treatment. For some it was as low as 6 or 7.❖ Expressing the importance of disclosure early and by parents, children said, it was shocking to learn about the status on their own, when we searched and found the records, there was also one boy who found his own status by looking through his personal records on his own (this boy got infection through the negligence of the hospital authorities).❖ Three children in the group said that they waited for their mothers to disclose their status and so asked many questions, creating the opportunity for her to tell them, though they already knew about the status. But very often they were given wrong answers or even being told lies. This hurt them.		
Adults on disclosure		
<ul style="list-style-type: none">❖ Adults say the fear of being stigmatized, especially because of a the moralistic overtone of the issue, influences them against disclosing their / the children's status to their children		

- ❖ Adults also felt that getting to know the status may affect their studies and performance in school.

Treatment related issues

What children told us about issues around treatment was completely unexpected. Through a role play children depicted the following:

- ❖ Issue of doctor not available to check them up during their monthly visits to pick up drugs.
- ❖ Doctors being shown as busy, distant and insensitive – by showing them as continuously attending phone calls and / or working all the time on the computer. (This is probably because of the TANSACS policy that data entry of every individual attending the center and should be maintained by the medical officer).
- ❖ They also felt that if they could call doctors “aunty or uncle” that would make them share concerns more freely.
- ❖ Children defined a Child Friendly environment – as one in which they did not want sign boards – declaring that it was an ART center. This was because they were scared that they might be identified by their relatives, friends, neighbors or teachers.
- ❖ They also expressed the fear of being identified while waiting in the long queue.
- ❖ They also mentioned that Information booklets often have the words HIV and AIDS mentioned prominently. They would instead prefer if the cover page is with a cartoon design and had general words like healthy living etc.
- ❖ During the role play this was demonstrated by children carrying the information book with lot of fear and throwing it in the dustbin as soon as they leave the hospital premises.
- ❖ Limited quantity of food at home even affects them taking food
- ❖ Sometimes the side effects themselves makes it more difficult to eat.

Observation in the field

- ❖ Girl children are especially neglected – They do not access the hospital for any ailment.
- ❖ There were at least 5 children in our group who did not go to the hospital due to viral attack, because they thought it was ordinary infection and needed less attention. Until we took them to GH after our visit.
- ❖ One child who was on ARV stopped for nearly a year and was followed up only during our visit.
- ❖ Lack of information on care of children has affected the children's access to treatment and health care services.
- ❖ Repeat TB has been found among most of the children under the care of grandparents as once the symptoms reduce, they tell the children to stop the medication.
- ❖ Even ARV has been stopped in the case of 2 children because of lack of information and lack of proper food.
- ❖ Children under the care of grandparents were forced into taking up the role of running the house; they often had to also prepare food for the

household, these responsibilities at such a young age sometimes led to their health being compromised.

- ❖ These children are also attached to their grandparents. One day when we had a residential workshop these children wanted to go home or wanted their grandparents to stay with them. And this facility was provided to them.

Interpersonal relationships

- ❖ Fear is still a dormant feeling among all children living with HIV.
- ❖ Fear of being discriminated by friends was the strongest fear that all children had and expressed.
- ❖ It seemed that children were keener on peer acceptance than about acceptance from their relatives.
- ❖ Two children have attempted sharing the status to their friends, one child was very successful in gaining acceptance, while the one girl shared that while her friend treats her well at school, once they enter the village, she does not talk to her nor even gives a casual smile. She said that her friend behaved that way is because of the pressure of her mother.
- ❖ The issue that was emerging in the discussions I had was that children living with HIV were now reaching the adolescent stage are were engaging in casual relationships and also looking towards / thinking about committed relationships. But none of them have disclosed their HIV status to the other person.
- ❖ So the need to talk about prevention and sexual and reproductive health was found important to be addressed
- ❖ Some of the girls and boys have also experienced abuse, sexual, physical and emotional from close relatives and neighbors during their stay with them.
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Education

- ❖ School performance of children living with HIV and who are on ARV treatment is adversely affected. This was also reported in a study [in UK] which attributed this to memory loss due to the drugs¹.
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Issues of orphan children under the care of grandparents

- ❖ From few visits it was found that there is a perception of burden of care by grandparents towards the care of grandchildren especially if it is paternal grandparents.
- ❖ There is a noticeable difference in the care of maternal and paternal grandparents, with. maternal grandparents show great interest in care, even if the children are HIV positive.
- ❖ The expressions towards children are more negative, if the children are HIV positive.
- ❖ Though care is provided in ensuring periodic monthly visits to hospitals, the stress is often ventilated upon children
- ❖ From the 14 individual cases of children in the support group, 7 are under maternal and 7 are under paternal grandparents care.
- ❖ Children under the care of paternal grandparents have suffered from repeat TB episodes; two boys have run away from home, pointing to a very casual attitude towards the children. While in the cases, I have seen among maternal grandparents there has been better support and care and the access to the treatment facilities has been regular.

Working With Care Takers of Children Affected By HIV/AIDS

While working with children it is also important to work with their care takers. The support group members that were formed as part of Nalam were mostly grandparents. Working with old people needs lot of patience and also ability to adapt training sessions that fits the ability of the group. Having worked with only children living with HIV, their knowledge on the facts around what is the effect of HIV on the system and the role of ARV could be easily grasped when participatory techniques were used. But it was a challenge for us as at team, especially in working with people who have not been exposed any technical advancement, so sessions had to be adapted to fit in educating hem for better care. So the training was adapted to fit with day to day examples to teach them.

Example: How HIV attaches to CD4 and multiplies inside the body, Like how if a color is added to white iddli batter ,and the iddli's coming out will be in different color instead of while iddlis.

CD 4 cell is like the police protector cell which fights against any disease that comes in. HIV is like a thief which enters in the disguise of police dress, so CD4 cell is cheated by HIV in police dress and is accepted and not fought against. Once HIV in police dress attaches it starts making an army with the support of the CD 4 cell and destroys the strength of CD 4 cells in the body.

*Another example in explaining the importance of adherence in treatment;
(Example shared by a trainer in another workshop)*

Imagine a land with crops and you have a cow in that area. What do we do to the cow; we tie, so that it will not eat the crops. If it is untied, what does it do, it damages the crop. In the same way, apply the land with crops as our CD 4 system and HIV as the cow. ARV medicine is the rope tied around the cow, If you forget to take the medicine for one day, it is like loosening the rope of the cow, which might result in the damage of the crop. So as you forget, it is like loosening the rope further and that might affect a greater area, same is applicable to our health system.

Child Based Policy Analysis

Understanding the OVC framework and training facilitated for children in advocating for the gaps in the framework

The Orphan and Vulnerable Children (OVC) framework was developed by UNICEF and NACO as part of mainstreaming process the framework has been developed to facilitate a collective response of all the departments towards orphan and vulnerable children in the context of HIV and AIDS. The other ministries include - Ministry of Women and Child, Ministry of Human Resource Development, Ministry of Health and Family Welfare.

The framework was developed on July 2007, until the fellowship however I did not find myself keen to read the document with a deeper analytical thought. I wanted an opportunity to engage children over this policy framework as I felt that their voice will convey a stronger message than our efforts.

Opportunity came in through Positive Women Network; a community based organization of women living with HIV which has been strongly advocating for women issues and since 2006 have been actively representing children's issues as part of the advocacy process. A review of the OVC framework was proposed and I was invited to be involved in the process. The task was quite challenging as it was not limited to merely reading the document, but was also meant to look at ways to help children understand the framework and then enable them to review the document. For this, apart from reading through the OVC framework document, I had to read through different participatory approaches to engage children in discussions and documentation. A list of energizers and ice-breakers were prepared with care as the workshops were being held at the state level and included children who were very new to each other and some who had already participated in workshops organized by Positive Women Network. I usually ask for the list of representatives of the workshop to prepare myself and if I am able to identify anybody I have seen or have been part of workshops, I try to pick them up in facilitating the energizers or ice-breakers as this gives a better opportunity for us as a facilitator to establish a rapport with the new participants and also an opportunity for children who had attended workshops to feel comfortable to be with us.

As it was a PWN+ initiative supported by UNICEF, a person from UNICEF was also supporting me technically in developing the module. This helped me very much as the person has been involved in the complete development of the framework process, so this technical support enabled me to work towards a process in helping children review the complex framework. Discussions with a number of persons enabled me to include examples and change the flow of the workshop process such that it was easy to link every session with the one that followed.

The module included ice-breaking, team building process, personalizing issues through river of life presentation of 2 case instances, then working on issues through dream tree exercise. The river of life is an exercise which enables sharing of one's ups and downs in life from the age he remembers. This exercise facilitates a better understanding of the individual. This was adapted into the session using two experiences of children I have worked with and explaining their experience through river of life.

The dream tree exercise is an adaptation of the problem tree exercise which is commonly used as a technique to identify issues and root causes of the problem through group exercises. The problem tree was adapted as dream tree, as in this exercise, once the list the problems in the trunk area, they look at the changed situation they foresee in the top part of the tree.

Following that understanding basics of rights and referring to the dream tree exercise identifying the right violations, then looking at what the schemes are offered for each age group - What children already know, then the OVC framework is explained. Then a comparison is made by children with the dream tree and the framework and gaps were noted and then depicted through role play with recommendations displayed. This was also shared with key stakeholders through role play and submission of handwritten memorandum.

The effectiveness of children's potential in presenting their problems and finding solution and strategies in addressing the expressed problems if proper techniques are employed, is presented below:

These are the depictions they made in presenting the gaps and the recommendations they placed on the strategies listed in the framework. The children did not take the first strategy in the OVC document of UNICEF on the prevention of parent to child transmission, while all the other four strategies were discussed and recommendations were prepared and then enacted to the key stakeholders from TANSACS in Tamilnadu.

Issues	Solutions
Situation at the ART center	
<ul style="list-style-type: none"> ❖ Fear of the children of being identified as HIV positive, while waiting in line for the treatment - child worrying if their teacher sees them, or if their friend came to know their status. ❖ Booklet given at the center with HIV and AIDS is held with hesitation and torn completely as soon as they leave the premises. ❖ Coming to the center by taking leave on school days causes suspicion among school teachers ❖ Doctor busy on the mobile phone and computer 	<ul style="list-style-type: none"> ❖ Children showed a booklet with the cover page with cartoons and information about HIV only on the inside. ❖ Doctor being friendlier and child able to address him/her as uncle or aunt and no phone calls or working on computer, giving full attention to the child. ❖ Saturday as a day for children and also having small group meetings for all children that day ❖ No name board ,but instead have it as medical center or children health center and have all health related problems for children given through the same center
Care and Support	
<ul style="list-style-type: none"> ❖ The family, husband, wife and two children and the affected child is staying there. It is his aunt's house. ❖ The care the aunt shows on her children is different. She feeds them 	<ul style="list-style-type: none"> ❖ The solution they depicted was the child going to a support center near their house which has meetings for children and he is happier as everybody is

<p>attends to all their needs, while the care of the affected child is completely neglected and it was depicted by showing that he was given a separate plate.</p> <ul style="list-style-type: none"> ❖ Then the second situation was the two children were playing, but when he wanted to join them, they said amma has told us not play with you because you have HIV. ❖ Then the child is made to do all the household work. ❖ The final situation is the entire family going for marriage and the child is asked to clean the house. 	<p>concerned and talks to him.</p> <ul style="list-style-type: none"> ❖ The final expression with which he ends the role play is "Appa, amma (mother/father) even if you are not there, I am happy when I come here, especially when I interact with children like me". <p><i>The solutions they presented:</i></p> <ul style="list-style-type: none"> ❖ Was to have a support center for children ❖ Have special counseling services for children ❖ Creating more awareness among the general public ❖ To create opportunities and services so that children can be with their parents.
<p style="text-align: center;">Prevention education</p>	
<ul style="list-style-type: none"> ❖ The situation depicted was of a group of children having a wonderful time. Once they see a friend of their group whose status as HIV positive was recently known to them they move away from that place and avoid him completely. ❖ The child comes out of the group and asks, "What have I done? Why do people discriminate me?" 	<ul style="list-style-type: none"> ❖ The children say that, though adolescent education is mentioned in the OVC framework as strategies, it is not implemented in schools. ❖ They said that teachers do not even talk to them about issues surrounding HIV/AIDS. ❖ They felt that Red ribbon clubs have to revive. They also suggested that these clubs should do events throughout the year and not only on World AIDS Day.

