A journey through the wisdom in community health

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This report is dedicated
to millions of children living with HIV and
children orphaned by HIV AIDS around the world…

Acknowledgments

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Overall, I am thankful for all the resource people, the CHC team worked hard to bring them to share their experiences with nine of our fellows. Such a rich experience sharing and wisdom is difficult to get even if one is ready to spend any amount of resources.

Another learning experience by observation is the staffs of CHC; truly I saw an invisible structure without any hierarchy. I would sincerely thank all the staff at CHC who helped me fell friendly and comfortable during the course of the learning programme.

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Things that really disturbs me…

The HIV and AIDS epidemic has a long wave length and the limited number of people accessing ART in India means the impact of orphan hood due to AIDS will be an ongoing burden. It is important to note that AIDS orphans reflect the history of the epidemic; therefore health and social support structures must be in place to accommodate any projected impact.

An overview of the most recent estimated numbers of children affected by HIV and AIDS in India suggests

- *150,000 children were infected vertically,*
- *1,500,000 orphaned due to AIDS and*
- *7,000,000 with HIV positive parents.*
- *220,000 children currently living with HIV*
- *Over 50,000 children born HIV every year*[1]

More detailed estimates have not been attempted as the country does not have a national generalised epidemic. However, the vast population size and prolonged nature of Orphans and Vulnerable Children (OVC) issues means that its true impact is widely felt and its scope significant. UNICEF has documented that the estimated total number of orphans, due to all causes across India (2005) was in the region of 25,700,000. A fair approximation of number of orphans due to HIV and AIDS equates to 6% of orphans as a result of AIDS.

This serves as a reflection of the countries status and the challenge posed from children directly and indirectly affected by HIV and AIDS. Importantly, the number of 'vulnerable children' to HIV and AIDS is deemed so vast, amounting to tens of millions, that previous studies have found it difficult to incorporate this group into any meaningful research.

Over these emerging issues among children orphaned by HIV AIDS epidemic, the role of Government and civil society organizations were so much limited in providing just the ARV therapy, nutrition and education. Unfortunately, the under mentioned issues were neglected and often not considered by Government and the NGOs implementing programmes for children affected by HIV and AIDS.

Some of the important issues that affect orphans and vulnerable children includes

- Sexual abuse
- Child laborers
- Sickness and burden of drugs and treatment
- Discrimination (school, family & community)
- Early marriages of girl children of positive parents
- Deprived on joy of child hood
- No social security

[1] Richard Matthew Lee, UNAIDS, September 2008 – Orphans and Vulnerable Children - Research Study

- Fostered children as domestic workers
- …….and the list goes on and on

These concerns made me to firmly decide to dedicate my life in supporting and empowering children affected and orphaned by HIV and AIDS. Support the children and make their voices are heard by various stakeholders and Government working for them and with them in the fight against HIV.

What inspired me to join CHLP?

The information given above is the major reason for me to live. In 2001, personally I made a strong commitment to support children affected by HIV AIDS in India to the best possible means and ways.

I was then a business man along with my brother and my friends, but I decided to quit myself from the business and pursued MS (NGO) management. I completed my degree and landed up with a job in Rural Innovations Network.

Though I was working with RIN, deep in my heart my desire was to support children. I started visiting many websites related to children and HIV AIDS, learnt the burden of HIV AIDS upon children and child headed families. In my self interest, I started subscribing A to Z of all publications, brochures and booklets from national and international organizations that work on HIV AIDS through the sites I visit on the web. I started receiving parcels over parcels all on HIV AIDS to my residence address. My father and mother started to stare at me, what's happening to my son? Why such an interest for him on HIV AIDS all of a sudden?, but they never questioned me or talked with me about it.

After around 18 months of working with Rural Innovations Network, I gave up and decided to volunteer with Indian Network for People living with HIV AIDS (INP+) in Chennai. I got to know about INP+ through my well wisher and mentor for life Mr. Jacob Varghese. Only then I started focusing myself and started understanding lives of friends living with HIV AIDS and about their families. I got my Job with INP+ as a miracle. It is definitely a miracle because a national organization giving the position of Project Manager to me with no health or medical background nor prior experience on HIV AIDS. And that "Positive Living Center" project is the first pilot project at grass root level for INP+.

Positive Living center is a comprehensive project that aims to address prevention, treatment and care and support needs of people living with HIV and their families in the HIV high prevalent district Namakkal by establishing taluk level centers.

It was there through this project in Namakkal; I started witnessing with my own eyes and started experiencing the lives of children living with HIV and those families situation of hopelessness and bleak future of their children. I started realizing there are so many other issues beyond the scope of the project that made me to get passionate about working with children affected by HIV AIDS. Later I joined World Vision India and then PWN+, whenever and wherever possible I started pushing the agenda of children in to organizations that I came in touch with.

Though there is passion, experience of working with people living with HIV groups and families at the grass root level, I still felt there is something missing in me that I need to learn. I found the gap and linkage between HIV AIDS programs by government and the

public health system on one hand; on the other hand, with so much of resources and effort put on targeted interventions and prevention programs the prevalence rate is always on the rise.

It was then, I strongly felt the urge to learn from experts in public health and improve my skills and knowledge when I wanted to do engage directly at the field level. And that led me to apply for CHLP which helped me exactly at the time of burning out on my job.

My expressions of 5 week Orientation program of CHLP at CHC

Personally, the 5 week break from my regular work and commitments waived away the burn-out situation I was facing in my work life. I sincerely thank the members of interview panel for having mercy on me to select and enabled me to have this break.

- **Inner Change.** The 5 weeks were not just about knowledge, but more about an inner change. I am a witness, right from day one, when I was observing each facilitators and staff, I could experience and learn the humbleness and ready to serve attitude to every one of us. I was moved by this, and am in the process of adapting myself to that kind of character
- **Availability.** I would like to thank from my heart on the availability of each facilitator, coordinators and staff to clarify our doubts ranging from silly to tough ones. I was so glad, when everyone openly agreed that all are in confusion like me in addressing the public health situation in India.
- **Learning. Learning. Learning.** Introduction of participants and facilitators, Introduction of each fellows to new facilitators, going around the departments in CHC, games and sessions at CHLP, field visits at Hanur, Hospet and Raichur, meeting activists, professionals, staying at Holy Cross convent, discussions and chat with fellows were all packed with LEARNING LEARNING LEARNING. Glad to be part of this type of orientation.
- **Remembering Names and Books.** I was overwhelmed by the way Dr. Ravi, Dr. Thelma, Dr. Rakhal, Mr. Premdoss, Dr. Sukanya and other facilitators mention names of people and names of books and authors. I felt am so weak in my memory as I couldn't even remember some of my classmates names in school and college.
- **Commitment with Community.** Every one including the fellows with me expressed their commitment to the community. Often we are taken up by the systems and work pressure, but one thing I learnt very strongly is that everyone has a deeper meaningful commitment and passion for the community.
- **Seeing is Believing.** It was all knowledge when we listened to stories and situations in the training hall, but all that knowledge transformed to experience when we had our field visits. It breaks our heart and increases the commitment and passion when we face the realities of lives of the oppressed and challenges they face in life.
- **Inputs from Experts.** It is impossible to get inputs from all top experts in different areas of health. CHLP breaks that and made it possible to get expert people to provide inputs to the fellows. And the most exciting thing is that all of the experts can be met in one point (CHC) and all of them are part of People's Health Movement (PHM). I am glad that I am now part of such a great movement for People's Health.

My objectives for the 9 months Community Health Learning Program

1. To learn various intervention model programs from selected NGOs and Activists working on children issues on a rights-based approach
2. To network with many Govt and Non-Govt organisations working on children issues
3. To understand and analyse Orphans and Vulnerable Children (OVC) policy for India and compare on program implementation at state and national level
4. To develop a child-friendly story-booklet on community health approach for children
5. Build a resource library of books, reports and publications related to various children programs including HIV AIDS that would help organisations and people who work with children and HIV AIDS

In order to continually work on these issues, I also understand I need to learn and sharpen some skills with in myself. To improve on my personal skills;

- in developing position/status papers of Govt Programs
- in writing to journals and understanding national and international journals
- on creating cartoons for social issues
- Learn 'epi-info' software and analytical skills

Things to focus on my three month final project is

- to review the Orphans and Vulnerable Children (OVC) policy
- develop status/position papers as an evidence for collective advocacy
- To form an Advocacy Collective of Individuals and Organisations concerned on children affected by HIV AIDS
- To document Govt Schemes and Programs aimed at children at Tamilnadu and Kerala state level and National level
- To share the document with National and State level organisations working with children and HIV AIDS

What I did in the past 9 months in line with the objectives set

To learn various intervention model programs from selected NGOs and Activists working on children issues on a rights-based approach

THE School

Dr. Suchitra, a humble, committed person in improving the lives of children through THE School, Krishnan Foundation in Chennai. Thanks to Dr. Rakhal for introducing this person to me in the fellowship. She has tremendous experience of over 13 years working in the areas of child counseling, child participation and more specifically in child to child approaches in the area of health.

I met her only once, but she made the meeting so wonderful that I felt as if I have known her for years. In spite of her daughter's ill health, she spent over two hours early in the morning sharing all her experiences and guiding me through my areas of interest.

