

Acknowledgement

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ACRONYMS

AIDS	-	Acquired Immune Deficiency Syndrome
ANC	-	Ante Natal Care
APAC	-	AIDS Prevention and Control Project
ART	-	Anti Retro viral Therapy
ARV	-	Anti Retro Virals
CBO	-	Community Based Organisation
CCC	-	Community Care Centre
CD4	-	Cluster of Differentiation 4
CPSU	-	Central Public Sector Undertakings
CSO	-	Civil Society Organisation
CVCTC+	-	Community based Voluntary Counselling and Testing Centre
DIC	-	Drop-in-Centre
DGP	-	Director General of Police
DLN	-	District Level Networks
F2M	-	Female to Male
FHI	-	Family Health International
FIRM	-	Foundation for Integrated Research in Mental Health
FPAI	-	Family Planning Association of India
FSW	-	Female Sex Workers
GBT	-	Gay Bisexual Transgender
HBC	-	Home Based Care
HCP	-	Health Care Provider
HIV	-	Human Immunodeficiency Virus
HST	-	Humsafar Trust
ICTC	-	Integrated Counselling and Testing Centre
INP+	-	Indian Network for People Living with HIV / AIDS
KNP+	-	Karnataka Network for Positive People

KSACS	- Kerala State AIDS Control Society
KSAPS	- Karnataka State AIDS Prevention Society
LFC	- Life Focus Centre
MSM	- Men who have Sex with Men
NACO	- National AIDS Control Organization
NGO	- Non Governmental Organisation
NHRC	- National Human Rights Commission
OI	- Opportunistic Infections
OPD	- Out Patient Department
ORW	- Out Reach Work(er)
PEP	- Post Exposure Prophylaxis
PHC	- Primary Health Centre
PID	- Pelvic Inflammatory Disease
PIE	- People in the Immediate Environment
PLHIV	- People Living with HIV
PNP+	- Parallel Network of Positive People
PPTCT	- Prevention of Parent To Child Transmission
PSW	- People in Sex Work
PV	- Per Vaginal
SHG	- Self Help Group
SIAAP	- South India AIDS Action Programme
STI	- Sexually Transmitted Infection
SWAM	- Social Welfare Association for Men
TANSACS	- Tamil Nadu State AIDS Control Society
TB	- Tuberculosis
TDNP+	- Tamil Nadu Network for Positive People
TG	- Transgender
UNAIDS	- The United Nations Joint Program on HIV / AIDS
USP	- Universal Safety Precautions
VCT	- Voluntary Counselling and Testing
WINS	- Women's Initiatives

Background of the project

The AIDS epidemic impoverishes people in many ways including ill-health and early death. Additionally, it isolates people and increases stigma and discrimination against them. PLHIV or people vulnerable to it, are thrown out of jobs and evicted from homes; children are denied admissions; hospitals refuse treatment; women are denied their rightful share of family property; violence and harassment of sexual minorities increase. There is a drastic fall in the income level when people become sick, forcing young children to drop out of schools and seek employment. These factors in turn, further fuel the spread of the epidemic by driving people underground.

AIDS is commonly associated with values about sexuality and sexual behavior, and traditional societies, such as India, usually discriminate against non-conforming expressions of sexuality. Thus PSW, Gay, Bisexual, Transgender, and Transsexual people (GBT), PLHIV and their families are often discriminated against. This makes them more vulnerable to AIDS and unable to access prevention, treatment delivery, care and support services that they need even more than other people.

The "Sarvojana" project was envisaged as a unique intervention that would bring considerable change in the life of the communities that are most vulnerable to HIV. The project was implemented in five states of which four were states with highest HIV prevalence, namely Maharashtra, Tamil Nadu, Andhra Pradesh, Karnataka and the contiguous state of Kerala. All these states have implemented considerable interventions to contain the epidemic, and, their impact was in terms of increased

treatment availability, expansion of different services including counselling and testing which was mostly institution based. This left a wide gap in the availability and accessibility of services by the core groups / high-risk communities like women & men in sex work (PSW), Gay, Bisexual, Transgender, and Trans sexual people (GBT) and PLHIV and their families.