Learning About Community Health From THI and Thulir

Tribal Health Initiative (THI)

Tribal Health Initiative is a community centered hospital that caters to tribal people of sittlingi and parts around the village. I spent two weeks in August and had opportunities to interact with the health workers and auxiliary workers. Field visits were also made to understand their work in the community and the role of auxiliary workers in enabling women and children to access the health services at the village level. In addition to this I also accompanied the team to their new establishment at vellimalai in the neighboring district of dharmapuri.

The unique feature of the Tribal health initiative is that the community involvement is seen at every level. The staffs, other than the doctors, are all managed by the tribal population. Except for four staff, including Dr. Regi and Dr. Lalitha all others are trained tribal representatives.

The THI hospital though primarily functions in promoting health, has five major programme components:

- Out-patient services at THI in Sittlingi
- Health care providers training and internship that develop young tribal girls in managing and administering ANC care and other ailments in the in-patient care.
- Auxiliary workers, that comprises of village community women to be contact and resource person in treating minor ailments within the community.
- Livelihood wing that has Porgai Unit that empowers tribal women in creating embroidery on dresses, cushion covers, photo frames ,purses etc and there by providing the majority profit to the tribal women.
- The organic farming unit also encourages farmers in production of crops organically. The unit is managed by trained tribal population. Self –help group has also been initiated among the auxiliary workers and savings pattern among them has been initiated.

The major learning I have had in the brief exposure to tribal health initiative has been:

1. Rapport with the community: Rapport building with the community was a slow process; it was built over time through multiple home visits and also engaging the community through participatory techniques. These participatory exercises also seemed to enable better participation of the community. Selecting representatives from the community as auxiliary workers and also some of them as health workers in THI has facilitated better acceptance from the community. The approach made by the team, when visiting villages is more people friendly, in addressing the individual by name or akka or anna.

2. Work with the community and engaging them is a prolonged process: Dr Regi said that the entire team of auxiliary workers and health workers has been through hard work and required constant support over many years. He also said that there have been many drop outs, but consistent effort has resulted in facilitating better involvement of tribal communities.

3. *Encouraging community participation:* This was the most interesting part, where the community members have been trained to work as health workers and auxiliary workers in their own community. They need to identify the different strengths of the community and to respect the community as an active participant in the whole process comes through effectively in their daily work. Having been involved with the community representatives, the people who access for out patient or in-patient services felt a close link to the hospital thanks to them.

4. *Transparency of work with the community:* This aspect of the work of THI was truly a revelation. I found that almost everybody who works there, including the auxiliary workers, have an idea regarding the funding of THI and the various activities that they are engaged in. Personally I feel because of this, each staff takes responsibility in maintaining the hospital, from cleaning to maintenance of things.

5. *Integrated approach:* Though THI primary role is providing health care services, it also serves in addressing the economic concerns through a unit focusing on handicrafts called "Porgai" as well as a group working on organic farming. The formation of self help group among the lambadi community and the auxiliary workers have also empowered women in a great way. For instance a tribal woman age 28 years in Thanda village is part of the Porgai unit. She is from the lambadi tribal community. Prior to this she was a house wife and looking after two children at home. Now having engaged herself with this unit, she is part of the self help group and even supports in the organic farming unit. She said that being part of the unit has enabled her to be part of the decision making in the family and respect has been facilitated through the income earned from being part of the Porgai unit

6. *Respect of the community:* The impact that you make on the individual or community depends on the commitment and respect you have for the individual and the community. This was another major learning I got in THI.

Thulir

Thulir is a school for tribal children that looks at the holistic development of the individual and approach is building them as effective citizens. I spent two days at the school and had opportunity to interact with Anu and Krishnan the managing trustees of the school and the tribal children benefited through the school.

Major learning in their approach and work with children:

1. Rapport building with the community was initially started with tuitions and having gained support from the community (as the need for child's improvement in studies was the top most priority for the community) they later introduced the skills based mode of training, which was easily accepted by the community.
2. Trained children in Thulir have become co-trainers for children of the community. The respect and cordial approach of the trustees of Thulir created an amiable atmosphere for children to be share freely.
3. Understanding the interest and skills of children was essential to work with children. Through this approach the children who would not even write a sentence on joining the program, were very soon writing reports that were more than 2

pages. Every skill they had learnt was implemented as a project activity through team work. This also ensured that planning and reporting skills have been learnt.

4. Using resource poor materials but being able to teach them the different scientific concepts.
5. Importance of learning children's psychology
6. I learnt that the interest spans of young adolescents is very short. Thus engaging them in livelihood options is difficult as they keep changing their mind. This means that one has to teach them diversified skills, so they are able to make individual choices to engage in the skills that they desire.
7. Story telling method was an effective process of teaching children.
8. Having been engrossed within HIV and AIDS field, I felt the need to know more from other child based organizations. As all agencies working in HIV and AIDS and with children have only seen them as beneficiaries, but outside the sphere of HIV and AIDS, I learnt from Thulir (for example) that the various agencies working with children have children at their center and respect children as active contributors in all matters that affect them.

Capacity Building

Self Development Workshop at CHC

This workshop was truly a wonderful workshop. This was organized by a team, from Sukrut. The facilitator's ability in engaging all the participants' attention revealed her skill as an effective trainer. Using stories as a means to convey strong points was another technique I found effective in her training approach. Though the training was for two days it really brought in lot of information that we could use to personally reflect on our own lives.

The activity use the concepts of 'warm fuzzies' and the 'cold prickly' was a good exercise. In this we were made to sit in the center and the group members share the qualities ('warm fuzz' or 'cold prickly') that they have noticed in us. It was also a revelation when the trainer pointed out that some times the 'warm fuzzies' that we carry with ourselves as individuals may not be the best qualities if we take up the role of a leader. For .e.g. in my own experience everybody's trust in me to handle situations, especially in hostel may be good as a friend but as a leader, I am actually restricting each individual's capacity to deal with the situation effectively. That helped me realize how sometimes my personality makes people dependent on me. From then on, I have tried to encourage people to handle their own issues. This is also important that as an organization we do not make the people dependent on us, but ensure and facilitate process that helps them to handle issues that can be managed by them.

ART Therapy – Special Training in Building Rapport With Children

The training was for a 5-day period in using art therapy as a form of counseling. The trainer had experimented with different groups of people and is an expert, practicing art therapy for the last 18 years. The training I attended was only a basic course. Advanced level of training will enable the trained person to analyze and interpret more deeply the paintings or images that the client drew.

The major learning I have had from the training were:

- Art does not mean only painting and drawing
- Art therapist does not have to be a person who is proficient in drawing or painting
- There are no designated colors in expressing emotions, as it differs from person to person and from culture to culture, for example. red is a sign of anger for some but for some people it is sign of happiness
- The density of the color may express one's emotional level. Lighter shade reveals a milder level and darker or thicker shade reveals a stronger level of the emotion.
- Almost any object, including clay and other materials like flower sponges, feathers etc. can be used in art therapy.
- A scribble can also convey a lot if the therapist leaves it to the client to share what can be transcribed from the scribble.

This skill building not only enabled me to introduce the basics for children that I intend to work with, but it was also a healing process for me. There was a particular activity called "inside the box, outside the box" that I liked. This brought out a lot of expressions from

the participants. It also helped me understand that what was 'inside' the box, often remained hidden. And it is what is inside this box that sometimes enables us to shine on the outside. If there is something affecting some part of the inside it also reflects on the outside too.

Field Project Work in Elanagar village

During the last three months of the Internship, I proposed to explore the perceptions of children in the community about HIV and AIDS and then facilitate their right to access information on HIV and AIDS and other health related issues. This was mainly due to the fact that children affected by HIV/AIDS had expressed that peer support and acceptance were their most important priority.

For this, the area that was chosen was Elanagar village, in Namakkal district. 3 children who were attending the support group of the Nalam child development center were from this village. Secondly the village is at a distance of 12 Kms from the center, so the identity of the center as one working for HIV and AIDS was not known.

Prior to approaching the community, we had prepared the children in the support group. We met them (as if for the first time) at the bus stop and they acted like guides to us to familiarize ourselves with the village. The village is located 3 Kms inside from the bus stop. Initially we used bus and then our own personal vehicle which was also parked at the main road for saving time. The village is not easily accessible due to limited bus services.

The first visit involved in meeting with the key influential people including the local panchayat leader and other local leaders who had an influence in the life of the village community. Following this we met with the children with the support of the already established contacts. This way rapport building with the community was much easier. Initially two groups, one consisting of boys and the other of girls were formed. The first 3 meetings were disappointing as only 3-4 members in each group turned up. This really frustrated me. However I recalled that even Regi of THI had shared such similar experiences and that for them the group formation took a year long process. Then my support staff and I did a detailed study to understand the community dynamics. We learnt that the attendance was poor because the meetings were organized on holidays, and in most of the families the children are forced to go for work on holidays as they get better wages if they work the whole day. Later the meetings were scheduled for the Friday of every week for both boys and girls separately. It was also learnt that sessions for girls should be completed before six as that was the limited time permitted / acceptable for girls to be in groups. After that they had to go home and help in cooking and other household chores.

Understanding and learning all this was through interactions and visits and realizing during those visits the vulnerabilities the children in the general community are exposed to were major learning.

Learning and understanding the living condition of the children from the general community who were not affected by HIV / AIDS, forced me to expand the definition of an orphan and vulnerable child to include all children of any disadvantaged group (and not only those affected by HIV/AIDS) who have limited access to any forms of services that contributes to them enjoying good health. With this in mind, we moved forward to organize our meeting and in the conclusion of three meetings we learnt that HIV and AIDS was a well accepted infection. Children seemed to be interacting very normally and casually and even sharing food from the households identified as having HIV positive

individuals. The sexual mode of transmission of HIV and a moralistic perception of HIV was less and the prevalent myth that HIV can be easily detected through symptoms as an added understanding that has been gained from these interactions. Not wanting to focus or being identified as an agency that works only HIV and AIDS issues, the discussions were centered around general health, as the need to equip the children on this topic was recognized as vital too.

Discussions

The nine month learning programme has been very fruitful especially as an individual in understanding what community health is and to see the link in various factors and their influence on the health status of the individual.