One more interesting thing I learnt is about THE school. The philosophy of children's education and growth happening close to the nature, another interesting thing was that till 8th standard there is no marks and grades in this school. Children are given freedom of expression and to walk in truth in the pathless world.

One of the strong points that came from this expert is that life skills education as a stand alone intervention cannot address children's needs or issues. When our discussion started focusing on engaging children affected by HIV AIDS to support other children affected by HIV AIDS in a community, she shared her insight on child to child approaches that she does among govt school children in selected villages near Chennai.

Learn – Do – Teach is the principle behind developing children to encourage other children. She also assured that she will be able to support in developing practical day to day life needs training module for children that includes SKILL – Reflective Components – Evocative Exercises. In her experience, she explained that life skills education as a stand alone exercise may not help children in difficult circumstances.

The key learning that I take from THE School is the Child to Child approach. It is a practical approach that empowers children and enables them to prove their ability to convey any type of message to their peers. I believe it is a vital component in addressing concerns of children affected by HIV and AIDS.

Balamandir

On July 11th 2008, I had a meeting with Dr. Maya Gaitonde at Balamandir. She and her colleagues shared that "Sometimes care homes are luxury for children that are with fan, light and access to good water". The reason for their statement is that children in the home, when they go back to their residences during long holidays couldn't adjust to live

in the community. They look down on their widow and destitute mother and decide to come back to the home even before the holidays gets over. At Balamandir, there is network developed among parents to share the development of children both in terms of education, moral values and behaviours. Balamandir, a highly respected organization in Chennai is over 25 years old with rich experience of supporting thousands of children and their families.

My key learning from Balamandir, is the relationship building among the parents and participation in development of the children. Understanding parents' expectations and behaviors of children is so important to build families and communities with values.

Santhosh Siruvar Maiyam, Melur

In the month of August 18th to 22nd**,** I spent 5 days in Melur Taluk, Madurai Dist, understanding more about the project goals, staffs who are women living with HIV themselves except a social worker and was able to observe some of the issues in the taluk related to the work on HIV and its impact on children.

The project has reached to more than 180 children and support services facilitated through the project has encouraged positive living among children affected by HIV. This comprehensive model has also facilitated positive response from the local authorities and stakeholders towards support for children affected by HIV. It focuses more in facilitating access to essential services like education, treatment and social welfare.

Santhosh Siruvar Maiyam is a child-focussed center in Melur Taluk of Madurai district in tamilnadu. This center is initiated by Positive Women Network (PWN+) with the support of UNICEF with a goal to have sustained the comprehensive community and home based care model program "Santhosh Siruvar mayam" for children affected by HIV in Madurai district.

The Goal of the project is,

> ***To have sustained the comprehensive community and home based care model program "Santhosh Siruvar mayam" for children affected by HIV in Madurai district by strengthening Madurai District PWN+.***

Major Activities of the project are;

Formation and strengthening Community based Childcare Committee

In order to strengthen the community response to the issues affecting children, the community based advocacy team from the "*Community based Childcare Committee"* were formed comprising local panchayat leaders, religious leaders, SHG leaders, school authorities, children and parents, including affected families, in two villages and one committee at the taluk level.

In their previous phase, the experiences have revealed that women and children are not comfortable to reveal their status to their community members due to fear of being discriminated by formation of children advisory committee at the village level for children affected by HIV. So in this phase it has been proposed that the committee will be formed to focus on issues that affect all children, like education, health and later HIV will be included as one component. Simultaneously sensitization programmes and information sharing on HIV/AIDS will be organized for all the members of this committee which will be facilitated by the WLHAs and some of the members of the "*Community based Childcare Committee"* in that area. "*Community based Childcare Committee"* will meet once in a quarter to address the needs of children identified by the committee. This will be done by networking with the relevant departments working in the region.

At the Melur Taluk level and village level where ever child care committee is formed, comics campaign by children were planned to be organized where children will make comics on existing issues and will campaign at the taluk level to encourage debates and discussions among the audience to create a supportive environment for Children affected by HIV/AIDS.

Support for formal education and nutrition of the children in the community

There is a direct support of education support for 100 children and 50 children for nutrition which is continuing now and expected to do till end of the project. During this phase, Santhosh Siruvar Maiyam and the Madurai District level PWN+ have planned to focus more in generating support from the community and other donors and NGOs locally to sustain these efforts. In this phase efforts were made to source private sponsors to ensure that the educational support facilitated through the project will last till the child completes a certain minimum level of education. The project is also focusing to advocate with the district authorities to prioritise support to children from poor affected families for educational support (under the schemes that are currently being implemented).

Nutritional provisions under the ICDS and mid day meal scheme are to be ensured for all children as identified above through advocacy and sensitization of stakeholders like local leaders/religious leaders/teachers and community workers like Anganwadi workers under the government scheme. But the field workers are finding it tough to negotiate with certain staffs of ICDS and other government schemes.

Medical care referrals and linkages

Networking and linkages with the district medical hospitals and care centers are strengthened to facilitate better care and support services for children who are in need of specialized care and treatment. A Qualitative Survey done by UNICEF in four villages of Melur block, has also listed several government schemes that would benefit women and children, these schemes would be made accessible in this phase by the outreach workers and the volunteers.

The total number of affected families that have been reached through the program are around 120 (with 180 children) from various blocks and villages of Melur Taluk. Many women were willing to volunteer their time and share the information to other affected members in their own community. Hence these women were recruited as volunteers in the community and supported by the outreach workers. Volunteers were encouraged through training programs, gifts and honorarium to support more children access schemes from government.

Organizing Peer group meetings at the center

Peer group meetings are organized for children who are affected by HIV within the age limit of 0-8 years. This is organized at the center in Melur. In order to prevent the center being identified as center only for HIV AIDS affected children, community children were also provided with services in areas of health checkup, life skills education and educational support. Around 50 community children benefited through these programs.

There have been no specific programmes enabling these children cope with the infection. In this phase, peer group meetings were planned in order to encourage support among them and also provide information on positive living. This is organized on a monthly basis for children between the age group of 8-11 years and 12-15 years.

Life skills education

Two groups of children were formed at the village level with representation of children also from the general community. Each group has around 15-20 children and between the ages of 12-14 years. The Life skills tool kit developed by FHI is used and the LSE meetings are organized twice a month.

Building awareness and capacity building of parents and caregivers of children orphaned by HIV in the district

In order to increase the awareness for the parents on HIV; sensitization cum training workshops are conducted especially to increase the capacities of the affected families to help the child in coping with the situation, in accessing the services and also in accessing the entitlements for the children and future planning for orphan children. Support was also taken from legal aid centers and professionals to arrive at the right form of succession planning for these children, which is relevant and applicable in each state.

Special support group meetings are organized for mothers to encourage disclosure within families, promote treatment adherence and better care services for children who are on ARV treatment.

Taluk and District Level Advocacy on CAHA issues

Advocacy meetings are organized at Melur taluk and Madurai district to advocate for the issues of the children affected by HIV. These activities are in the plan but yet to be done. At the taluk level, 30 members will be invited with representations from the local administration, school authorities; self help groups. Two meetings are under the plan to be organized in this phase and these meetings will be organized to coincide with prominent days listed below.

At the district level, around 50 members will be participating in the advocacy meeting to advocate for the issues. One meeting will be organized at the end of the year. Sensitisation programs will be conducted also on other prominent days like:

- Children's Day
- World Aids Day
- Women's day
- Candle light memorial

Organising mothers as self-help groups and access resources from Tamilnadu women development corporation

One of the pressing needs of Women living with HIV is the economic support, women's health and their children's health are deteriorated due to lack of money towards basic livelihood. Hence to promote health of children and their mothers, self help groups are planned to be formed. Self-help group formation training and maintenance of books and accounts, opening up bank accounts and accessing revolving fund and economic development fund for businesses were planned in near future.

Mobilising women as volunteers

It was widely accepted and observed that Women living with HIV when given some responsibility as a job and provided with guidance, it helps them in building confidence for their life. Volunteers were selected from selected village to work for the community based programs, these volunteers are supported by each outreach workers to help them access remote villages and also in organizing community based programs.

In my experience on those days at Melur, I observed that people at all levels have some knowledge of HIV AIDS but the issue is the sensitivity to the issue. In an instance, the headmaster of a government school publicly pointed out an orphan child studying in his school saying "your parents died of AIDS", when the boy was trying to hide that fact and trying to live as normal as other children, such instances create mental stress and loneliness among children.

While I was interacting with the staffs there, mothers living with HIV who are unknown to me, shed their tears and share their concerns to me of how their children are ill-treated in orphanages, “If my child is tortured when I am alive, what would be the condition when I die”.

Her issue is that her boy child, who is tested positive got admission in a orphanage home that is run exclusively for HIV positive children 70 kms away from her residence. Her child, came back to her home once when she visited the orphanage to see her son. The boy cried and shared how he was beaten and ill-treated for some mischief he did. Orphanages are started with good intentions, but as the days go by many do not adhere to the initial interest and care.

Another fact that I observed and sometimes shared is that women who work as (including WLHA) field level workers lose the drive to actively reach out and support children after witnessing problems over problems that are unanswered. Staff shared sometimes we feel that we are just reaching out to more children but the situation is not much changed except for the hope that there are people and a center to care for those affected by HIV AIDS.