The eight coalition partners of this project are organizations who have been working with vulnerable communities and PLHIV for over two decades and have a proven track record of bringing in the community's perspective to any intervention they implement. The coalition, through this project, aimed to improve the quality of life of the target communities and empower them to address their sociological, psychological and medical needs that make them vulnerable to HIV & AIDS, through establishment of community based VCTC for more equitable access to prevention, treatment delivery, and care & support services.

It also aimed at developing an alliance of SHG for target communities and other Civil Society Organizations (CSO), to advocate against stigma and discrimination.

The project supporting marginalized communities for a period of four years has considerably achieved its objective of reducing poverty and improving the quality of life of the community. In all 7 CVCTC+s and in the district level network of INP+, direct and indirect services were provided to 3,18,000 beneficiaries and their family members. This has also established and strengthened 30 community SHGs that are empowered enough to take the activity forward. As a result of this project 34,000 PSW & GBT, 30,000 PLHIV (ages 5–50) and more than 1,50,000 PIEs, have received benefits.

Project Design :

The project was designed with an overall objective to reduce poverty and improve quality of life of poor and traditionally marginalized communities disproportionately affected by or vulnerable to HIV & AIDS; and empower civil society organizations to check the spread of HIV and reduce the impact of AIDS in the highest prevalence states of Maharashtra, Tamil Nadu, Andhra Pradesh, Karnataka and the contiguous state of Kerala.

This objective was planned to be achieved by reducing stigma and discrimination and increasing equitable access to HIV & AIDS prevention, treatment delivery, care and support, for people in sex work (PSW), Gay, Bisexual, Transgender and Transsexual people (GBT), People living with HIV & AIDS and their families (PLHIV), and people living in the immediate environments of the target communities (PIE), through establishing Community based Voluntary Counselling, Testing, Support and Care centres (CVCTC+); and promoting self help groups of members of target communities to address sociological, psychological and medical factors that increase their vulnerability to HIV & AIDS.

In order to achieve the overall objectives, the different activities were arrived as a result of consultation among the local partners and member organizations, all of whom have many years of experience in the field of HIV & AIDS. As a result of the consultation, the project was designed with the following ten key components:

1. Establish and operationalize CVCTC+, as hubs to promote health seeking behaviour and to advocate against stigma and discrimination.
2. Sensitize and mobilize target communities in project areas to access CVCTC+ and other services

3. Quantify existing levels of stigma and discrimination among target communities through a baseline survey in specific project areas.
4. Meet SHGs of communities to develop plan of action to identify & address specific cases of stigma discrimination, educate public and seek legal redress when necessary.
5. Advocating at Government, private and community levels for action against stigma and discrimination.
6. Capacity building of health care personnel in order to improve quality of services at government, private and community facility.
7. Monitoring the availability and quality of treatment at government hospitals; and their adherence to universal precautions and to protocols for Post Exposure Prophylaxis (PEP).
8. Establishment, formalization and operationalization of an umbrella organization of coalition members to build capacity, and manage future projects in this area.
9. Identifying changes required in policy and legislation to facilitate future work of coalition members of the umbrella organization in this area.
10. Facilitation of government and private agencies by coalition members of the umbrella organization with the objective of replicating CVCTC+, and mobilizing self help groups of target communities.

Through these set of activities, the project constructed a clear and concrete roadmap to achieve its objective of improving quality of life of poor and traditionally marginalized communities. It was considered that provision of a non-threatening, stigma free environment for the communities would encourage them to access counselling, testing, treatment, care and support

services without any hesitation. This, by itself, would help in the improvement of quality of life by educating communities about their risk, accepting their sexual orientation, providing confidential counselling for change in their risk behaviour, and linking them with various treatment and care services. Prevention of infection and maintaining the quality of life of those who are infected alone can reduce the poverty caused by HIV & AIDS among the target communities.

Moreover, people in the immediate environments of the target communities (PIE), have a great influence in the quality of their lives, and therefore it was planned to sensitize them and encourage them to be supportive to the target communities and help with project implementation. Similarly each member organization conducted training for care providers from other agencies, using the CVCTC+ as the hub, as an effort to engage government and other NGOs in its efforts. This also helped plan for the sustainability of this model project.