Community health stresses the importance of engaging the community, and the experiences in THI and Thulir especially have reinforced the importance of engaging the community for effective change. Engaging the community cannot happen instantly. It is a long process. This was made clear during my visit to THI. I am experiencing the same truth as I am working with children in the community in the final 3 month project. The depth and extent of community involved depends a lot on the attitude of the individual. In Raichur, though atrocities were experienced, we could see how people could gather as a group and voice their concerns. The same was seen in THI, where the young tribal girls have been trained as health care workers and are performing deliveries equivalent in quality to a professional degree holder in the cities; and in Thulir empowering the children they work with by adapting the learning mode to fit their interest. I realize the importance of this attitude and patience and have experienced the same during the seven month I formed and worked with a support group of children who have now gone on to become district level advocates.

The gender aspect is another factor that I was able to witness in my personal life, while settling down in Namakkal. The stereotypes, that women are meant to do certain jobs and men should do certain jobs. The community held similar stereotypes, where access to treatment is restricted for young adolescent girls, if there are no adults available at that time to take them to the hospital. An instance was witnessed in THI during the community visit, where a couple's daughter had a heart problem. In the previous visit, the mother had come alone with the daughter and so the doctor had explained the condition of the child was severe and needed a surgery and also informed about the free heart surgery scheme of the government and also had given a reference letter. But as he had anticipated she had come for the next visit with her husband and with the same complaint of the child. The doctor had to explain the entire process and the decision as taken instantly as it involved the men, who only have the power to make decisions.

Understanding caste and class differences is also important in working on health related matters. What was exposed in Raichur, where the environment of the people of the lower caste is always with minimum facilities, was seen across the Tribal areas and the community I work with in Namakkal district, as the village I work in is dominated by people of the Scheduled caste community.

I have also learnt that our approach should be people centered and not with vested interest. When it becomes people centered, engaging with them and ensuring Thulir I could see they gave importance to what the children desired and their approach is completed on a child centered approach and the same was noticed in THI, the community's role was given so much importance that the ownership of the hospital functioning is of the community. This brings a sustainability of any initiative taken forward.

A critical thinking on the work of THI on HIV and AIDS reveals that an imposed programme does not sustain, while a felt need of the community sustains. The HIV and AIDS programme of THI has been imposed by the TANSACS official, who had awarded a project to them when then project director had visited the center. So the involvement of the community has been less as it has been imposed one, while the ANC care in the community still has the same effect as it was the need of the community. My own community work through the three month project revealed the same, that entering the community, and learning about it is essential and unless the children brings in their needs the involvement is lesser. From the experiences I saw in Raichur, Thulir and THI I am careful in not focusing too much on my ideas or views, but moving at the pace of the community with the focus of improving the health status of children in the community.

The need to integrate and work with all the departments like NREGA, NRHM, PDS, anganwadi center etc was realized in my community work during the last 3 months. As addressing any issue should be comprehensive and involves the role of all schemes in ensuring improved health of the community. Though initially I did not feel the importance to know and learn, now I am able to see the importance of learning them too.

All these experiences have also helped me redefine orphan and vulnerable child as any child who is disadvantaged or discriminated by caste ,class and gender is orphan and vulnerable and not merely restricted to a child only HIV affected households. I would like to further reinforce my redefinition in this tabular column of looking into the similarities of children of the scheduled caste experience and the children of the HIV affected families' experience

Children of the HIV affected families	Children of the scheduled caste community - Elanagar village
Poor and limited services to water and electricity ,economically poor and employment of adults mostly as daily wages	Poor and limited services to water and electricity ,economically poor and employment of adults mostly as daily wages
Adult children managing the household due to loss of parents or families having single parents- <u>widowed father/mother</u>	As parents go for work – outstation for long periods ,children are under the care of adult siblings and grandparents
Children under the care of <u>grandparents-complete orphans</u>	
Adult siblings drop-out from schools to manage household income	Children drop-out rates higher ,especially girls are restricted if the income is less
Young boys run away from homes,2 cases reported especially under the care of paternal grandparents	Sudden disappearance of young boys ,who go as lorry cleaners and come after long periods of staying away from home
Living in environment ,where	Domestic violence especially

drinking and conflicts are open	after drinking in open space In addition children are exposed to tobacco chewing
Children are not aware of any information about HIV and AIDS, except that they are living with HIV	Ignorance and lack of knowledge about HIV and AIDS
Lack of adult guidance ,so explorations are high	Lack of adult guidance ,adolescent boys and girls exploration are high Myths are also strong that One can say HIV by their symptoms Though the community and the children have not discriminated against families affected by HIV, myths and ignorance at the same time makes these children highly vulnerable too

Looking Inward

What I learnt about myself was that initially when I started this fellowship I thought I was doing so much and giving the best to the children's community that I was working with. However through the exposures to other organization I realize how much more I need to learn and how little I was actually doing.

Learning also includes a change in my personal attitude to be more patient, especially while working with community representatives. Initially I was very restless but from my exposure with THI, I learnt the importance of being patient and basic respect of the community that we work is very essential in our work.

When I entered the fellowship programme, I thought it was easier to manage my learning programme and family, but the emotional bond did affect my decisions at certain times. My son's ill-health really affected me and with due support from my family I was able to move forward.

Having exposed to the tribal environment, I realized the comforts that we are in and how less privileged they are with access to many services that we enjoy in being in the .But with the limited resources they are more satisfied than us.

I had great fear of frogs, cockroaches, snakes and lizards and having had to manage all these on my own in THI have helped me to overcome the fear of living with it also.

I always thought I was a bold person and not easily influenced by ghost stories, but when I was told ghost stories especially related one incident that had happened in the cot adjacent to the room, I realized how scared I was and how easily I can be influenced to the situation.

My personal conflict in settling down in Namakkal, with strong stereotypes on man's and woman's role has been a challenging one with my interaction with the community I am staying.

The caste system is very strong and the inquisitiveness of people also affects my personal space. Having had limited interactions in cities and the curiosity into our background and what caste we belong has made me very uncomfortable in many occasions.

Looking Outward

Understanding community can only be through by living with them. Staying at Namakkal helped me explore the many issues that affect the community that I work with.

I was able to see gender as a major factor influencing the health status, like for instance a girl child to access the health service is difficult especially if she is an adolescent aged girl and has to be dependent on family or the others sometimes, if the family member or the care taker is not available on that day, her access to the service is restricted.

The economic factor, influences the choices of food, that affect the nutritional status, the educational status etc., that has an influence on the health status of the individuals. So through these exposures a broader understanding to social determinants to health was learnt.

Through this my approach to the children I work with, I am not only looking at addressing the treatment information, but also looking at facilitating access to old age pension scheme, creating awareness in the free note book scheme etc.

Experiences going to Raichur also helped me understand the need for community to realize their rights and entitlements to access PDS, NREGA, and NRHM etc and the importance of engaging community and encouraging community participation for sustaining the programme.

Personally I learnt the importance of having awareness on the various government programmes so that will facilitate linking up the existing services for the community I work with. In addition it is merely not education, but also to work with them to realize their rights to access these services is essential in any kind of sustenance of the programme.

Looking Ahead

The learning from the community health programme have helped me realize the importance of addressing issue as a whole. Unless the programme is holistic in its approach, it will not result in effective or a sustainable change.

The learning programme has also helped me realize the importance of working with all children (orphan and vulnerable), not only those affected by HIV and AIDS and the complexities of issues remain the same for all children who are disadvantaged by caste, class, gender, education etc.

So at the end of the fellowship, I would like to redefine that any child who is disadvantaged by caste, class and gender are vulnerable, so orphan and vulnerability should include all children of such category and not merely addressing only children from HIV affected families. Experiences of working with children of HIV affected families in a focused manner and explorations into the community have helped me realize this new definition of orphan and vulnerable children.

Annexure

Annexure-1 Case Studies

From the field - Namakkal District

Rajaram (name changed), 15 yrs, living with HIV is living with his parents in a small hut given to the family who are working in the brick industry. He is studying 11th standard and aspires to become a government official of high rank. He had come to know about his HIV status when he was admitted for treatment for prolonged cold and fever. He lost his appetite and so was losing weight drastically. Worried parents took him to a nearby government hospital, but there was no improvement. So he was referred to another hospital in Perundurai, an autonomous hospital which is about 45 min travel distance from his residence. He was admitted for nearly a month, as his recovery was slow, the doctor expressed the need to test for HIV. His result was positive, so his parents were also asked to test for the same and they were negative. The test result was not told to the child based on the doctor's advice as he was doing his 9th standard. He was treated for TB and the parents were advised after the TB course, they could go for ART treatment. As the child was told that he had chest infection (did not say about TB) too but advised that the treatment should be continuous and his parents regularly monitored the progress.

Rajaram become suspicious about his status, when both his parents had gone for work, he took his test result and saw his status. He immediately even referred his parents' reports and found both negative. Knowing the status that way, affected him very much and as there were no proper support systems to handle his condition, the situation was quite challenging. He had attributed the cause as sharing the same syringe among patients in one of the PHC, where he had gone with the complaint of fever, as he has had previous knowledge on HIV transmission through his text book, he was greatly affected, especially fear of being discriminated by friends and teachers in school. His fear affected his health that he stopped going to school for more than 3 months. With the motivation from a government appointed counselor at GH, he completed his 10th class successfully.

He is now on ART treatment, but lives with constant fear that his status might be known to others. He has to go to the ART center on week days and as it takes nearly 2 hrs to Namakkal from his village, he loses one day every month. His classmates even suspect and mock him as TB patient, as he is thin. He says that words affect him and if they come to know about his HIV status, he is more worried about the fact of further being discriminated.

His parents do not have much knowledge on ARV treatment and the need for adherence, so this makes it more challenging, as if he is emotionally down or upset with anybody he does not take his drug. He is gaining confidence now through the peer group meetings conducted in the Nalam Child Development Center, where information on treatment and care is also shared. Lack of proper information and programmes focused on children affect most children like Ragu especially in coping with the stress of living with HIV.

From the field - Tiruchengode

Anita, 8 yrs old belongs to Karutupalyam village in Namakkal. She and her brother stay with her paternal aunt. Her aunt was married to a very old man, who also stays in the same house. The income for the family is from her aunt's husband who does collie work. But due to his health condition, he earns very little for the family and so the nutrition and care is compromised.

The aunt has very less information about HIV and AIDS and the co-infections that affect children. Anita had a big swelling in her throat region behind the ears on both sides. On testing it was found to be TB. She was taken to Namakkal Government Hospital [GH] as she was also HIV positive. The hospital is about 1 hr 30 minutes by bus drive from her home town, about 32 km. Though the team had provided information about TB and the need for completing the course completely without any treatment drop out, her aunt was very casual. She stopped the treatment for Anita when the swelling came down. The Tamilnadu government (State AIDS control society) appointed field counselor was in-charge of following up the child, and repeated advice by the person to the aunt was futile.

Soon Anita had a relapse of the TB episode affecting her health further. She is now under the category of repeat TB. The child has not been counseled or informed of the treatment. She was also tested for her immune status. The CD4 count was above normal, but due to the second episode of TB she has been advised for ARV treatment and will be starting after the course of the second repeat treatment.

The family condition is very poor and the nutrition adequate for the child's health is not provided. Anita does not desire to take the TB medicines as it causes hunger and as the food is restricted at home she does not feel encouraged to continue the treatment. Due to her HIV status, her aunt, who she is staying with also does not motivate her much and only perceives her as a burden and uses very negative words against her. Her access to hospital services is also affected by her aunt's interest as they need to travel to Namakkal. She is followed up by Nalam child development center and health status is monitored periodically by the volunteer staff of Nalam center.