Over all this, the government staffs who work as Integrated counseling and testing center (ICTC) Counselors, harass women living with HIV mentally and sexually. Some women living with HIV shared that because we are HIV positive the men in the society always look at us only as bad women and they don’t hesitate to approach us with a thought we should be female sex workers. The stigma and understanding of the community need to change first for us to live a life with dignity.

On day 4 of my visit, there was a support group meeting for mothers of children affected by HIV AIDS, almost all of the mother’s care is about marriage of their sons and daughters. Though their son is HIV positive or not, they want to see their weddings before they die. There are many child marriages happening among families affected by HIV AIDS in Madurai as well as in other high prevalent districts. Sometimes, though the children are negative their parent’s HIV status stands as a sign of shame that stops their weddings. In a village, three orphan girls at 19, 16 and 14 are taken care by their uncle. This kind and good hearted man, wanted to get the eldest girl child to get married, but when the boy’s family got to know the status of the dead parents of that child through a local community member, the wedding was stopped.

Another important matter that the mothers were curious is about the when will the drug will come that will cure HIV. They also expressed how they could get updated on the progress of such researches?

Bangalore Orphans and Vulnerable Children Project
World Vision India

World Vision India has a focused project among orphans and vulnerable children in the city of Bangalore at three target wards. It was perfectly a community based approach where the children from the community were also involved in the project though the project by itself sounds to OVC and Children affected by HIV AIDS.

The Project Goal is to *"Mitigate the impact of HIV and AIDS among the OVC aged 0 to 18 yrs in Bangalore city."* With the following outcome objectives.

Outcome 1: Reduce vulnerability to HIV among OVC aged 0 -18 yrs
Outcome 2: Utilization of care and support services to OVC and PLHIV.
Outcome 3: Reduce stigma and discrimination towards PLHIV and OVC

The UNAIDS working group on definitions[2] has defined the term orphan to refer to a *"Child below the age of 18 who has lost one or both parents or lives in a household with an adult death (age 18-59 years) in past 12 months or is living outside of family care.[3]"* The concept of vulnerability is a complex construct and may include children who are destitute from caused other than AIDS.

World Vision defines
Orphans as children below 18 years of age who have lost a mother, a father, or both parents to any cause[4].

Vulnerable children are: Children whose parents are chronically ill. These children are often even more vulnerable than orphans because they are coping with the psychosocial burden of watching a parent wither and the economic burdens of reduced household productivity and income and increased health care expenses

Children living in households that have taken in orphans. When a household absorbs orphans, existing household resources must be spread more thinly among all children in the household.

Other children the community identifies as most vulnerable, using criteria developed jointly by the community and World Vision staff. One of the critical criteria will be the poverty level of the household. In South Asia, these children may include children in

[2] Report on the Technical Consultation on Indicators Development for Children Orphaned and Made Vulnerable by HIV/AIDS, Gaborone, 2-4 April 2003
[3] Children living outside of family care are taken to include: homeless-street children; children in institutions; and children living in other country specific settings such as on commercial farms, in brothels, in mining areas, in the military forces, etc.
[4] ADP Toolkit for HIV/AIDS Programming – South Asia Edition, 2005

extremely difficult circumstances, such as street children, child labourers, and the children of sex workers.

Prevention efforts were more focused with the children in the community including orphans and vulnerable children. The various methods used under prevention strategy included recreation, exposure visits, PPTCT, *Life Skills Education*, community awareness programs among women, youth and school children. During the project period, over 14000 community members were reached through various prevention activities mentioned above.

During my visit, in one of the children's group meeting, there were discussions on how Life Skills Education has helped them?. It was observed that children not just at knowledge level but also have skills to prevent abuse, stress and HIV through life skills education. Children have learnt to utilize their skills very positively and their attitudes towards people living with HIV and their children were very positive and welcoming.

When asked about what benefits they see being part of LSE group?, Children expressed

"We learnt we are able and equipped to solve some of our problems"
"We can protect ourselves from abuse and HIV"
"We learnt we need to think alternatives before we make decisions"
"Initially we thought HIV and AIDS are same, but now we know the difference and will also care for those affected by HIV AIDS"
"We learnt Communication skills and skills to cope up with emotions and now we are self confident…"

Some of the key project components that I observed and understood are;

Drop-In Centers
Drop In Centers located in Sriramapuram and Flower garden were providing services for 565 orphans and vulnerable children that includes both children living with HIV and children affected by HIV AIDS and 375 parents living with HIV. Drop in Centers have helped the team as well as the community to be in regular touch which facilitated not just in providing services but also in sensitizing the community on HIV AIDS and to provide a supportive environment for families living with HIV AIDS in the project sites.

Counseling
Counseling and follow up services were provided effectively at the Drop-In Centers by counselor and community volunteers. The decision to select people living with HIV as community volunteers, selection and roles were well defined that has helped staff to reach out to over 295 families spread out around Bangalore City.

Support Group meetings for PLHIV
At the drop in centers the staff regularly organize support group meetings in partnership with the community based networks and organisations. These meetings help PLHIV to

relate and see other PLHIV living life with dignity and quality that builds their self-esteem and confidence in life.

Management of Opportunistic Infections

Initially the project has appointed physicians to provide out-patient clinical care to people living with HIV in providing treatment for opportunistic infections and management of HIV. Later, this service was brought down to provision of Opportunistic Infections drugs and re-imbursement of drug bills. And since the government services are available, the project volunteers refer the clients to government health centers.

Educational Assistance for affected children

This is one of the most crucial and pressing need, that I have witnessed of the PLHIV community. The project has very well addressed this component in supporting affected families to continue their children's education in schools and colleges by providing educational assistance to children of families affected and poor due to HIV AIDS.

But In spite of this I also noticed that around 15 children are at home out of which 9 girl children are at home. This shows how parents doesn't want their girl children to study more and wanted them to be get married. Still the issue of HIV positive children at school is the major concern everywhere, because most of the children's status are not revealed in school. But these children end up taking many leaves by falling sick often. This problem still persists everywhere (Madurai, Cochin, Bangalore and Chennai) I have visited.

Nutritional Assistance

Another important need that the project addresses in improving the health status of parents and children is the nutritional assistance. Discussions with parents living with HIV revealed that the nutritional support extended by the project has helped them at the right time to save their lives while on drugs.

Economic Development Assistance(EDA)

52 families of OVC were provided with Economic Development Assistance from the project, which supported 84 children. The vocational skill building programs and the assistance provided has substantially improved the quality of life of certain families. One of the EDA beneficiary who runs a "mobile iron shop" is able to live life with dignity and able to earn nearly Rs. 6000 per month with a simple support of Rs. 6,000 for the mobile 4 wheel trolley and brass iron box. Since the person had prior experience in this business and hard work of just 4 months has helped him achieve this. This program component not just improves the economic standard but addresses the issues around psychosocial support, educational support of children, dignified life, health and housing of parents and their children affected by HIV AIDS.

Home Visits

World Vision India acknowledges and follows the SAARC regional framework for the Protection, Care and Support of children affected by HIV AIDS that Promote family- and community-based alternative care for children affected by HIV AIDS, and ensure that institutions are not used as a substitute for family care, or used to gain access to education and other essential services. Hence a focussed attention was provided that children are not just put in institutions by the parents, but essential support services and education is provided for parents on the best family care and environment verses institutions.

"Myself, my brother and my mother, all are HIV positive, but World Vision has supported every one in my family to stay healthy and continue my studies"

– 16 years old girl living with HIV

"I want to talk openly to my sister but I am not able to as she doesn't know her status, but I know my mother's status. My sister is living with HIV and I want to support her"
–Sri, 16 years old boy affected by HIV

I also saw an endline survey study shows that stigma and discrimination are still prevalent in the community. Over 60% of the respondents has shown negative attitude towards people living with HIV AIDS and their families. The project is now consciously looking at this issue and are developed appropriate strategies that have worked in other parts of the country and even other countries to be implemented that an enabling environment is created for OVC and their families.

Strengthening PLHA Networks

Support Group Meetings and Capacity building programs were found to be the two key strategies planned in strengthening PLHA Networks. The support group meetings were focussed in healthy nutritional diets, managing opportunistic infections, motivating to form savings groups and in strengthening relationships among members and members in the local community. This has found to be useful for the participating members but the goal of strengthening the network towards advocating for issues affecting their families including children.

Channels of Hope

A unique program developed by a HIV positive church pastor and his team in south Africa. Channels of Hope aimed at Church leaders provides basic knowledge and helps the participants to reduce negative attitude towards people living with HIV AIDS. This has worked well in African countries where majority are Christian population. Now World vision India also implements these with Indian church pastors so as

to prepare the congregation and the leaders to accept people living with HIV and not merely codemn them as sinners.

In the city it has impacted the congregation and the leaders to respond positively to the increasing concerns of HIV prevalence and needs of people living with HIV AIDS. Church Leaders had started speaking about it in the Pulpit Ministry; it was been taken up as one of the prayer concerns for the city. Pastor of Methodist Church in Koramangala added that during the first week of December they were planning to have a week dedicated on awareness on HIV. This is a major change brought by Channels of Hope in one of the mainline churches in Bangalore.

One independent church pastor is actively visiting people living with HIV AIDS at their homes and are praying for them at their church. There are church members living with HIV AIDS who are referred regularly to the project for follow-up and some have become community volunteers of the project.