Uniqueness of our project:

The project is unique bringing different organizations working in different states to come together under one umbrella with the sole objective of empowering the community. This has been evident for over five years, from conceptualization till the completion of four years of implementation of the project, where all eight partners felt respected and their voices heard. Every partner showed great level of commitment for the target communities with whom they worked under this project. The partners felt that every concern of theirs had been heard by other partners in this coalition. The different ideas and initiatives tried out by each partner organization were discussed periodically and considered for incorporating by other partners. All partners shared one common concern about the poor quality of service delivery with regard to treatment, care & support.

In the initial stages of the project, policies and code of conduct for the coalition was drawn up which was helpful to bring a common understanding across the board regarding finance, budgets, donor reports etc and in handling field-related / organizational issues. Any differences that arose between the coalition partners were sorted out amicably through healthy discussions and transparent communication. Since each partner agency worked out their respective targets by properly weighing their strengths, it was not a problem in the achievement of the planned target. A similar exercise was conducted once again in 2007 after the revision of the data by USAID on the number of infections in India, and targets for each partner agency appropriately revised.

Out of the eight partner agencies including the lead partner SIAAP, 7 CVCTC+ was planned to be established, one by each partner agency except Indian Network for People Living with HIV/AIDS (INP+). The seven CVCTC+s were established in areas where the community people were present in considerable number and where the partners have worked over a period of time. INP+, on the other hand, took the responsibility of building capacity of the PLHIV in four districts of Tamil Nadu, namely Ariyalur, Villupuram, Tiruvallur and Kancheepuram and one district in Kerala, Trivandrum. Thus the demarcated roles and responsibilities helped us to take this coalition forward without any issue.

Why CVCTC+ was our primary project strategy?

Voluntary Counselling and Testing (VCT) service model is a proven successful model in HIV programmes throughout the world. Here, people who voluntarily walk into the centre are provided with information on HIV & AIDS, counselled on safe behaviour, tested for HIV and linked with treatment, care & support services. Currently all counselling and testing and care services are based in government hospitals, where caregivers are often prejudiced against target communities and hence they discriminate them. Also, the hospitals are usually located in urban towns or cities and difficult to access because of distance, time and cost factors. In turn, the target communities with whom we work are usually poor, more vulnerable to HIV infection due to their profession or sexual orientation, less able to access prevention treatment and care services, as well as traditionally marginalized or discriminated against. In the light of these circumstances, CVCTC + was identified to be the most appropriate intervention model within the reach of the community people and succeed in reducing their poverty and improving their quality of life.

The CVCTC+ was planned and established within easy reach of 'target' community members. Each CVCTC+ was managed by the local partner in association with member organization of target communities, or other regional CSO. The member organizations developed ethical guidelines and policy framework for the CVCTC+ through consultative workshop. This guideline emphasized the need for non-discriminatory attitudes and practices, confidentiality, quality services and preferential access to target communities. Each CVCTC+ was provided with appropriate infrastructure facilities and equipment to provide quality counselling, testing, care and support services.

Apart from that, each centre comprised the following set of staff, out of which a significant percentage of project staff belonged to target communities :

1. A project officer responsible for the proposed action in that area
2. Medical officers for diagnosis and routine medical care
3. Nurses to support the doctor.
4. Counsellors for counselling
5. Lab technicians for testing
6. Outreach workers to mobilize target community members to the CVCTC +
7. An Accounts person as part of the administrative team
8. An Assistant to facilitate the work.

The team was oriented on the project, its objectives and their roles and responsibilities. Besides, there were periodic refresher trainings provided in addition to the meetings convened to share their experiences.

As envisaged under this project, the establishment of the CVCTC+ at the doorstep of communities to provide quality treatment, care and support services have helped them come forward to access services without any inhibition, understand their risk, prevent the spread of infection to themselves and to others. The centres also helped in sensitization of the people in the immediate environments who had a great influence in the quality of their lives. This helped the community to garner support from their immediate environment rather than depending on external sources to rescue them in times of need. The CVCTC+ centres were located in the following places :

1. Bangalore in Karnataka - Managed by Sangama, Bangalore
2. Raichur in Karnataka - Managed by Samraksha, Bangalore
3. Theni in Tamil Nadu - Managed by SIAAP, Chennai
4. Chennai in Tamil Nadu - Managed by SWAM, Chennai
5. Tirupathi in Andhra Pradesh - Managed by WINS, Tirupathi
6. Trivandrum in Kerala - Managed by FIRM, Trivandrum
7. Thane in Maharashtra - Managed by Humsafar Trust, Mumbai.