Looking through the eyes of orphaned children living with HIV - Adherence to treatment and the reality

The importance of ARV adherence is known to all. There are many factors that affects one's treatment adherence and the free ARV programme has come as a boon for many especially the families that are economically poor and more so for children, especially orphans who are under the care of grandparents.

The Free ARV programme has been made available since 2004 in India and this has helped many to enjoy good health and even for children to be in families with good parental care and support. But there are a group of children who have been orphans or semi-orphans before 2004 and their condition has been very less explored.

The health status of the child is influenced by the child's knowledge level about treatment information, access to medication, social, psychological and nutritional status is a known fact and has come in many field researches and documents. But often times we fail to see whether these factors have been dealt effectively in order to facilitate better health of

children, especially children under the care of grandparents. For most of the grandparents, it is an additional responsibility and even perceived as a burden to take of children in their old age. Though the love and affection in the relationships exist, the expectations they have on children is leading to frustration and sometimes emotional burn outs that affects the treatment pattern of the child. Most of the children have expressed that they do not take medicines in such situations, which is quite disturbing. There are extreme conditions being observed where children have ran away because of lack of affection in the family.

Two boys in the age group of above 12 have left the village and one have been traced to be in Chennai working in a hotel for daily wages of Rs.50/-. This child is on ARV and has not been taking medicines since he has left the village. Though he has knowledge and also understands the importance of drug adherence, the family condition has affected his treatment condition. The other missing boy is yet to be traced. These are the few realities we find with a small group of 40 adolescent children living with HIV that we work intensively in Namakkal district, Tamilnadu.

This sets the importance of addressing the issues of children using a holistic model with children at the center of programming and policy making.

Annexure-2 OVC Policy Review Module by Children

Objective:

- ✓ To enable children to form a State level advocacy forum
- ✓ To enable children to understand child rights and existing policies and programmes in the context of issues affecting them.
- ✓ To facilitate a review of implementation of the Policy Framework for Children and AIDS within the purview of NACP III

Session details	Time
Introduction and getting to know each other	(60 min)
Introduction using double –wheel process In this all the participants need to count one, two then they are paired. Later ones and twos should stand in concentric circles and then at the sound of whistle .Each one should get their pairs and sit down. The last pair sitting down is out, while getting out they should introduce the other person and their interest/hobby.	20 min
Mime an interest In this activity the children should think about a hobby/activity, then should select and introduce with a name and the activity. Later the children should introduce each other using the hobby or activity. through this the entire group learn the names of each other	15 min
Sheet game: In this activity the group is divided into two groups and in between them they will be separated using a thick sheet. The two rows will line up and when the sheet comes down they have to tell each other name. The first groups that says the name is the winner and the loser joins the group. The longest remaining groups are the winners.	20 min
Setting up ground rules The participants are divided into two groups-green and orange. The two groups come together and develop ground rules in the form of a collage. Later both the groups come together and agree on common objectives for the group. As an acceptance to the ground rules, each child puts a thumb print on the chart in their respective green or orange colour. At the same time, the group will also work on one ground rule and present it to the larger group. With this	30 min

the session gets over. Then the facilitators present the objectives of the consultation and get a unanimous agreed plan for the consultation.	
Risk Assessment Using quiz method (fact and fiction and risk /non risk assessment) Session covering the basics-PWN+ representative	30 min
River of life Create two life instances one child affected by illness and the other one a normal child who is not affected by the illness. This can be shared in the form of river of life chart by the facilitator. Then ask the children in groups to identify the needs of the first and the second child.	40 min
Here time was given for children to understand what are children's rights And thereafter explain how many of these are 'needs' and how many are 'rights'. Explain why they are rights. Who is responsible for fulfilling these rights for these two children? Please explain the sequence of responsibility from parents to international agencies. You may do this creatively, divide them into two groups ask the participants to state the 'needs' of the two children in the form of drawings or slogans. Pick up the rights and explain why they are rights and what we should be doing as a children's forum to realize these rights.	20 min
Dream tree exercise: Divide the groups into two and ask them to think of all the problems children face due to their status, HIV affected child and HIV infected child. Then the problems are pasted on the trunk. The children work through a dream tree where they plot what will be the dreamed situation. One issue will be taken up by each group and will role play the situation and the dreamed condition they desire. Following this the rights of the child will be discussed and identify the rights that have been violated due to the status. Following this, as children what we can do as an advocacy group will be planned.	40 min

<p>The second questions could be what aspects of the Policy are not implemented well. Again opinions in writing without names./role play method</p> <p>Compile these opinions and prioritize them to form the Charter which will be presented to NACO during midterm review.</p>	
<p>Elephant and the blind men game will be handled</p> <p>Team building exercise: Building a tower with straws. Select few children to work on a tower individually and divide the rest into three small groups and ask them to build a tower. From this the need to work together by coming together is emphasized. Presentation on the principles of child participation.</p>	
<p>Group formation: After the above exercise you may now pose the question to the children as to who all would like to work for a forum which will be engaged in advocating for their rights with the government and other stakeholders.</p> <p>Here you may also ask each of them what they will contribute towards the activities of the forum. List the activities and prioritize them. Using may be diamond ranking method with inputs from the children.</p> <p>Now try to link each activity with the 'rights' that it will address.(examples)</p> <ol style="list-style-type: none"> Organising the meeting of members of the forum- right to participation of each child to be kept in mind. Holding a discussion on an issue- could be sensitive- with members of the forum-how to ensure that all relevant issues are brought forth- again participation principles and rights Wall paper campaign on health services, education services—advocate with teachers, community members- right of all affected children to access elementary education – now a fundamental right of all children; right of all children to access health services Team work planning for organizing a campaign; Development of a charter of recommendations for government – right to equal participation; right of say for every member; other related rights like right to health, education , protection etc. 	

- | | |
|--|--|
| e) Holding meetings of the forum in a safe place –
selection of the place based on right to safe
space and prevention of harm to any member
due to exposure of HIV status or other reasons. | |
|--|--|

Annexure-3 Report on the Orientation Session

Introduction to my journey of learning

The one month orientation programme was more of an eye opening experience from the so called focused approach to a holistic approach. This entire month was more of unlearning the knowledge I have gained in my work for the last 10 years to a community health approach. What lead me to this learning programme was the deep urge to know how to involve the community to address the issues around health and not looking at the affected or the community only at a beneficiary level.

Children affected by HIV and AIDS have always been my interest and through this programme I have gained a wider range of understanding on how to look at children's health in a community health perspective.

The key learning I have had in brief include, that there are various determinants to health and understanding those determinants and addressing them will enable the individual to enjoy health to his/her fullest potential.

Understanding oneself and the blind spot region according to Johari's window was a very enlightening one, as some qualities within ourselves may play a positive and negative role in our work and unless we know the negative qualities, we will not be able to work upon it.

The other major learning was on the holistic approach to health and how physical, mental, social, intellectual and spiritual influences an individual. The point that environment plays a vital role in the context of health was a very significant learning. On the whole the process of lecture, reading time, reflection time and field exposures helped us gain a lot on the total aspect on community health.

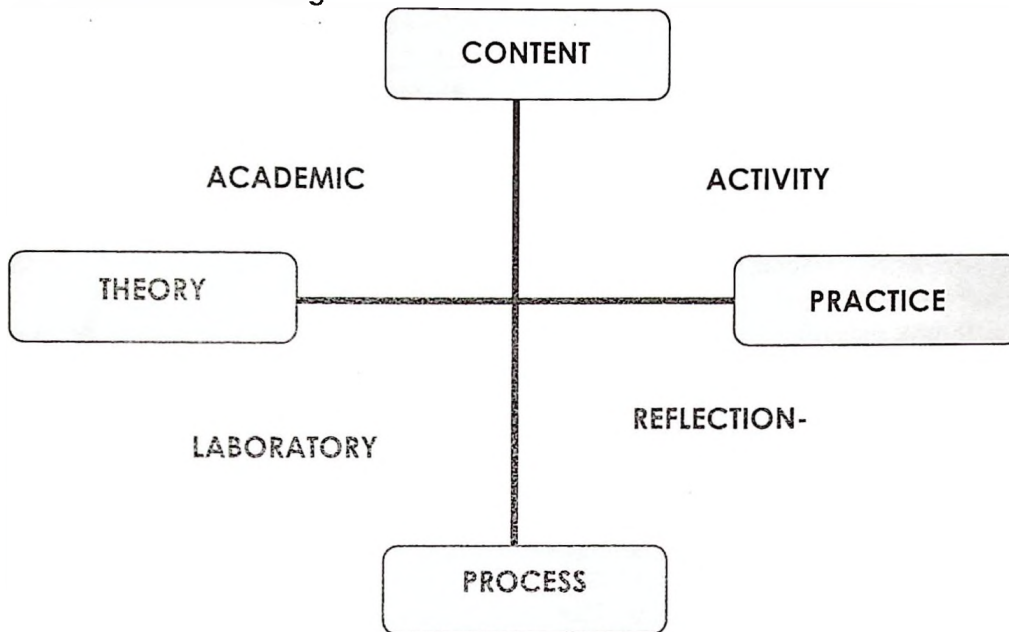
My personal reflections

First day was with fears and aspirations, one about my son and the other whether my expectation will be fulfilled in this training programme. The first day with round of introductions enabled an ice-breaking moment for me personally to learn about each other and the background they represent.

Following this through the **introduction of SOCHARA and the community health learning programme**, I even understood the diversified experiences that I would gain from being part of the programme. The unique nature of the programme that this whole programme not being academic but also gives importance to reflection was an enlightening one. The one aspect I hated about school system was the focus was more on academic and the toppers usually were the ones who had memorized the whole book word to word without understanding the meaning. So this kind of learning was something, I always desired and was very happy to be part of it.

This has also personally helped me to restructure my training process to include the framework of learning in my work with children at Namakkal district in Tamilnadu. This will also help me in my planning of curriculum in all activities that will involve some information-oriented sessions.

Framework of learning



The session on ***understanding health*** was one that really helped me to look back on the areas that I have forgotten to focus in my work with the community. The multi-dimensional aspect of health, complexity of various determinants to health and the concept of health as a human right, enabled me to understand the focus areas I need to do in my future work with children. Till that time, I was always thinking that providing the information on positive living was enough to encourage women to lead a healthy life. I sometimes used to wonder, in spite of all the counseling and information provided why women were not adhering to a healthy life style. But now in the session I realized the multi-dimensional aspect of health, like low income, lack of nutritious food etc, environment etc would have been the factors that I have failed to address in my work.

In addition, mere availability and accessibility alone cannot help an individual to enjoy good health, that his/her capability also plays a vital role in determining the health of the individual. *"I remember one child from middle-class family, who is living with HIV. Though medicines were available and even accessible, she was not adhering to the ARV treatment, which is very crucial for her health status. On enquiring she expressed that the size of the tablet affected her, as till that time, even children had to take adult dosages. Then with the efforts of Positive women Network and representation of children, the pediatric formulation was introduced. In some way this has benefited her. But there are children from the lower economic class who are not able to access and in addition further influenced by poverty that affects the individual's capability"*

The example of a TB patient not adhering to treatment due to poverty was another instance that helped me to reflect my own experience with women and children in the poor-socio-economic conditions.

The case studies on various situations helped me further to understand the various determinants and even environment plays a vital role in the health status of the individual.