Capacity Building of PLHIV/OVCs/Community Volunteers

Days of commemoration are best utilized to be as capacity building programs for PLHIV, OVCs and Community volunteers. Family Camp and Children Camp has empowered children and their parents in self-confidence and relationships.

Bangalore HIV AIDS Forum

Bangalore HIV AIDS Forum, is formed to advocate the concerns of HIV AIDS in Bangalore City with the involvement of over 25 NGOs that includes Bangalore OVC Project of World Vision. This is an excellent opportunity and platform to include the agenda of raising the concerns and needs of children living with HIV and affected by HIV AIDS for the project.

Challenges

Some of the challenges faced during the implementation of the project were expressed by the field level team,

- Sensitizing parents to send children for Life Skills Education was a major challenge
- Since almost all of the staff were women in Srirampuram DIC, bringing in boys for LSE was found to be difficult at initial stages
- Eve - teasing by community youth was a major challenge in implementing interventions at the community level.

Issue of Foster parents – a complete orphan +Ve child under the care of a relative, nutrition and education support is provided, but we are not sure whether it reaches the child. Foster parents do not care for HIV+Ve child on taking them to hospitals for ARV or CD4 countor any other OIs. They don't even give 1 rupee for him to make a call to me – *community volunteer*

Another major issue was the ability of adolescent children to see life beyond their current status. The impact to HIV AIDS is so strong that they are able to see themselves only as simple day to day workers to bring in money at the earliest to home than do higher studies and then do great things for the family. I would say the grown up kids are “Living for Today with No dreams”.

Trainings that I participated and facilitated (some) during the fellowship

Life Skills Education

Life skills education training in HIV/AIDS was organized for four days for alliance partners at Trichy. Having previous experience on attending and implementing life skills in namakkal, this training provided me a space to learn and even train the representatives from the non government organizations.

In addition to the training, interaction with the NGO representatives revealed the impact HIV has on children and widows, The stigma is so high that even the representatives are mocked as AIDS patient by the community .They also expressed that some of the colleagues had problems because there was a rumor spread that those engaged in the work on HIV/AIDS were sexually promiscuous that affected their field visits.

Life Skills Education for children helps children in developing their skills on knowing about themselves, communication skills, decision making skills, coping with emotions, preventing and living with HIV and in setting goals for life.

Since the sessions with children are activity and games oriented, children enjoy these sessions and naturally develop their skills in the above said areas. This is very vital in the approaches adapted to work with children in vulnerable conditions and those orphaned by HIV AIDS.

Children Parliament

It has been my passion and interest to empower children to voice their concerns that affect them. From my experience working with networks of people living with HIV, I have learnt that the representative and advocacy of issues is very powerful when it is directly represented by the people who are affected by it.

Personally from the training I have learnt one approach to involve children and ensuring child participation. This approach also benefits children to represent and advocate issues better. I had the opportunity only on the orientation of the concept of children parliament, but I personally look forward to participate in the one week training program where the entire concept of Children Parliament from formation, operation and advocacy will be explored.

Disclosure Workshop for mothers living with HIV AIDS

This has been a major issue that is affecting many women to disclose their status to their own children. In the discussion held in madurai district and my previous experience working in namakkal and kerala, most of the women living with HIV expressed that disclosure is very essential but the fear of being discriminated by their own children affects them to take the initiative to disclose.

In Madurai for around 17 mothers living with HIV, two day training was organsied with support from UNICEF consultatnt who facilitated sessions.

The Women expressed their concerns in disclosing;

- Fear of being discriminated or perceived as bad woman by their own child
- Fear that children may disclose their status to other in the community
- Stigma about the disease
- Lack of family and relatives support.

Though there are these fears, at a point everybody agreed that disclosure is essential and they needed support to disclose the status to their children.

In August 7th and 8th 2008, I attended two days workshop for Caretakers of Children living with HIV AIDS at Cochin organised by Kerala Positive Women Network (KPWN+).

Some of the major issues shared by the mothers gathered there is of disclosing the HIV status of the mother as well as the child; they also expressed that there is lack of moral support from family and community for women living with HIV and the stigma is so high in that high literate state that some women need to vacate their houses and settle in different town without disclosing their status. I observed that such caretakers education sessions should happen regularly, so that that would help them prepare themselves to disclose their HIV status to their children, give better care for HIV positive children.

These trainings helped me understand that once a person makes a decision the role of the social worker, or counselor should be at the support level. One successful case study was that of one woman who had disclosed her status to child and with the positive response from the children other women in the group are motivated to attempt disclosure with their children. At the same time, It is also important that children also are prepared with the basic information on HIV and AIDS and treatment with life after HIV, which will help them accept the status better.

Comic Workshop in New Delhi – World Comics

The three day training was a wonderful experience. During my fellowship programme, I have been exposed to different approaches to work with children, one life skills, second children parliament and the last one comic workshop. This workshop also helped me to use my personal skill in drawing towards advocacy related work.

In the comic workshop, I observed children learnt the process easily because it is one that involves colours and funny figures that children learn easily. Using this approach as an effective tool for advocacy was one that impressed me very much. Almost all the drawings depicted what children experience in their day to day life situation. One instance is from a child from Manipur who depicted picture on stigma and discrimination faced from relatives because of the HIV status. This showed the extent of impact children are experiencing due to HIV.

(insert comic that was developed)

Advocacy Events that I participated

At National Project Director's Conference

In July 14th – 16th, 2008 Positive Women Network (PWN+) organized a National level Women living with HIV AIDS Workshop in Chennai where around 25 women living with HIV AIDS from at least 9 states of India participated. The objective of the workshop is "Looking back on achievements and failures and re-energizing for proactive actions".

As the workshop was coming for a closure on 16th, the leaders of the network were actually promised to be visited by the Director General of NACO. But since at last minute they cancelled the plan, all the 25 women living with HIV and some of us went to meet the Director General who came down to Chennai at the same time to attend the three days Project Directors Conference organised in a star hotel in Mahabalipuram, Chennai.

The team reached there during the lunch time and demanded the needs of women and children affected by HIV and AIDS. The DG, NACO and some Project directors were upset about the way the group entered the premises, but remembering the need to involve people living with HIV and the commitment given on GIPA, they rearranged their schedule and gave ten minutes for the leaders to share their concerns and needs to all the project directors present there. DG, NACO promised to support the women's network with specialized drop-in centers for women and children in 59 districts of India.

Key Learning:

- It was a sudden plan to approach the DG, NACO and the project directors at a conference with out proper agenda or demands
- Each women started expressing different things once the DG was available to listen to them but there was not a concrete demands were set in
- But fortunately, DG agreed openly to support PWN+ and its district and state level networks to set up Drop in Centers in the list of districts they would submit to NACO
- Follow up action from PWN+ and its member networks is absent

3rd National Consultation of women livign with HIV AIDS in Delhi

A decade of Women's voices and positive thinking

Hon. Minister for Labour Mr. Oscar Fernandes, presided the National Women's Consultation organized by Positive Women Network (PWN+) on the occation of the World AIDS Day, to address the increasing need for prevention, treatment and care of women living with HIV and their children. He stressed that National Council on AIDS headed by the Prime Minister of India, is giving importance to the issues faced by women living with HIV AIDS and the parliamentarian forum is committed to address this through HIV mainstreaming. This focuses on providing a healthy environment for women to uphold their rights. He said quality of women living with HIV can be improved through Yoga and other means of allieviating stress in life along with medical care and support needs of women.

He also added that together with the support for women living with HIV AIDS, it is also important to ensure that no more new born becomes HIV positive. He also added that when women are given correct and complete information it would reach maximum number of people in the country. He pledged the complete support for the efforts of positive women network who have started their signature campaign on 'prevention for women'.

Ms. Anne Sten hammer, Regional Director of UNIFEM encouraged women and appreciated the vision of Positive women captured in the video released to mark the 10th year celebration of Positive Women Network. She appreciated that both UNIFEM and PWN+ were natural partners with the development and upliftment of women being the center of the core response to HIV and AIDS.

Ms. Anandi Yuvraj, Representative of International Community of women living with HIV AIDS highlighted the transmission of HIV among married women and wanted the National AIDS Program to take a proactive role in HIV in marriage initiative led by UNAIDS, UNIFEM and UNDP. She also highlighted the compromises that happen towards women's issues when networks which highlights both men and women's issue and strongly emphasized the need for an exclusive space for women living with HIV within the National Program. She also congratulated the concentrated efforts of PWN+ towards Positive Prevention among Women living with HIV by initiating a signature campaign today to mark the need for focused prevention with millions of women who are at risk of acquiring infection from their spouse and their intimate partners who are at high risk. PWN and its partner networks at state level will have to be involved in designing meaningful interventions for this initiative. NACO and UNAIDS co-sponsors must

involve them in all their policy and programme developments to demonstrate their commitment towards GIPA with women living with HIV/AIDS.

Ms. Kousalya, President of PWN+ says, as women living with HIV, every day is a World AIDS Day for us. 150 Women gathered here have braved floods, blasts and HIV AIDS to be here from nook and corner of this country to find and raise the common voice to the issues of women living with HIV AIDS which is a grave concern. As a beginning to an end, Mr. Oscar Fernandes inaugurated the WE shop, an effort by Positive Women Network to provide socio-economic empowerment for women living with HIV AIDS.