Having provided the services and required support in their immediate environment, the project helped the communities come forward and make more informed and responsible decisions for their life, advocate for their issues, practice safe behaviour, reduce their vulnerability, communicate openly with their family members and neighbours about their sexual orientation, seek their support and lead a quality life that is free from stigma and discrimination. The trainings each partner organization provided to care providers of government and other

NGOs was a successful strategy in sustaining the efforts even after the completion of the project.

Our experience in the establishment of CVCTC+ (Success and challenges) : The establishment of the CVCTC+ was very helpful for the target community who did not have any mechanism to link themselves to quality care, treatment and support services. In order to gain the best results out of this, the location for establishment of these centres was chosen with great care in order to facilitate greater community people's access. The main criteria that were considered for establishment of the CVCTC+ centres in a particular area were:-

Prevalence : HIV prevalence was considered to be the key criteria based on which the district & place were selected. Except Kerala, all the states were high prevalence states. It was much more important to consider the best location for this centre to benefit the community and create greater possibility for general public to access services, as mainstreaming and acceptance of community members among the general population was also a major agenda in this project.

Prevalence of high-risk activities : This is another criterion which was considered to understand the different high-risk activities that people engaged in. Many of these districts were high risk areas due to the migrating nature of the population or high number of tourists. The floating nature of the population attracted more PSW to these points which was helpful for the project in reaching more PSW and providing quality services to them. Some of these places were familiar for bars and pubs as well, where high-risk activities were on the rise.

Proximity to the service points: In order to successfully implement this intervention, it was considered that the centres be located within a reasonable distance from the basic services like ART centres, Community Care Centres (CCC) and Drop in Centres (DIC) which could be accessed easily if communities needed them.

Risk perception: Similar to the high-risk-activities that happened in a particular area, the risk perception among the people in that area was also taken into consideration while identifying the location of the CVCTC+.

Development activities : In a few locations, the government's expansion programme and the corresponding infrastructural development activities increased the level of migration to those places. Many construction workers were hired from different states and/or districts that stayed in settlement colonies. The level of risk behavior in such areas was quite high when compared to other areas.

7. Impact of the Project

Success of the CVCTC+ :

The establishment of the CVCTC+ as part of the Sarvojana project was very helpful to educate, build capacity of the communities and ultimately empower them to make more responsible decisions regarding their risk behavior and bring about positive behavior change. The success of the project can be explained under the following heads:

A) Community needs assessment : This project was implemented as a community driven intervention with the communities decisions being given priority from the initial conceptualization to the selection of the CVCTC+ points.

The community's needs were assessed through periodic interactions with individuals and discussion with groups and priorities drawn as part of the project.

B) Quality service delivery : Based on the assessed needs of the community, quality services were provided to the community that included counselling with regard to HIV prevention, treatment, informed choice, and testing service, referral services for ART, CCC and follow up services for the members. At periodic intervals the quality of these services were reviewed by the respective partners. PLHIV received the best services under the project with all those who tested reactive for HIV in the CVCTC+ being followed up regularly, referred for necessary services, joining the networks and accessing available government support schemes. PLHIV evolved a monitoring method for CD4 testing. Those who did not get their CD4 test results on time were discouraged from attending the meeting, which motivated them to get tested immediately. They also supported each other in providing nutritional supplements.





CASE STUDY

Family Support for a 'Kothi'

Raju is from a remote village settled in Bangalore. He was born to rich parents and has 2 elder brothers and 1 younger brother. He used to identify himself as a kothi and lived with other kothis in Bangalore. He was introduced to CVCTC+ by one of his friends and underwent pre-test counselling and decided to test for HIV. Before his report was revealed to him, he was happy and confident that he would test negative. But, it turned out that his report was positive. He was accompanied by the project staff to another testing center as he insisted on verifying the test result. There too, the result was positive. A few days later he came back to the CVCTC+ for follow-up counselling and started to reveal his experiences.