From the session on right to health, I could associate the role of pressure groups. *Having associated with Positive women Network movement, the successes that they have been able to achieve in the right to health of women and children in treatment and care in government setting is one noteworthy example of pressure groups. For that moment I even had a sense of pride of my association with the strong advocacy network.* At the same time, the struggle that the organization now is experiencing troubled me the whole weekend.

SEPC analysis –Monsoon Game

This was the most interesting session of the whole programme, really enjoyed playing the role of a villager in a household. The entire sequence of activities remains fresh in my mind still. Through this activity I have been able to learn a lot of important things. Some of the most interest learning from this session, I would like to present are:

- In this session I learnt how the social, political and cultural factors play a vital role in the health status of the individual.
Eg. Though many programmes are available, but if this is not need based, it does not serve the purpose.
- It also helped me reflect my past experience, when I set an agenda with the field team to mobilize women for HIV education session; the number that would turn out is very less. This helped me realize that I had prioritized this as important, while the women had other pressing issues that affected them and HIV and AIDS was just another issue.
- Another important point was the acceptance of rules of the society, even if it discriminates one particular group. That was indeed a really shocking experience, as I have raised my voices against people discriminating against women and children affected by HIV and I this game I was part of discriminating the dalit family due to rules of the society.

In the same way, I realize I have actually accepted the norms that people in the lower caste are poor and educational qualities for them are limited. Sometimes when there were arguments on reservations, I used to wonder why there is a need for special category when their overall rating is low. I failed to realize that their achievements are out of the limited resources and opportunities they have had due to the social caste and class.

Understanding society

In this session I got a clear understanding on how caste, class and gender play a vital role in defining society. The simple exercise of taking a walk around the Koramangala area, helped us to realize how wider sections of people represent that particular area. It also helped me to realize how the social, political, cultural status affects people's representation in the society. With the inverse triangle a clear understanding of how 20% people enjoy 80% of the resources and 80% of the people have to struggle with 20% resources revealed the benefits enjoyed by the privileged group, while suppressing the marginalized. This privilege is affected by the caste, class and gender. This helped me realize how the society is stratified and any programmes that has to be initiated, should look into all these aspects, only then community health is comprehensive.

Looking inwards

A session to personally reflect into one's own self. Through the Johari's window I realized that there are four sections in us and we need to look at all the four areas to know more about ourselves. The different way of introducing ourselves with the other person introducing us, helped us to know how much more we need to know about each other. In addition sharing the negative aspects of oneself depends on the built trust one has about the group was another learning I had.

In this session though I was hesitant a bit to share my personal negative experience and I could later, because of the trust I have gained from the majority who stay with me in the hostel also learnt that to share one's positive's experience is so easy while the negative part is quite difficult. Soon after the session, when we sat together, we realized the need to know each other more to help each other learn the blind spot.

Alternative paradigm in community health

The session on paradigm and paradigm shift was truly an eye opening session. The need for paradigm shift was realized. The examples of the normal school system and ABL system was one that helped me understand the term better. Through the role play, it was further clear on what we expect in a paradigm shift. And through the paradigm shift the differences in approaches was very clear.

From the;
Medical model to social model,
Individual to community,
Patient to people,
Providing to enabling

With the case studies helped my understanding enhance better.

Skills and values needed for community health

In this session, it was so easy to list down all the skills and values, one need to have while doing community health. But with the screening of the movie of the doctors and Binayak sen, it made me realize, it is very easy to list down the values, especially like humility, commitment to the cause, but in practice it really needs lot of conviction. The documentary was very motivating and encouraging especially in my decision to work with the community in Namakkal district. I could personalize my own experience, with the doctors moving out from the comforts to a less comfort setting, and this really has motivated me to move into the community.

Historical overview of the health care system

The main points gathered from the session include, the functions of the system of health are service provision, resource generation, financing mechanisms and planning and monitoring. The history of the health system was traced from the industrial revolution, where the worker's ill-health caused a concern and forced the government to take responsibility and with that the public health system got evolved.

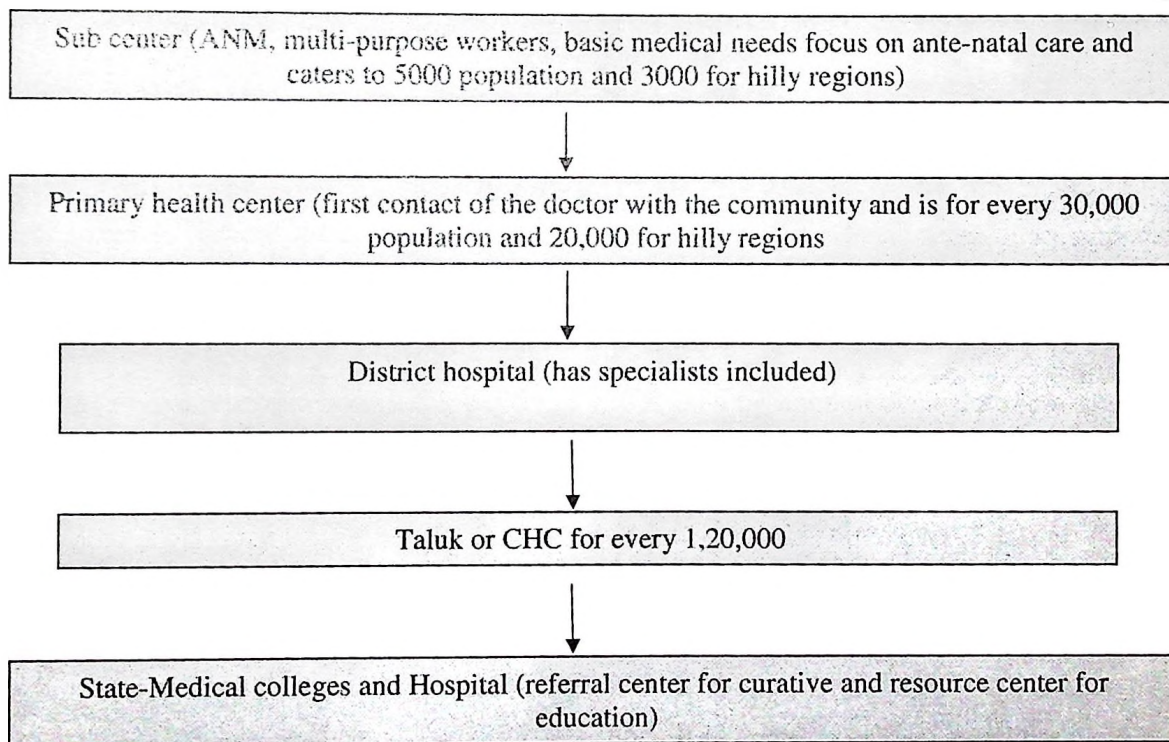
The three levels of care were also discussed. Primary level chiefly includes health education, basic services and preventive care. In the secondary level, includes infections that cannot be managed at the primary level like typhoid and pneumonia, are dealt and finally in the tertiary level, advanced treatment is catered. The four types of funding for

the health system are tax paid, social insurance, private insurance and user fees were also discussed. The public health system in India is chiefly tax based system, while in the private sector it is mostly user fees type.

Difference between the vertical programme and the comprehensive programme was discussed. Vertical programme means it has an independent structure top-down, while comprehensive programme is an integrated model was also discussed. For me personally this session helped me to realize the need for integrated approach in HIV and AIDS programme, which is currently not available.

Introduction to Public health system, structure and its function and public health approach

For me personally this session was quite interesting as looking into the public health system in detail was a great learning, especially in my work in Namakkal district. The learning from the session has been diagrammatically represented:



The department of AYUSH and its functions was a new learning. But in spite of the department being in place, the real functioning remains a question mark.

Learning about the various departments under health and that manufacturing of drugs was under the control of directorate of chemicals and fertilizers were a real shock to me. In addition as drugs are under this department, I learnt medicines are seen as a product for money. There is also less focus on the social pathology of the disease, like pollution, patents trade.

From the health system functioning, the role of ANM seems to be over taxing with additional data entry in the registers. The terms on health promotion as a step in developing the capacity /skill of the individual/community in dealing with the health status by creating facilities to come out of the status was a new dimension .Till now my understanding on health promotion was that providing information and making home visits. This explanation further broadens the aspect on community health.

The role of ASHA was learnt from the session. Though I have heard about the terms being mentioned in many programmes have not really gone through the process in detail. Now these also made me realize how much I need to explore and learn in the area of health system.

The session on looking at data, the difference between ratios, population rate was clearly understood. From this session, the various sources for data like the census, NFHS, sample registration system, National sample survey organization was learning for me. This also will definitely provide me some insights on how to look at the health status of children in the village that we intend to focus in our work.

Understanding the concept of primary health care

The slide presentation on Raku's story and from there understanding the role of primary health care was a clear representation .Through the presentation; it was almost a direct journey into a real village situation. I could personally relate to some of the beneficiaries I have met in remote areas of Namakkal district. It was a moving presentation and the major learning I have had from the session was looking at the various factors causing the death of the child and what best solution is needed to avoid such situations. Through this the concept of primary health care was learnt.

The key principles include, that the services should be universally accessible, technology should be appropriate, community participation, should be acceptable, affordable and co-ordination between various sectors and all the principles enabling social justice.

In this session, one thing that I would take in applying it in my future work is looking at the broader factors that affect the status of the individual and then bring in solution based on the principles of primary health care. On learning these principles I learnt that a comprehensive care has been well intended, but in reality this is not seen. With the increasing number of reported death due to diarrhea in our country, it shows where we are and what more changes we need to have in the existing system.

Discussion with Fr. Claude

A very enlightening interaction and the most captivated points during discussions were

- If we want to work in health-we need to be in touch with people
- The learning in community health is the same but the difference is it shows a broader view to the situation.
- The one who understands health is the one who listens to people
- Trust is essential in a work relationship
- Be optimistic and cultivate that spirit in the area of work

Session on Alma-ata

A very interesting session that brought in the concept of primary health care, though the declaration was made in 1973; the history has been traced since 1946 from the Bhore

committee. The key principles prepared then mentioned, is applied in the declaration. With the formation of UN in 1948, the definition on health was formulated.

Between 1948 and 1978, doctors and nurses were trying to understand the definition of health and later social workers and activists joined the movement. Later the Indian government passed in the parliament the national health policy in 1983 that included the components on primary health care. Later with the global crisis in 1993, focus of health was on the young people as they were productive. In addition health was seen as expenditure and not as an investment.

In 2000, WHO in its meeting even did not mention the Health for all by 2000 and failed to focus its discussions around it. With the civil society's participation in 2008, the focus on primary health care has been revived.

Major learning was that, though this primary health care was conceived in 1946 and later formulated as a declaration, yet the programmes have taken so long to be implemented. But with the community involvement and active advocacy positive changes have evolved. When there is active participation and involvement of the civil society, positive changes can be facilitated. For example the success of availing generic drugs through Treatment access campaign is a well learnt example.

The concept of primary health looks at a more integrated approach and previous experiences has shown how vertical programmes have not been successful and integrated programmes are effective. Yet HIV and AIDS is implemented using the vertical approach. Creating an entire new system and structure further complicates and people's access is also limited.