The demand set in by PWN+ during this consultation was to actively and meaningfully involve women living with HIV in decision making processes at all levels. NACO agreed to it, but now PWN+ do not have adequate skilled women to represent for GIPA at various levels.

First State Level Consultation for Children at Ernakulam organized by KPWN+

In February 14 and 15, 2009, Kerala Positive Women Network organized a two day state level consultation for children affected by HIV AIDS at Rajagiri College of Social Sciences, Ernakulam. Around 25 children from two age groups participated in the consultation. 9-12 years and 12-15 years were two age groups.

The objective of the consultation were to help children learn the basics of HIV and AIDS and bring a feeling of togetherness among themselves; and
To enable children to represent the issues that affect them and advocate for better services and programmes to the stake holders.

The activities for children had sessions on understanding more about HIV AIDS, improving health, positive living and setting goals for future. The consultation had lots of participatory activities, games, question time, time to build friendship with other affected kids, talent evening and curious questions in secret box. Children enjoyed the two days consultation and expressed their desire to have such get together at least every quarter.

On the second day, various NGO representatives and Director from women and child development department participated to understand the issues faced by children by

directly seeing the charts, plans they have made and by interacting directly with the children. The director of W&C also gave commitments to support KPWN+ for pioneering its work with children in at least two districts in the next quarter.

ITPC Research Application

In October 2008, there was a call for research and advocacy proposal from International Treatment Preparedness Coalition (ITPC), I discussed this idea with my mentor for his views on it. He encouraged me to apply for the same and also assured me of his support to do the research and analysis of the same. This is the brief of the research question and justification of why we attempted to try it. Though I applied, unfortunately I didn't get through this research project.

Discussion of why you are interested in researching and advocating on these issues, with reference to the status of HIV prevention and treatment services for women and for children in your country

Our Key Concerns on this topic that interests us to research and advocate are;

- Women constitute over 40% of HIV infection in the country
- Prevention of Parent to Child Transmission and Targeted Intervention on Commercial sex workers are the only core prevention strategies for women. The research and advocacy will focus on increasing HIV prevalence among women in general community
- Increasing trend of HIV among young girls and women and lack of women-friendly sexual and reproductive health services
- Inadequate palliative care services for women and children
- Lack of provision of second-line ARV
- ARV provision for children are more number oriented and there are no programs over child counseling and support for children on ART
- No program to reach out of school and specially challenged children on HIV prevention
- There is no data on children living with HIV or affected by HIV at state or national level
- To monitor the status of OVC policy framed by NACO and UNICEF in 2007

Organisations that I networked with during my fellowship

1. The School, Chennai
2. World Vision India, Chennai and Bangalore
3. Kerala Positive Women Network (KPWN+)
4. Santhosh Siruvar Maiyam
5. Karnataka Network of People living with HIV AIDS
6. CHES, Chennai
7. Balamandir, Chennai
8. HUNS, Namakkal
9. CFAR, Chennai and Delhi
10. UNICEF, Chennai and Delhi
11. UNAIDS, Delhi

Understanding OVC Policies in India

In September 2008, Richard Lee from UNAIDS was making a study to ascertain How does the provision of public goods and services affect the response to Orphaned and Vulnerable Children (OVC) due to HIV and AIDS?

In this regard, he made a visit to Chennai and luckily I was also a respondent in his research on the above. This enabled me to get more understanding of HIV AIDS issues and his report also focused more on Tamilnadu and its services for children orphaned by HIV AIDS epidemic. This also encouraged me to collect various documents and data available on OVC policy framework by UNICEF and SAARC. I was also able to read and understand the National guidelines for Protection, Care and support for children affected by HIV AIDS.

These policies and guidelines are well developed, but there are still gaps and issues that are unaddressed at the ground reality. UNICEF and NACO are working on model projects to implement and monitor how the guidelines given are realized at the grass root level. There should be mechanisms to monitor the policy implementation through programs and there should be space to align the policies at every learning level, at least once in a year.

Building resource library of children related documents and schemes

One of the objective, I set during the initial stages of my fellowship is to build a resource library of books, reports and publications related to various children programs including HIV AIDS that would help organizations and people who work with children and HIV AIDS

This idea came up while discussing with my mentor Dr. Rakhal in Chennai. I was sharing with him that over the past 5 years of my work in HIV AIDS and my wife Julie's work around 9 years, we have collected several books and PDF documents which are of Training Modules, Information Education Communciation materials, Research papers, Policy documents, advocacy papers and links of many organizations working with children and HIV AIDS around the world.

Then he suggested, that why don't we make those collections to be useful for all those who want to pursue working with children?. That's when we decided to build a website which will have the pool of resources on children and HIV AIDS.

With the support of my friend who is a web-designer, I designed the above page and developed home page content, but when I was in touch with the webspace service provider, he alerted me about the copy right issues of these collections of resources. Also the web space required was also very high and it demanded annual budget of around Rs. 1 lakh plus the maintenance charges. That's the end, I set aside the idea of web space, but continued to do the activity to have it in a DVD or CD and provide only to people who may need it as a collection of resources rather than creating a brand of it.

Following is the home page content of this e-resource center.

KIDS and AIDS | e-resource center

Welcome to Kids and AIDS | e-resource center!

Kids and AIDS, e-resource center is an online collection of comprehensive resources on prevention, treatment, care and support programmes on children and HIV AIDS around the world. It shares valuable tools that help assess, design, plan, implement and manage programmes that are of high quality and sustainable in the developing world.

E-resource center fosters sharing of relevant, effective and innovative resources and constantly update to enhance the delivery of programmes for children living with HIV AIDS and affected around the world.

Explore! Enrich!! Empower!!!

Because my document and my focus are completely on children and HIV AIDS, it doesn't mean that I see the issues of children affected by HIV AIDS independently. I have learnt well that children in a community need to be protected and supported in social, economical, cultural, political and environmental areas. But the reason to focus is that many a times the special needs and issues are unheard, so a special attention is provided to highlight the concerns amidst other concerns of the community.

This activity is still under preparation, and it needs some more time in arranging the collected documents and to create a e-library in CD or DVD format with technical assistance.

Government Schemes for Children in Tamilnadu

This is another area, where I felt there are so many schemes and programs from the government but the knowledge and information to these are very limited. Hence during my interim meeting at CHC, I decided to work on this too. I searched on internet and got some good documents from Tamilnadu government website of various schemes for people of Tamilnadu.

With the support of a volunteer friend, we are now segregating those schemes for children. Class 1 to 10, 11 and 12, above 12^{th} and general are the four categories under which we are collating the government schemes. This activity is in the process and is expected to complete by March and print 10 sets to be used at grass root level.

Learning from Namakkal visits – January 2009

This Namakkal trip in January was an interesting and turning point in my life. We wanted to meet with the families and staff members we served during 2003 to 2005, so myself, my wife Mary Julie and my 1 year 10 months old son John Elijah packed our things and started our trip to Salem and Namakkal.

Namakkal district that accounts to more than 9000 people living with HIV registered and accessing the government ART center. Of the people accessing the centre 300 children living with HIV are benefited through the center.

We visited Salem Government Hospital – ART Center, where one of our ex-colleague is the ART doctor providing services to around 10,000 PLHA in the district and neighboring districts.

We also met women living with HIV who were our ex-colleagues in Namakkal when we worked on Positive Living Center project and learnt about situation of children in the district. Following are the list of people we met during our voyage to Namakkal and Salem.

Ms. Prema	-	VCTC Counselor, Salem
Ms. Muthulakshmi	-	Counselor – Children Project, YWCA Salem
Ms. Rajeshwari	-	ICTC Counselor, PHC, Erode District
Ms. Amaravathy	-	Outreach Worker, HUNS, Namakkal
Mr. Nackeeran	-	Board Member, HUNS, Namakkal
Ms. Vijayalakshmi	-	Counselor, ART Center
Dr. Arunachalam	-	Medical Officer, ART Center, Salem
Dr. Ramesh	-	Medical Officer, ART Center, Namakkal
Mr. Karunanidhi	-	Board Member, TNNP+

Key observations:

Treatment has been very positive and even could see cases of children in the age group 18 and 19 years. This has encouraged children (especially young adults) for marriage. Many questions the doctors, that if they can live so long and healthy with ARV, why they should not be married off?

So this puts a question to us on how to help children, especially issues around informed consent and issues like marriage and future for children living with HIV AIDS who are in their adult hood.

Understanding children's education needs, Salem government hospital and Namakkal hospital have scheduled children's ARV treatment day for Saturday, but no specific programmes or get together is arranged to help children. Staff also reported that when there is a visit then there is a make up of toys and children activities during that time.

On the day of our visit children also stand in line with the adults for treatment and receiving ARV drugs. They also go through the process of visiting doctors with the medical record and collecting medicines.

We were concerned that whether the child knows his or her status and the need for child counselors at the center as there was no attention or care given for children. The patient load is very high in both salem and Namakkal, so proper counseling is not ensured.

In Salem, with CIFF programme and partnership working follow-up is made by NGO's in the field, while in Namakkal now there are no NGO's for follow-up, so clients who come on their own avail treatment. Currently, the district level network in Namakkal covers few areas, but not all clients are reached.

The death percentage said by the ART Medical officer shocked us that even after taking ARV it is 10% death rate among those on ART. And people who have not started/or not on ARV the death percentage is about 13-14 %.

Majority of children who avail treatment is Salem hospital are from the grandparents, while the turn over of children from Namakkal who are with grandparents are less. The working hour of the hospital is 8am -12noon and approximately 150 attend the clinic every day.

From personal experiences and client observation the counselors (who are also women Living with HIV) expressed in the initial 3 months of ARV treatment if supported with good nutrition and vitamin B complex tablets of good standard, recovery from side effects and adaptation to drugs has been found very effective.

Regarding the topic on disclosure, mothers often think the children do not know the HIV, but children are inquisitive and have previous knowledge of the status before the actual disclosure.

Community children observation:

In any intervention programme, the community's culture also needs to be observed:
In vellakalpatti, Rasipuram Taluk, Namakkal a schedule caste village, children are married of at an early stage. Girls from the HIV affected families have more pressure for marriage and are married of at an early stage (between 14 to 16 years old). Due to culture pressures, young girls have eloped away from home and got married. eg two girls who have just completed 10^{th} std.

Challenges ahead of us:

- *Proper guidance, counseling and programs are essential for adolescent boys and girls*
- *Parents pressure on children to get married at an early stage affect their plan and interest and even resulting in risk conditions like running away from home.*
- *Encourage adolescents to plan through LSE programme and even facilitate a center for grievances or support for children who are in such difficult conditions.*

<u>Psycho-social issues</u>

1. Mother, especially trained peer counselors have found it difficult to express their status to their own children. The child is also HIV positive and now has recently started on ARV.
   - *Rajeshwari.*

2. In one instance they have taken the support of another peer counselors and trusted person of the child in disclosure process. The child has been able to accept and support towards the mother has been more positive.

- *Ganthimathy*

3. Fear of stigma has been found less among the women that we have interacted and family support has helped most of the women to adapt to a healthy and a planned future.
   - *Muthulakshmi and Amaravathy*

4. Children availing treatment do not have special care or even opportunities to come together. It has been found shared feeling help cope better, but there are no opportunities for them in namakkal district.

5. Side effects caused by treatment also affect children, but the sharing between the mother and child helps them to cope with the stress.

6. Fear of disclosure is very prevalent among mother, but all want to disclose

7. Stigma about HIV is experienced by children only around the age group 0f 14 and 15 years, if proper support mechanisms are available it helps them cope with the stress easier

Economic issues:

1. HIV does affect the economic condition, but family support helps one cope with the situation.

   Eg. Muthulakshmi's brother has supported her with land and she could use the produce of the land to manage the expenses and even her children's future
   Support from family is more seen in rural settings

2. Concerns over children's education and future is found mostly among parents, specially among widows

3. Due to poor economic conditions, there is compromises made in putting them in hostels and Tamil medium schools (where expenses are less)

4. Food style is compromised due to poor economic condition.

Support systems in the district

There are few agencies like Christy factory that provides nutrition support for children in Namakkal district

Key Issues that affects children living with HIV as expressed by ART Medical officer in Namakkal are:

1. Children living with HIV under the care of Grandparents and foster parents (relatives) do not come for center though they are eligible to receive ARV

2. Most of the children are under ART without knowing their HIV status or not prepared for knowing one's status
3. No support mechanism for adolescent children to accept their HIV status and move towards a positive life
4. Supply Chain of Pediatric ARV drugs are often affected. In last 2 years the Adults and pediatric drugs have been changed 4 times
5. Most children on ART are less than 11 years old and are not much aware of HIV status but children who are now in teenage and adolescents adamantly deny taking ARV
6. Over 4600 PLHA on ART with 6 counselors and no time for child focused services or counseling
7. Psychological issues are high among children affected by HIV AIDS

From Mr. Karunanidhi, TNNP+ on his experience of working with children Krishnagiri District

Over 800 positive children are registered in this district. Even here most of the positive children are under the care of their grandparents. Here outreach workers are given the designation of Children Protection Officers at the block level that has elated their dignity and response to children affected by HIV AIDS.

District Administration is very supportive to the initiatives in the district. Caretakers are trained on how to care for their positive children, but there is no specific developed module in that area.

Looking Inward – What did I learn about myself?

When I joined the fellowship, my mental state was that I was deeply troubled in the work that I was engaged. Many questions ran through my mind of my commitment in social work and work with children, but later I realized that I have burnt out completely and I needed a break free from my work.

Thank God and thank CHC that I got through this fellowship. One solid month of orientation at CHC, though week ends were taking me away from my family and my one year old beloved baby John, it was the best break I had with inspiring leaders, motivating sessions, questioning systems and immeasurable learning to my spirit, soul and body.

The regular introspection of the inner man to use the knowledge and skills with a right attitude in serving our community is essential for every community health steward.

"The eye see only what the mind know…"

Dr. Ravi, said this and added "many a times we see things in very superficial node but one needs to go deeper to see things beyond our mind…so the best way is to learn more and renew your mind"

This really struck me strong, because after having worked in Namakkal, Positive Living Project for almost three years, I always believed that the work that I do is the best one as there was no such projects in the district by any other NGOs. The project really got attention of many working in HIV AIDS Care and support programs and took me to various platforms and conferences to share our experiences and learning. I think that's where knowingly or unknowingly the pride took hold and my eyes could see only what the mind knew.

Though I have visited many projects, my mind always blocked me from learning from good and bad experiences of other projects and people in community work. This has rooted deep in my mind, but Dr. Ravi's group learning exercise helped me to unleash my thoughts and strong holds of my mind and helped me to renew and revive my spirit to focus once again on the barely reached services for children.

Many questions kept coming to my mind throughout the learning sessions at CHC. Some are given here for the benefit of myself and those reading my report.

1. Am I strongly convicted on my vision and add strength to it by all possible means?
2. Do I walk my talk?
3. How many children and their families affected by HIV AIDS have I really supported and helped them lead a life with dignity?
4. Do I need to learn more or do I need to start doing with what I have known already?
5. How much did I unlearn to learn more?

6. What are the things I need to sacrifice to belong to the community?
7. Will there be constant reflection and encouragement to see beyond what I see now?
8. Do I criticize or critically analyse and reply? – from group lab
9. what are the values you are really following on a day to day basis/
    a. sincerity
    b. integrity
    c. honesty
    d. equality
    e. simplicity
    f. justice
    g. truth and genuineness
    h. humility
    i. compassion
    j. openness to listen or dialogue
    k. sensitive to nature and people around you
10. What are the values that are still lacking within me?
11. How do I manage my family?
12. Or should I leave all this and take up a good position in any NGO?
13. How much am I self seeking? And how much should I die to self?

Group Learning Experiences

We are conditioned

When Dr. Ravi, revealed this learning that we always share only what our MIND thinks and very rarely on what our HEART feels. How true it is, that we share only our thoughts about a situation and never share the feelings we have upon certain issues that has affected our heart. Every team must have a value framework and from time to time we need to check whether we are really there in the values we have set in. And prepare ourselves to share what our HEART feels.

We are not able to share negative or things that we feel sad about

Two reasons that we are not able to share our negative feelings are 1. we are conditioned in life like that and 2. we do not have a trustful environment to share. I often personally felt that I am mixed with both these factors. I am also conditioned, may be as a gender role that as a man I shouldn't cry or express my sad feelings which would put my dignity down and sometimes when I have felt that I should share, the environment wasn't that trustful to express my feelings and even cry when I want to.

I can personally count in my life after 18 years of age, how many times I have really cried about certain things that have affected me. As I type this, I also remember while I was doing my class 10, when I cried watching "Anjali", a tamil movie when a child dies in a family of love, joy and affection. In 2006, after marriage again I cried one night

watching the same movie in television. The environment was so private that I was able to cry aloud ventilating out my feelings that was so twined within my heart for children.

Share your negative feelings, more positively

This is still another challenging area and a lot of practice that I need to share my negative feelings, more positively. I have seen myself, expressing my negative feelings, so sharply to those who cause it and those around them. I have understood personally that I need more perseverance to withstand injustice and fight for justice. What I have done many times is always expressed my anger and frustration and have lost some good friends. Now I am in the process of learning to share more positively.

You are mentally ill – if you are "CASTE" bound

I acknowledge and appreciate such powerful words from Dr. Ravi, "You are mentally ill – if you are CASTE bound". I could experience his words in many humiliating instances I personally see in the lives of my friends who belonged to dalit community. And during orientation of CHLP, we also witnessed the same in our field visits to villages in Raichur.

NIMMA – NAMMA Test

People have to experience you in the community as someone belonging to them. For instance if we say we are a community worker, the community that we work with should say he/she is OUR person and not the NGO's staff or person. This is a crucial and strong lesson that I have learnt, but truly to express sometimes I have had reverse discrimination for being negative to work among HIV positive people's networks. But still, its important for me to be unequal to be equal to all.

Looking Outward – What did I learn about the community?

Go to the people
Live among them
Love them
Learn from them
Start from where they are
Build upon what they know

But of the best leaders,
When the task is accomplished,
The work completed,
The people all remark:
"We have done it ourselves"

Lao Tsu

Lao Tsu wrote this around three thousand years ago. Various translations of it are found in http://www.scn.org/cmp/modules/emp-go.htm

Go to the people…

It is more so important to Go to the people, while working with children and HIV. In my personal experience and journey through these projects, the strategies have tried to address some of the most vivid concerns of children affected by HIV, but there are still deeper issues that can be well understood only by going to the people to understand and help them address it.