National Rural Health Mission

A session that I desired to learn and explore for my future work in Namakkal district, a vast programme with various structures and services included in facilitating better access for people in rural areas. The key points I gathered from the sessions include:

- Only 0.9% of the 5.2 % of the GDP of health sector is spent in public sector
- NRHM came into existence in 2005 and its approaches include community involvement, capacity building, flexible financing, human resource management, monitoring against milestones.
- After 2005, integration of departments of health and departments of family welfare along with vertical programme was made, except HIV and AIDS programme
- The role of community in the monitoring of the programme was the biggest advantage for the people.

Example from Tamilnadu on the community monitoring programme reinforced that the community's involvement plays a vital role in ensuring services for the community. This also has encouraged me to look at children's involvement in being part of community monitoring on services around child health.

Understanding Globalization and its effect on health

The session was very disturbing but a very enlightening session to know what globalization is and how it affects the individual's health status. My understanding from

the session on Globalization was it is a process of increasing inter-dependence, decreasing boundaries and reduces cost by distance. At the initial part, though it looks too good, but with more deeper understanding its influence on health was learnt. Through this with fewer boundaries each country becomes more interdependent and this affecting the poor making them poorer. Due to this, Developing country like India, due to loans from IMF and World Bank has to compromise on the country's priorities.

The session also made me feel guilty of how I have also been part of the exploitation, by purchasing goods, food stuffs from MNC's and Supermarkets due to personal convenience.

People's health movement role on Globalization and health

What interested me most in the session was the role of people's health movement and as a pressure group how they have ensured quality of health services to certain levels.

Gender and health

The exercise helped us personally to see how the various factors of being a girl or a woman are defined and how it affects the status of the woman. The factors discussed include low educational status, early marriage, and lack of mobility due to cultural restrictions, role of care taker affecting her access to health care, violence against women, economic dependence and disempowered status of the woman.

Following the discussions, we were asked to find solution to help women enjoy good health. Through the exercise we learnt how various factors are interlinked and how each factor plays a vital role resulting in the empowerment of women. Then through a matrix the life of woman in Rakku's story was analyzed and how different it was for different sex groups. The matrix component includes/gender norms or values/activities and access to control over resources.

Understanding Raichur district - prior to the visit

This session was to enable us understanding on what are the rural realities, especially Raichur district. We divided ourselves into groups and started looking at what was the condition of Raichur district. Through the group discussion, Raichur sex ratio in the age group of 0-6 yrs was 965/1000 in 1991 and 962/1000 in 2001, while for the total population 978 /1000 in 1991 and 980/1000 in 2001. In the Human development index was 0.399 and literacy rate was 34.3 .Both the data show Raichur was in the bottom lowest categories.

Learning about Raichur-Through exposure visit

Interaction with the JMS

Our first meeting was with JMS representatives, who shared the process of evolvement of their movement. The movement had its existence nine years before. It was attached to a school initially and now has moved separately. It initially started through home visits and through motivational songs that brought people together. Now currently they are 24 sangas.

The situation of dalit population was that they had to work only under Gowdas and mostly the women were in bonded labour. The group is exclusively women and started through small saving scheme. The savings scheme was one motivating factor as they felt the

need for education for children and treatment. This was from the experience, when in emergencies for educational and treatment support, they had to avail for loans and mostly they are delayed. The main objective of the sangam is to voice for the voiceless and to reach the unreached.

The dalits had to face extreme atrocities like not being allowed in temples, no job opportunities, and harassment of women. Though initially they brought in other caste groups, they were not interested to be part of the dalit movement, so JMS is now functioning exclusively for dalits. It was also noted that in the 42 sangas only 3 of them are educated. On asking the members of their experiences, there were instances where women had no encouragement from their family members at the initial stage. In the case of an old woman in her 60's, she was beaten up by her husband for attending the meeting. Later she along with 12 women complained against her husband. After the warning her husband had not resisted her attending the meetings. In another instance, the saving scheme pattern has motivated her and in turn has motivated many other women to be part of the movement. In addition, husband has been a support. There were few who also shared that family member's support has further enabled them to be part of the movement.

Some of the successes that they shared as part of JMS were:

- ❖ Demand of PDS shop with list of items and price list
- ❖ Training on herbal medicines has enabled them to treat health infection to an extent treating paralysis and skin problems
- ❖ Women's empowerment has been possible through maintaining accounts of the savings scheme

Session on herbal medicines

This unit was introduced as an initiative to empower dalit women for economic independence. This has been a 5 year long process of training. The various herbs and the process of preparation was explained to us. It was heartening to know that the skills of the dalit people have been pruned to earn a living for themselves and in addition, while treating complicated infection this has brought in a trust within the community.

I see this also facilitating de-stigmatising process against dalits. With economic independence the culturally discriminated women can be empowered. The major learning I identified was using the resources within the community and developing further enables sustenance of the programme.

Some of the struggles that they have represented in JMS

The major learning from the many instances quoted revealed that mostly dalits were oppressed and many rumors were created alongside to bring in conflicts.

One instance was that of a young woman from the nomad group who was raped. Though it was not brought to the immediate notice, women from the various sangas came together and protested against the rape incident. The strength of the collective was brought out through this and this created an awareness in the community of the dalit pressure group.

There were many instances of rumors of love affairs which were inter-caste and was used a strategy in creating conflicts.

Some of the issues they had expressed about discrimination of dalits were

- ❖ Differential treatment in the hospitals
- ❖ Verbal abuse by the staff at the hospital

Visits to villages and PHC's

A very interesting time of learning to see what the reality is when it comes to health access through the health system. First we visited the sub center in Maladaguda. The center health worker was staying in the same premises. The observation was that it caters to the population's health needs, but as stated the delivery area in the center was very shabby and not well maintained. As there is a provision for stay within the premises for the health worker, what was observed was the sub center reception area is more used for personal use. The health worker covers a population of 7918 and looks after ANC registration and even looks at immunization, TB and leprosy affected patients. She also is in charge of taking pregnant women to PHC after their 6 month.

Thorathini PHC

The center was very less represented, which was attributed to rains. The local transport on one side of the center is not available and people in that part have to look for private vehicles, for transportation. From the list, the beds were available and though the quarters are available for the staff, the doctors are not using it. The toilets are available, but very badly maintained. One surprising factor was that all the toilets were western closets in rural PHC's. The ambulance was not available and due to power failures the vaccines were transported to another PHC.

Meetings of the sangha members

Very charging group members narrated their experiences of being motivated by songs. Their main encouragement has been saving scheme and the uniformity across all the groups has been to support the children's education and meeting the hospital and treatment needs. They meet once in a week and for most of the members they see the sangam as only a saving group and not as a pressure group.

Meeting with the anganwadi teacher and ASHA worker

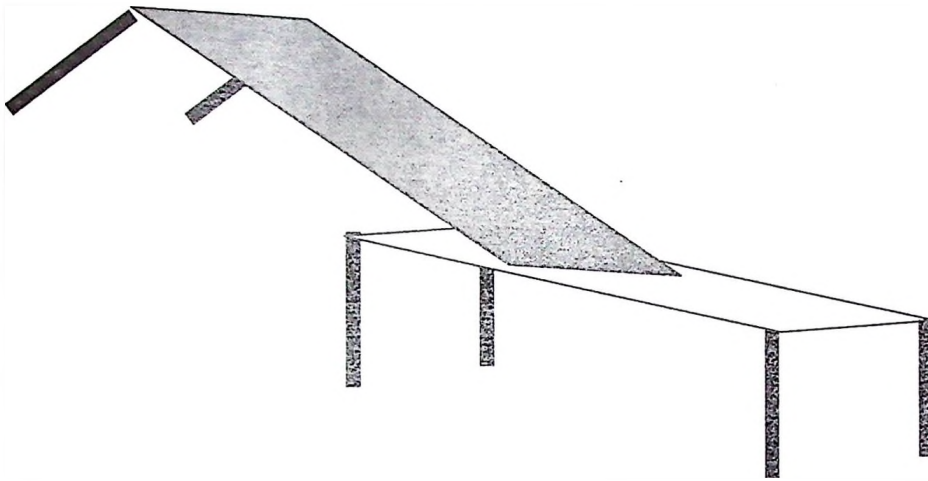
For the anganwadi teacher, as we met her in the place of the meeting, we could not probe and find much on the area and the type of work. From the interaction we understood, she assist the health worker with the follow-up of for ANC, in addition to looking after the anganwadi. She caters to 40 children for the age group between 0-5 years. She is aware of the schemes and has been able to encourage the community members in accessing the scheme. She is also a DOTS provider in the village.

ASHA: She was recruited very recently and had attended the 21 day training programme at raichur district. She looks after ANC accompanies the women for delivery to PHC. She is also a DOTS provider and looks after immunization schedule of the child. This ASHA worker has not been part of any village meetings.

PHC visit at Dhonaniridi

It was better than the previous PHC. The hospital was busy as they had the sterilization camp that day. Due to rains there was power failure and so immunization was not there. In addition though the sterilization camp was arranged the generator was not available. There were beds but not with sheets. The most shocking view was the sterilization unit,

which was made of two benches. One placed diagonally vertical over the other. Though the modern version of the cot was available, it was not used due to time consumption. What really hurt me was the women just 21 days after delivery had to undergo such inhumane treatment as they are available free of cost. The basic respect for the individual is lost due to lack of money.



The above illustration is the way the tables were set for sterilization process to be done in that PHC.

In both the PHC's the basic tests for pregnant women were not available, so for these tests, women in these villages have to travel to the taluk hospital for the tests. From interacting with the taluk medical officer, it was learnt that there are many vacancies, especially for specialized services. In places where they have not been able to recruit specialists like gynecologist and anestheologist they hire consultants from private and pay them separately.

One interesting factor was special incentive for ASHA workers catering to high risk pregnancies like High BP, late pregnancies and HIV included.

Interaction with the TB In charge officer revealed that there are few cases of MDRTB and no specialized services for MDR TB is available at districts but only at Bangalore hospital.

Visit to PDS

The PDS was totally under the control of the upper caste and is managed in the building of the co-operative society. The PDS caters to 5 villages which are about 8 to km away from the existing PDS. The list of items and the rates have not been displayed.

Chillipilli school

The main objective is that like children are like birds and they ought to free like them. Most of the children in the school were child labors that have been rescued and trained for a period and later put back to normal school education stream. This was started in 2000 and every 2 years they have been changing location, now in the current existing place it has been there for last 4 years. The training is more of activity based and song based. Every year about 50 children are collected from different parts of the district, trained and then integrated to normal schools.

One clear observation was that this exposure has encouraged many children involved in child labor to get back to school. This was found from 2 children sharing on how they are going to face when they return home. The successful experience shared by a girl in the first PUC was also an encouraging factor of the school.

Social boycott

A very depressing experience, though it was shared in the training session it did not affect me much personally, but visiting the place directly moved me so much. The basic facilities like transport, hotels and even flour mills that are under the control of the upper caste was completely in accessible for the dalits due to social boycott. This started with the establishment of Sub center, which was forcefully placed in the dalit people's colony over night. And when the people revolted they were beaten up and the houses and the cattle were severely damaged. The shocking thing was that they did not even spare pregnant woman, who was beaten up in that conflict situation.

Having seen the damaged houses and testimonies of people, the power of the upper class in exploiting the poor was clearly realized. What was even more shocking that this recent incident was only two months ago but there was no news coverage, which shows how media are also influenced by power and status. In spite of an enquiry and notice from the social welfare officer, there has been no response or action taken up by the taluk officer due to power of the upper caste.