Going to the people isn't simply meaning physically being there, but coming/humbling down from where we are; understand their background, learning their language, belonging to the community and empathizing alone will help us to progress in the wellbeing of the community.

Live among them…

Heard and read that two of the interns of CHLP, made this a reality during the fellowship. Another interesting couple I met are founders of Tribal Health Initiative in Dharmapuri district. Literally they moved to live among the community members. In my past experiences, I have gone to the community only as a visitor and monitoring person, but now I am inspired to live among the community. As this is very crucial to explore and understand more the day to day issues faced by the community that we want to work with.

Love them…

I am reminded about what Jesus said in the Bible. The first greatest commandments is to Love the Lord thy God with all your heart, soul and strength and the second that is equivalent to it is to Love your neighbor as you love yourself.

I know many of us in the world loves ourselves so much, otherwise we would not like to eat good food, dress up neatly, learn more and so on. Similarly, we ought to love our neighbors as we love ourselves is what this poem is also trying to tell us.

It is so crucial that unless I love the children that I want to work with, I would be a machine delivering services to them and very soon I will get weary and will not be use for any one.

As we all know a community is comprised of people from different religion, caste, economical status, education and so on, working among them with love for all is practically a challenging task. Personally I have experienced when we love all in the community, some people in the community is not going to be happy about it.

For instance, in my recent visit to a village in Namakkal; to meet children from dalit community we (myself and my wife) took a women living with HIV who worked as a field worker earlier in that area. We were so comfortable talking with the children and their family members as we were meeting them after 4 years. We found many girl children of HIV Positive parents have got married at very early age (14 to 15 years) and are with children now. When we were returning we were discussing about this issue and on our way back, the field worker quoted that this is very common in this (dalit) community. It was bit demeaning the particular community.

I could personally reflect back, that when I work with children and their families affected by HIV, I understood that it's important for me to love unconditionally all the community members that I work with. And it's also obvious that we cannot move to the next step in the poem (Learn from them) unless we throw personal bias and conditioning of our mind.

Learn from them

My past work experience in villages of Namakkal actually gave me lots of insights and understanding about how HIV AIDS has affected families and the entire community. I have well learnt I have so much to learn from every member of the community that I long to work with right from a new born to the oldest person in the community.

There are both negative and positive learning from the community members. For instance, in my interactions with HIV positive children in Bangalore OVC project of world vision, a HIV positive girl expressed how she is affected by her handicapped brother rather than her own HIV status.

She was almost in tears when she said, "I don't have my father but only my mother who is HIV positive to support us, we want to do operation for my brother but we are unable

to do it because its very expensive. I don't worry about HIV or taking ART but only if my relatives of neighbors come to know my and mother's status".

That day I took so much of learning from her, that how HIV interventions and strategies need to be designed more humane rather than with policies, guidelines and strategies.

Start from where they are and *Build upon what they know*

50% of my job is completed in the community if I complete all the above steps and reach to this step of acknowledging that I need to start from where they are.

One experience to quote in *starting from where they are and building upon what they know;*
In villupuram, while working with the women living with HIV group in the district, PWN+ had little unspent money from a donor agency, to use it for Income Generation purposes of women living with HIV AIDS in the district. We had lots of ideas for the women, but it didn't get their attention or interest, then I asked them to share what they would do if we give them some loan. Two to three of them expressed they would do saree business. That's the spark. I worked along with them and developed a plan for a business unit that would buy and sell sarees and salwars. This business after going through some challenges and struggles have now received a loan of Rs 3,75,000/- and have also received a subsidy of Rs. 1,25,000/- from Tamilnadu Women Development Corporation. 13 women living with HIV AIDS are partners in this business unit and is doing well completely, initiated and managed by women living with HIV AIDS in Villupuram.

Looking Ahead – Where do I go from here?

Towards a community health approach to working with children living with and affected by HIV and AIDS

Principles to work with Children
- from Joint Learning Initiative for Children Affected by HIV and AIDS (JLICA) report, February 2009

1. support children through immediate or extended families and
2. deliver integrated family-centred services;
3. strengthen community action to support families; and
4. address family poverty through national social protection.

- from *Policy Framework for Children and AIDS – NACO, UNICEF and Ministry of Women and Child, India July 2007*

1. To create a non stigmatising environment, enabling access by children and young people to prevention services including complete information and skills to protect themselves from and reduce their vulnerability to HIV infection;
2. To identify HIV-infected parents and children early, and to provide high quality treatment and support to prolong and maintain the quality of life, and to ensure they are able to fulfill their potential and responsibilities;
3. To ensure that affected children – whether HIV positive or not – are not excluded from or treated differentially by service providers in the public and private sector;
4. To eliminate stigma and discrimination by overcoming myths and misconceptions in relation to HIV/AIDS, and by implementing regulatory and legal measures to address discrimination wherever it occurs.
5. To ensure social protection measures are in place to prevent and redress violations of their rights and entitlements.

From NACO Operational guidelines

The operational guidelines take account of the two broad principles specified in NACP III:

1. Increasing access to all services for most vulnerable children and strengthening child protection systems
2. Mainstreaming HIV/AIDS in the existing schemes and programmes for children

Models in line with the Policy Framework of NACO, UNICEF and Min of Women and Children

Policy Framework for Children and AIDS					
Intervention Models	**Prevention services**	**Treatment, care and support**	**Social Protection and Rights**	**Advocacy and Addressing Stigma and discrimination**	**Access to other Government schemes**
Santhosh Siruvar Maiyam Model	*Life skills education*	*1. Support for formal education and nutrition of the children in the community* *2. Medical care referrals and linkages* *3. Organizing Peer group meetings at the center* *4. Building awareness and capacity building of parents and caregivers of children orphaned by HIV* *5. Mobilising women as volunteers*	*Formation and strengthening Community based Childcare Committee*	*Taluk and District Level Advocacy on CAHA issues*	*Organising mothers as self-help groups and access resources from TNWDC*
Bangalore OVC Project Model	*Life Skills Education*	*1. Drop-In Centers* *2. Support Group meetings for PLHIV* *3. Management of Opportunistic Infections* *4. Educational Assistance for affected children* *5. Nutritional Assistance* *6. Economic Development Assistance* *7. Home Visits*		*1. Strengthening PLHA Networks* *2. Capacity Building of PLHIV and Community Volunteers* *3. Bangalore HIV AIDS Forum*	

Gaps Observed

From my field observation, other issues that are unaddressed in the policy and the intervention models studied are;

- Child Sexual abuse among children orphaned by HIV and AIDS
- Child marriages among affected families especially for girl children
- Increase in Child labour where the bread winner of the family is lost
- Support in disclosure for parents and children
- Understanding the desires of HIV positive children above 16 years to get married and providing appropriate interventions
- Empowering children and providing platforms for them to raise their concerns
- Support for grand parents taking care of HIV positive and affected children
- Uncertain future for children at grandparents headed households
- Poverty at grandparents headed households
- Issues of adolescent HIV positive children while knowing their status
- Sensitivity on care for children among health care service providers, schools and other public and private services need to improve

Basic Principles of a model that I would evolve

1. Encourage formation and empowerment of children support groups at the community
2. Age specific prevention and care and support services
3. Address vulnerable factors (like child abuse, trafficking, child marriages etc) effectively through coordination
4. Encourage family based care and support services
5. Provide special programs for children living with grand parents
6. Well subsidized economic development program for widows and grand parents managing children
7. Ensure Government and Private services free from stigma and discrimination

All of the above principles will be addressed with the cross-cutting themes of Child rights, gender and GIPA

Books, Journals, Movies and Reports read during the fellowship

Books, Documents and Reports

1. History of Child Rights in India
2. Learning to cartoon
3. YUVA comic books for children on health
4. Health Education for Children
5. OVC Research – UNAIDS Richard Lee 2008
6. NACP III – Policy Document [2007-12]
7. GIPA policy document
8. National Operational Guidelines for Children affected by HIV AIDS
9. Policy Framework for children and HIV AIDS – India 2007
10. SAARC Regional Strategic Framework for Protection, Care and Support of children affected by HIV AIDS
11. Situational assessment of HIV AIDS affected children in four villages of melur taluk of Madurai district in Tamilnadu
12. Life Skills Education Toolkit – FHI/USAID
13. Research document of CWC on Street Children

Movies

1. The Story of Stuff
2. Story of mine workers in Bellari, Karnataka
3. Story of Gold mine workers in Indonesia/Thailand
4. Flight 69
5. Amazing Journeys – a documentary on migration of birds and animals on earth

Annexures

I - JLICA Report Brief

As is so often the case in the provision of health care and deciding research agendas, children have been sidelined in the fight against HIV/AIDS. According to the latest UNAIDS figures, nearly 2 million children live with HIV worldwide, two-thirds in sub-Saharan Africa.

In addition, 12 million children in sub-Saharan Africa have lost one or two parents due to HIV/AIDS. Many more live with a parent or carer with HIV. A very small proportion of infected children receive antiretroviral treatment, and prevention of mother-to-child transmission is only given to a third of women.