Another unforgettable expression was from the women and a senior person from the village group expressing their gratitude to us for listening to their experiences. What motivated me was that the dalits all have come together to fight against this injustice. The collective action and the empowerment of women were also clearly revealed from the interaction.

Interaction with a representative from Navjeevan

Learned about the work they do among devadasi women. The common problems among children is school drop due to financial constraints and now with support from Infosys they have been able to facilitate support for children and also send them back to school. In addition they also support children for higher education. It has also been observed that when girls attend puberty they are dropped from school, so the agency has also been working on that issue. In instances of sharing on child marriage, the agency had shared experiences of stopping marriages by creating awareness on the rights of the child and the legal act against early /child marriages. They had quoted 4-5 successful interventions.

Community monitoring

The session was taken at the last, though the experiences would have been a useful learning, time was very less, learnt about how they had the village sanitation committee involved. The survey process was seen through the format under 11 categories. The successes through the community monitoring included:

- Anganwadi's workers duty has improved
- The gap in the utilization of untied fund since 2007 was identified due to lack of information
- Fast sanction of money through JSY was done.
- ASHA's role was redefined

- More people have been encouraged for institutional delivery
- 24/7 has been in place and 3 nurses have been placed on duty at PHC's

Understanding Mental health

The session was lead through an interactive mode. The question how do you define mental health and are we all mentally healthy helped us to realize it is the extent of coping mechanism and the period which defines the mental health status of the individual.

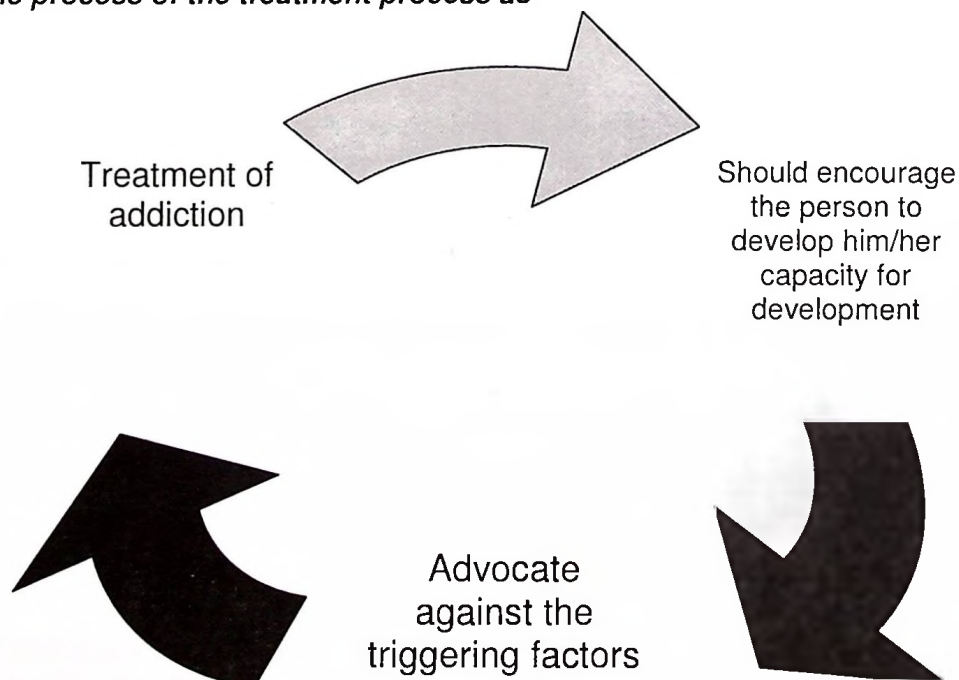
The new learning was the mentally affected people also have short attention and listening span. Realising this Basic needs looks at involving the individual in making decisions that affects and influences them.

The method of consulting the affected patient and the care takers in the treatment process showed the success rate of care of the individual. Sharing on how even the traditional healer can be used in treating possession syndrome was another area that was discussed.

Presentation through the slide helped us realize the hallucination is what is seen by the patient and the reaction to it is viewed as weird by people like us.

- *The terms that the care takers are wounded healers, so focus and support is essential was learning.*
- *Capacity building as a two way learning and if seen as a mutual resource enhancement was a very interesting aspect.*

The process of the treatment process as



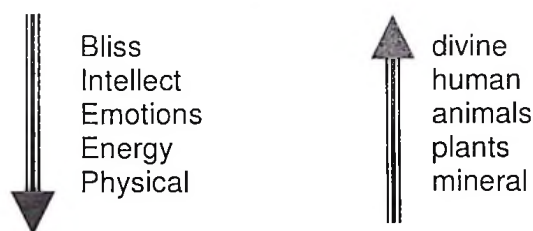
Alternative systems of health

A different experience from the usual discussion or presentation was the using cartoons to signify the message. How alternative systems of medicines have been suppressed by the allopathic medicines was beautifully depicted through cartoon. Then he explained why health was least focused as education and social welfare were seen as drains in the economy. He also expressed why AYUSH was not popular is because 5% of the total health care budget only was dedicated to this programme.

He also explained how the forms of medicines were originated and how the allopathy the alternative became a well established system. He also explained how allopathy is only treating the disease while the established system (AYUSH) is moving you towards health. He also explained the differences between AYUSH and allopathy as theories between

- Prana-breath-the concept of life energy
- Seed and soil concept-seed (disease) and so is the person. So the system of medicine increases the soil ability
- Holistic approach-both in diagnosis and treatment.

He also explained about the different koshas and how each plays a vital role and how it interacts with one another.



All human beings can reach the potential of divine hood but mostly we tend to stay on at the animal stage which is expression of emotions.

The direction of development should be from mineral to divine level and the holistic approach was defined in the following matrix

	Physical	Emotions	Intellectual	Social	Spiritual
Nutrition					
Protection					
Exercise					
Work					
Rest					
Environment					

Techniques in conducting training

The main aim for training is to bring about change. The three aspects we need to see while planning training knowledge, attitude and practice.

- Knowledge includes informing/sharing and unlearning
- Attitude includes emotional issue and is difficult and takes a longer time

- Practice includes demonstration/support and observation

He also explained on the consensus pattern and how consensus is reaching the highest achievement point.

Being active can be of two types reactive and proactive.

- Reactive takes a long time and will be conflictive
- Proactive –here you work on what you want and not what you do not want

The session was useful in further helping me to plan my work especially in the training process area.

Looking inwards-follow-up

In this it helped us to realize how much we need to look at working on the hidden area and blind spot to develop our potential.

The aspect of Transactional analysis was explained in detail. This helps us in understanding more of oneself. There are three characters within every individual i.e. parent, adult and child. The interaction between two persons is defined by the characters that we use and the person who interacts with us also takes it. Adult –adult relationship is the best form of interaction.

Then he also explained how the human brain has two parts and how the various characteristics are defined. The left part of the brain is masculine and the right part as feminine

Right (feminine)

Non-linear
Creative
Spiritual
Holistic
Perception
Imaginative/intuitive

Left (masculine)

linear
logical
scientific analysis
reductions
details-Goals/fact
assertive

Commercialization of the drug industry

The session was very useful in helping us understand how commercialization affects the poor in accessing better health services better. In addition he also explained the various multi-lateral instruments like GATT, WTO, TRIPS, Doha Round /declaration.

- ❖ WTO is an international body and defines how to trade between countries.
- ❖ GATT- is general agreement on tariffs and trade
- ❖ TRIPS-trade related intellectual property rights that give permission to produce generic drugs
- ❖ And patency, How India has signed and now patented drugs manufactured after 2005 cannot be produced
- ❖ In Doha declaration, how Africa was able to get the benefit of procuring drugs from India through compulsory licensing.

Group presentations on the plan of action

The training programme ended with different interns presenting the various plan of action. It was quite interesting to know the diversified areas that people are proposing to explore and learn.

Some reflection about the hostel stay

There were moments when I cried and was frustrated of the whole point of staying in the hostel. The food and the water triggered my emotions. But now when I look back, I realize that those things were small but it mattered to me a lot. The tough experiences we had at the hostel have made me more patient, tolerant and adjustable to any kind of circumstances. The transformation was so gradual, because in the initial stage, we were there to trouble Sukanya and all others in CHC with our complaints, but later as a team we found we have developed our own mechanisms to deal with the situations. So apart from all the learning on community health in the CHC premises, more of our own personality learning was done in the hostel. The problems and issues brought each one of us together and that bond has evolved into a wonderful relationship that would remain forever.

Application of the learning in my area of work

- The major learning from the orientation is on community health in a broader perspective.
- Understanding the various determinants to health which would enable me further in my programme plan and implementation
- Involving the community we intend to work with
- Have a broader look at the problem of the individual, even doing SEPC analysis on the community we intend to work with
- Developing a training plan will definitely help in planning my future trainings based on that.
- Looking at the care takers as wounded healers thus planning programmes for them also.
- Community monitoring same I intend in future to look at involving children

Conclusion

Overall the training package was very useful. Though it was for a month period, the inputs were so vital in unlearning the very facts I had in working with the community. It has also given me an interest to look at the NRHM programme in Namakkal district. Personally I intend to look at observing the learning from the training in the district I intend to work. The focus of work will also be in development of child health and involving children to actively participate in things that affect them.

As I step out of the orientation, I move on to learn more about community health from being in the community. As the Chinese proverb quotes, The best way for community health is:

*Go to the people, live with them
Love them
Learn from them
Start with what they know
Build upon what they have*

Annexure-4 Report on International People's Health University Course-2009, Bangalore

Dates: September 1st to 9th 2009

Purpose

- ❖ To have a deeper understanding on Health for All 2000
- ❖ To understanding the various approaches and initiatives towards struggle for health

Introduction

The IPHU course was more a refresher course in having a deeper understanding on the topics like primary health care, people's health movement, globalization and its impact on health. The new concept that was introduced during the course was conflict and health and the rights based approach.

The major learning during the short course has been presented below:

Neo-liberal globalization: The impact of globalization on health was that it increases inequity and further marginalizes people. Every child born in a developing country is with a debt of Rs. 5000 was a shocking revelation. The link between globalization and health, imposing rules and regulation through structural adjustment programmes was explained with examples. The introduction of WTO bringing in free trade, further affecting the developing country progress in health services was learning. Though there has been lot of gaps, the struggles by pressure groups like the treatment access campaign in facilitating in making generic drugs available to poorer countries through compulsory licensing was one that revealed the successful interventions for change. Successful experiences were from Brazil in bringing decentralization with the involvement of government and social movements and not heeded to pressures of the donor countries. The influence of globalization on agriculture resulting in rules on imports and exports affected the food supply in the developing country.

Technology in communicating health: It was an interesting session how graphics and tools can be used in depicting the magnanimity of the issue; this can be used as a strong advocacy tool.

PHM as a theory of social change: How PHM had evolved was taken through an action exercise in helping us understand. In simple terms that health is about equity and not equality, health is using appropriate technology, inter-sectoral and community participation. With that the session on the evolvement of PHM in facilitating health for all now was shared. In the discussion the interesting fact on how in the national TB programme the importance of nutrition was not stressed was quite shocking. The issues of doctors prescribing branded drugs, while the policy is there that doctors have to prove the quality of branded drugs are more effective than generic drugs was another strong learning

Social determinants and impact of neo-liberal globalization: Some of the key terms that were clarified in this session included:

- Inequity is about unequal distribution of resources between and within societies

- Improving health-creation of condition for people to lead healthy lives
- The drivers of health inequity are outside the health sector

And addressing inequity, the first step is to act at the immediate need of the inequity, the need to focus on the structural issue of the problem, the importance of inter-sectoral work.