Diagnosis in infancy is difficult and therefore often delayed. Child-friendly medication is lacking. 60% of children in southern Africa live in poverty. Now that HIV/AIDS is evolving from an acute emergency into a chronic epidemic, the way to deliver treatment

and achieve prevention needs to change radically from an individualistic approach to a broader strategic one. Children and families need to take centre stage.

In an excellent report, based on 2 years of research and analyses, the Joint Learning Initiative on Children and HIV/AIDS—an independent alliance of researchers, implementers, activists, policy makers, and people living with HIV—has presented recommendations for such a change in direction. Home Truths: Facing the Facts on Children, AIDS, and Poverty, released on Feb 10, points out three broad policies that will make an immediate and longlasting difference to children:

5. support children through immediate or extended families and
6. deliver integrated family-centred services;
7. strengthen community action to support families; and address family poverty through national social protection. Such policies are AIDS-sensitive but not AIDS-directed.

The family is the most important support structure for children. The report argues that the way orphans have been defined (as having lost one or both parents) and have become the centre of attention for many HIV/AIDS policies has been unhelpful, if not damaging. 88% of children labelled as orphans have a surviving parent and overall 95% continue to live with extended families. Additionally, children who live with HIV-positive parents have needs long before their parents die. Children need to stay within a family or kinship structure.

Infected children usually live with others who are infected with the virus. The whole family, not the individual, needs to become the unit for support and treatment. The report advocates home health visiting and early childhood development interventions together with strategies to encourage children's education. The use of schools as intervention platforms misses the opportunity to reach children early and to reach those who are not in education—the majority in some countries. Economic strengthening of families has to be the basis to allow many of these programmes to fully succeed.

The best immediate support for families is given by community groups. International donors need to work with these groups in partnership to avoid duplication, confusion, and waste of time and money. The authors suggest that coordination could be strengthened with a district committee that maintains an active register of community activities and devises a system of accountability that is understood by all and serves the community. All activities should be delivered within a framework that is based on best practice. Communities also have a crucial role to act as a backstop when families break down or when children live in an abusive environment.

Family poverty and undernutrition can be addressed through income-transfer programmes, such as Mexico's Oportunidades programme or South Africa's child support grants. These projects are efficient and simple, empower women, and can act as a springboard for other more complex schemes, such as microfinance loans. Such economic support increases school attendance, reduces illnesses, improves growth, and

encourages uptake of health services. The largest portion of money is usually used to purchase food.

Extreme poverty, rather than HIV infection, should be used as a criterion to avoid stigma and resentment. The report argues that "any developing country, no matter how poor, can afford social protection packages for children". The positive effect of this policy is now established beyond doubt and no further pilot studies are needed.

To integrate all these strategies, governments need to take the lead with national plans and frameworks to scale-up programmes for children and families. With this approach, society as a whole will be strengthened with intergenerational effects that will go a long way towards, but also go well beyond, tackling the effects of HIV/AIDS.

Putting children and families at the centre will show long-term vision with guaranteed future benefits.

II - Child Marriages

The challenge

Marriage before the age of 18 is a reality for many young women. According to UNICEF's estimates, over 60 million women aged 20-24 were married or in union before the age of 18.

Factors that influence child marriage rates include: The state of the country's civil registration system, which provides proof of age for children; the existence of an adequate legislative framework with an accompanying enforcement mechanism to address cases of child marriage; and the existence of customary or religious laws that condone the practice[2].

A violation of human rights

In many parts of the world parents encourage the marriage of their daughters while they are still children in hopes that the marriage will benefit the children both financially and socially and relieve financial burdens on the family. In actuality, child marriage is a violation of human rights, compromising the girls' development and often resulting in early pregnancy and social isolation, with little education and poor vocational training reinforcing the gendered nature of poverty. The right to 'free and full' consent to a marriage is recognized in the **Universal Declaration of Human Rights** - with the recognition that consent cannot be 'free and full' when one of the parties involved is not sufficiently mature to make an informed decision about a life partner.

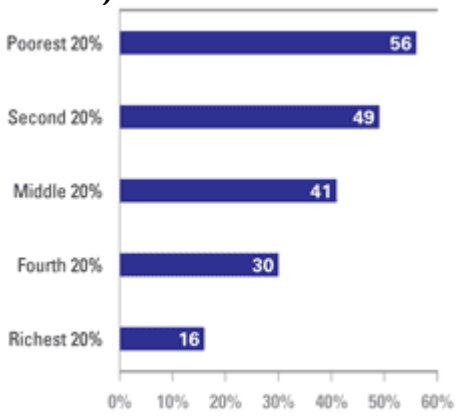
The **Convention on the Elimination of all Forms of Discrimination against Women** mentions the right to protection from child marriage in article 16, which states: "The betrothal and the marriage of a child shall have no legal effect, and all necessary action, including legislation, shall be taken to specify a minimum age for marriage...". While marriage is not considered directly in the **Convention on the Rights of the Child**,

child marriage is linked to other rights - such as the right to express their views freely, the right to protection from all forms of abuse, and the right to be protected from harmful traditional practices - and is frequently addressed by the Committee on the Rights of the Child. Other international agreements related to child marriage are the **Convention on Consent to Marriage, Minimum Age for Marriage and Registration of Marriages and the African Charter on the Rights and Welfare of the Child and the Protocol to the African Charter on Human and People's Rights on the Rights of Women in Africa.**

Source: childinfo.org

CHILD MARRIAGE IS MORE LIKELY IN POOR HOUSEHOLDS THAN IN RICH HOUSEHOLDS

Percentage of women aged 20–24 who were married or in union before age 18, by wealth index quintile (1987–2006)



Protection from HIV/AIDS is another reason for child marriage. Parents seek to marry off their girls to protect their health and their honour, and men often seek younger women as wives as a means to avoid infection. In some contexts, however, the evidence does not support this hypothesis and practice. Bhattacharya found that in India, 75 per cent of people living with HIV/AIDS are married[10]. In fact, the demand to reproduce and the stigma associated with safe-sex practices lead to very low condom use among married couples worldwide, and heterosexual married women who report monogamous sexual relationships with their husbands are increasingly becoming a high-risk group for HIV/AIDS.

Strategies to end the practice of child marriage

- Evidence shows that the more education a girl receives, the less likely she is to marry as a child. Improving access to education for both girls and boys and eliminating gender gaps in education are important strategies in ending the practice of child marriage. Legislative, programmatic and advocacy efforts to make education free and compulsory, as well as to expand Education for All programming beyond the primary level, are indicated by the strong significance of educational attainment in terms of reducing the number of girls who are married.

Increasing the level of compulsory education may be one tactic to prolong the period of time when a girl is unavailable for marriage.

- It is also important to capitalize on the window of opportunity created by the increasing gap in time between the onset of puberty and the time of marriage by providing substantive skills enhancing programmes and opportunities. There is a need to develop methods to protect girls at risk of child marriage and to address the concerns of girls and women who are already married by ensuring the fulfillment of their right to a full education and providing them with life skills-based training to ensure that they can earn a livelihood.
- Efforts are also required to protect girls who are in union. Decreasing the pressure on young women to conceive through education and advocacy on the dangers of early motherhood should be considered. Similar consideration should be given to ways to improve access to effective contraceptive methods.
- Services for survivors of domestic violence should be accessible. Outreach efforts should consider targeting women who were married before age 18 as potentially in need of assistance. Mapping child marriage levels within countries may be a useful practice for programmatic purposes when determining where to launch new prevention campaigns. It can also be used to track future progress by comparing child marriage levels at different points in time.
- Further data collection and research is also required to explore the impact of child marriage on boys and men. The demand-and-supply relationship of child marriage should be qualitatively explored to illuminate dynamics, such as the reasons why households marry their children and why men prefer younger brides, in order to inform programming strategies.

Source for figures: UNICEF global databases, 2007, based on MICS, DHS and other national surveys, 1987–2006.

III - Concerns of children living with Grandparents

- **Poverty:**
    1. *findings suggest that children living in elderly-headed households often do not get enough food and seldom have access to protein*
    2. *children from elderly-headed households are overworked*
    3. *even though grandmothers and grandchildren see education as very important, children living with grandmothers do not access education easily because of lack of money. In addition, if they do get to school, their progress is hampered, again largely because of poverty*
- **grandchildren as caretakers:**
    1. *another characteristic of the elderly-headed household is that children function as caretakers. When children have responsibility for the welfare of others they may become "parentified" - that is, they assume responsibilities performed more appropriately by an adult, including providing health and*

personal care, emotional support, caring for siblings and maintaining the household

- **an uncertain future:**

    1. *a further stress that is added to the lives of children living in elderly-headed households is the uncertainty they feel about their immediate futures. They worry about what will happen to them when their grandmothers die. The worry that a child in this situation faces is that he or she will have to move again and will likely have to live with aunts and uncles in a situation they know from experience is worse than their life with their grandmother*
    2. *also, the children fear (quite realistically) that they will not inherit property when their grandmothers die, leaving them with no means to make a living*

- **a generation gap:**
    1. *the gap between the grandparent's generation and the children emerges in the conflict between grandmothers and children over time to play and to socialise and rest*
    2. *Grandmothers expect that they will be looked after but the children know that their ability to do this will be severely hampered because of the missing generation. Parents would have provided the means for further training and income generation and would have taken responsibility for the grandparents*