Environment and health: The effect on environment on how it influences health was explained with the Bhopal gas tragedy, where even now children born now are affected with one infirmity or the other. The effect of pesticides that can kill the insect can also cause toxicity in human system. The example of experience of Kasargod people being affected by respiratory problem due to endosulfan poisoning that was used as a spray in cashew nut plantation was shocking revelation. But the successful step that the people had taken up in banning the use was an empowering experience.

Conflict and health: A new dimension to the health issue contributed by conflict was shared. Wars and other political system were usually perceived as conflicts, while even domestic violence, and family conflicts, environmental disasters also cause conflict was explained through participatory exercise.

Rights based approach: It was a very interesting session through case study method that provoked our minds to look at the health issue in the context of rights. Introduction to the various human rights instruments and the special conventions that focuses upon women, children were also shared.

Exposure visit to EveryChild: This was quite interesting experience, especially to see the focus of work among children. The rights based approach involved in encouraging child participation and engaging children with respect and dignity was reflected well in their activities. The networking and the advocacy role in ensuring the rights of child in Karnataka state revealed the long term efforts they had put in achieving a change. The mandate that the village panchayat meetings should have one meeting focusing on children was brought in through a network of organizations working on children and that clearly revealed consistent pressure can result in change. The establishment of neighborhood groups and how it has resulted in empowering children make major decisions were also shared.

Health rights approach: Major learning I have had in the session is right based approach tackles a longer time but the impact is sustainable. In this people take responsibility and fight for their concerns and issues. The difference between a service provision and the rights based approach was also clearly depicted through role play and also made us realize the importance of rights based approach in our own work settings.

Task group work: The group work was on facilitating representation of voices of children heard in the PHM movement through a pilot case study model in a village. The task group discussion was quite interesting and brought in a lot of insights from the diversified field that each member represented. Coming to a common consensus was stretched to almost two session, but once that was agreed the group got together to list down the process so well. The support and the various skills that each one had in even making the presentation like the role play, cartoon poster, preparation of the press release and power point was brought out through the task group.

Major learning

- The rights based approach in community health is consistent and takes a longer time
- Conflict as a determinant to health was a very new learning
- Engaging the community can result in a positive change, example of Kerala Kasargod experience in banning the use of insect spray in cashew plantation
- The presentation by Sant in facilitating better services in PHC through community participation and advocacy

What I liked most

- Almost all the presenters made the presentations very simple and case presentations and experiences from the field based on the topic presented made it more interesting
- The introduction of small group discussion after each topic also facilitated discussions and perceptions that each one had on the topic
- The participatory exercise made the presentations more interesting
- The new form of techniques in presenting feed back was one that I could also personally take it back in my field trainings
- The gender lens was another interesting part of the course
- The flexibility in the adaptation of sessions based on the review and feed back was also quite interesting.

Conclusion

On the whole the IPHU course could be said as refresher course in understanding community health approach and newer concepts on environment and health, conflict and health and experiences across the world, especially the role of PHM was more enlightening. This also helped me to have a deeper look and also review my own work in the field in a rights based approach mode.

Annexure-5 Court of Women on Violence Related to Dowry

27th and 28th July 2009, Christ College, Bangalore

Summary

The two day programme on the Court of women was a heart breaking but an eye opening process to realize the different forms of violence women experience in the context of dowry. This programme organized by Vimochana with support from other women organizations clearly revealed the need for better measures that protect women from being victims of violence. The court of women was held in two stages one a brief introduction to the forms of violence followed by round table discussions on various themes and the second part was presentation of various testimonies and recommendations from the jury on the situations presented. The process was quite challenging in triggering every individual's emotional level and also raising everybody's expectations for a change that empowers women to fight against violence.

Workshop proceedings

The workshop themes were of six types and included:

1. Reviewing dowry ,family, marriage in the context of post colonial societies and growing economic and cultural fundamentalism
2. Media reconstruction of violence ,identity, representations and autonomy
3. Reviewing legislation and alternative ways to justice in the context of responses to dowry and related forms of violence against women
4. Globalization and violence against women
5. Femicide: the role of science and medical technology
6. Resistance: The conference of the birds

The workshop I represented was the second theme Media reconstruction of violence, identity, representations and autonomy. The meeting was facilitated by Ms. Akhila from CFAR, the agency that monitors the programmes in television and print media in various contexts and includes depiction of women in media. The other facilitator was Ms. Anita Gurumurthy, IT for change.

Round table discussion

The deliberations of the meeting started with brainstorming on what media means to all of us? The discussion was initiated on advertisements and other forms of media portrayal of women. Almost all the activist agreed that media has lowered the status of women through its programmes, while the younger generation, mostly from the Christ College expressed that only positive messages were conveyed. The argument was quoting one horlicks advertisement which was perceived by the young students as an empowered status where she is portrayed in modern outfit and a multitasker ,while the activist expressed that it was a stereotypic portrayal as women as care takers of children. On a voting process on media as negative against women there was a majority vote from activist and media as a tool for change, only few voted for it. Following this the presenters made their presentations

- ❖ Bina paul and Sara Joseph from Chalachitra Academy
- ❖ Anita Gurumurthy-IT for change
- ❖ Namitha-outlook magazine

❖ Shangon Dasgupta-media

Key points gathered from the discussion

Media can make every news a commodity and for that they can indulge in undemocratic fashion.

Anushi from Kerala belonging to a dalit community joined a self financing college for engineering. But in the second semester she could not pay the fees and therefore committed suicide. But the news under the influence of an ex-minister was brought out as suicide due to love affair. Another case was that of a Shiney from Kootiam who was raped by six men and her minor brother who could not tolerate shot her dead. But the information that was brought out was that her brother killed her because of her illegal character.

All these case instances made me also reflect how sometimes as viewers we are not given the correct information and influences can use this as an opportunity for themselves. The facilitator also remarked that to know the correct information, it is essential to look at different newspapers or television channels and from the review the view can infer what is right. The jewelry advertisements are also contributing to dowry was a revelation, as the pictures or the scenes portrayed are the wedding occasions. The next topic was on the online campaign, especially the pink chaddi campaign that brought in a wide response. The campaign was against a minister who restricted socializing between young girls and boys. The draw back was that though it had a membership of 60,000, it got collapsed. So it was understood though online can be progressive it also has its own limitations. On the cinemas the presenter remarked that women's physical bodies are used as a playground without any message conveyed. Research study on media revealed that about 50 % coverage is on crime, entertainment and cricket. And in a span of 6 months survey of the 72 cases on crime, 32 were that of women. The crimes involving women are the mostly sensationalized. The discussion also centered that media has created a mind share in the community and hence working with them is important rather than antagonizing it. The strategies for working with media that was suggested in the discussions included:

- ✓ Consistent action with media
- ✓ Using state women commissioner as a monitor on violence against women report in the media
- ✓ Synergy of using different tools like online, print media, advertisements to cater to different groups

Testimonial presentations

The presentation was on different issues around dowry.

Violence of dowry murders: In this the mothers of victims shared their daughter's death due to dowry issues. The atrocities inflicted by the husband's family and in-laws were shared.

Changing forms of dowry violence: In this the sharing were related to direct and indirect ways to the growing practice of dowry. The harassment women faced due to giving broth to girl child, forced sex detection, increasing number of child marriage to pay dowry less etc were shared. In this there were a mix of both highly educated and illiterate

women, but what was common in their lives were harassment due to dowry. But one underlying factor was that all these women wanted to get back to their families in spite of experiencing violence in their marriage.

Dowry in the context of globalization: In this how the economic development invariably also affects women's status due to heavy demands in dowry was shared. What was so surprising was the increase in migration to earn more to meet the dowry demands, the government programme sumangali thittam which also indirectly supports giving dowry, though a prohibition act exists. Through the sumangali thittam young girls are exploited with hard work and are forced by parents to continue in spite of hardships. The increasing number of farmer suicides especially after a marriage in the family due to loans taken for marriage was another shocking fact.

Voices of resistance: This was the most powerful session. When the entire sessions depicted the disempowered status of women, the successful acts of women were shared. The increasing sensitivity not only at the individual but at the community level was also shared. A no dowry demand village in tamilnadu, Mahila panchayat, a woman who got her son in law and his parents put in imprisonment was some successful expressions of resistance to dowry.

Daughters of dreamtime: In this the jury shared their view points, some of the key highlights included:

- ✓ Strict administration of laws like dowry prohibition act and domestic violence act
- ✓ Advocacy towards bringing in women's representations at all levels
- ✓ Sensitizing the role of nurturer among men from younger age group so as to ensure gender balance

Personal learning

- ✓ It was a revelation that the dowry issue can be seen at various forms and is prevalent across every class and caste level.
- ✓ Even government schemes affect the status of women-Sumangali thittam- has contributed to further exploitation of women
- ✓ Media plays a contributory role in the demand for dowry.
- ✓ Media can also sensationalize news that can harm the affected individual

Learning and my application to the field

- ✓ Through this exposure I learnt even children; especially girls experience the effects of dowry violence.
- ✓ Advocacy materials like puppet display of different instances and a wedding invite that conveyed the message of dowry death was another shocking at the same time revealing the creativity in conveying message to the public.
- ✓ The court of women in bringing out issues and even facilitating sharing revealed the ground work that has been done by various agencies in advocating for any issue. In the same way, any advocacy that will be taken up in the work will be through an action research for better response.
- ✓ The music and poems also was a strong conveyer of messages

Conclusion

The two day exposure to the court of women was shocking, depressing at the same time a learning time in understanding issues in the context of dowry violence. Fighting against violence needs great courage and with support women can be empowered do so and the open sharing of women revealed that fact. Another fact is that, with regard to community health all aspects have to be understood to work effectively. Especially understanding the various networks that enable and empower women also need to be explored for referrals and support in the area of work.

Annexure-6 Photos from the Field



Orientation
Program

Raichur Visit





Capacity Building

**Art Therapy
Workshop**

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Interactions with
Children

**Elanagar
Community children**



Interactions with
Children

**Children of Nalam
Center Namakkal**

Annexure-7 Reference

Findings of Study done in UK

HIV and children

Thanks to effective HIV treatment, most children with HIV in the UK are now entering their teenage years and adulthood.

Although research on younger children has shown that there are often developmental and cognitive problems, there has been little research into whether having HIV has an adverse effect on the educational development of older children and adolescents. A recent study in New York suggests that young people born to women with HIV are doing less well at school, and have poor reading and language skills.

In addition to HIV, there was other factors likely to affect these young people's educational attainment – most of them were from migrant or other minority racial and ethnic communities, and many lived in areas with under-performing schools. Missing a lot of school because of ill health also contributed, as did having been exposed to illicit drugs in the womb.

However, when the researchers took these factors into account, they found that HIV-positive children had poorer word recognition and writing skills, and that children on HIV treatment did less well than those not on treatment. Children who were HIV-negative, but had been exposed to HIV before birth, did better than the HIV-positive children but less well than would be expected for their age.

The researchers therefore highlighted the importance of providing educational programmes to address the needs of these young people.

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Community Health Learning Programme is the second phase
of the Community Health Fellowship Scheme
and is supported by
the Sir Ratan Tata Trust, Mumbai



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