When he was studying, he had the desire to play with girls and considered himself as female. When he was dressed in a frock he was beaten by his father. As he had no interest in schooling, his father sent him to look after the cattle. His two brothers settled in

Bangalore and they brought him there and provided a job in a cloth store as a sales representative. He felt happy after coming to Bangalore as he started enjoying his freedom. He used to enjoy touching male customers. The shop owner noticed this and forced Raju to have sex with him. The owner used to give him less work and look after him well. He used to provide bonus to him and Raju also enjoyed this.

One day a customer from a neighboring state came to the shop. He observed Raju and noticed his activities and started visiting the shop more often. One day he asked Raju to quit the job to come and stay with him. The shop owner noticed all this and one day, a big fight ensued between the owner and the customer. On the next day, the shop owner called Raju's brother and narrated the incident. Raju was thinking about the new partner and decided to go and live with him. However, he left Raju after a few months. At that time Raju started falling ill and began to doubt his partner. Raju revealed to the counsellor that he got infected because of his partner.

Today Raju knows that both his partner and his wife are HIV positive. After a long time Raju met his ex-partner and had a long debate and fight with him. His partner convinced him and explained his situation. He gave some money to Raju for his treatment. Today Raju is staying all by himself. His parents often meet him and support him to access treatment. They also provide financial support for his treatment. Raju is addicted to alcohol and often suffers from OIs. The project provided him minimal medical support and accompanied him for treatment. He is regularly visiting the VCTC for counselling and for participating in the Sadhane support group meeting. He supports other PLHIV who are lonely and is an active leader among his community.

CASE STUDY

Peer Counselling in the face of Suicide

Mani and his mother lived in a rented house in Trivandrum district. Mani was the only bread winner in his family and worked as a driver. He was a bachelor. After some time, Mani showed signs of ill health frequently and was admitted to the medical college hospital. The test revealed that he was co-infected with TB and HIV. Mani and his mother returned home completely shattered and decided to commit suicide. The ICTC counsellor immediately informed the DIC about Mani's case and urged them to act quickly. DIC staff soon made a home visit and counselled them which helped them make up their mind to absolve all suicidal thoughts. Mani and his mother were facing some financial problems and the DIC staff referred them to the community care centre where they stayed for six months. Mani's case underlines the importance of peer counselling and how it helps bring back PLHIV to the right track of living. After completing the TB treatment Mani started to take ART. He is now healthy and works as mechanic in a workshop. Mani is now interested in marrying a girl who is also HIV positive and eager to live a life that is normal.



CASE STUDY

Counselling in a difficult situation

Kalavathy is thirty five years old residing near the CVCTC+. When her husband Mr. Anjaiah died, someone informed our outreach worker that 'someone' had died of HIV. Then we went and traced them. We spoke to the widow. She was not aware that he had died of AIDS. So, She did not even think that she should get herself tested for HIV.

Her husband was a TTD employee. She tried to get his employment on compassionate grounds. She knew he was having an affair with another woman. We supported her psychologically during her grieving period. She was very weak. She went for a HIV test and tested positive. After sometime she had to go for Pre ART registration. She accepted her positive status. She did not want our ORW to visit her house, because she did not want to reveal her status till she got the job, fearing that they might turn her down, on the basis of HIV, but was regular to the CVCTC+.

Nutrition and hygiene information was close to her heart. She wanted to confide about her relationship with another person, who was trying to befriend her when her husband was alive. She did not accept him then. He knew that she became a widow, and he continued to approach her and she too was in need of a companion. She learnt about using condoms, as her companion was not positive. The counsellor reminded her she should not shatter his (her companion's) family, just as her husband had drifted because of another woman. She was also sensitized that she should take care of her daughter, because her boy friend might abuse her daughter. She was sure about her limits with her boy friend, both were mutually dependent on each other, and were taking precautions as they knew the risks of HIV transmission.

CASE STUDY

Nutrition, Love and Care

Rajan (Name changed) an auto rickshaw driver lives in Chennai with his wife and two adult sons. Four years back he tested seropositive and has been taking ART for the past two years. His wife and children are negative and the whole family survives on his meager earnings.

Rajan's wife came to the LFC with a lot of worries about his health. He is working full time without proper food and enough rest. There is nobody to help him and no savings with them. Both the sons are unemployed. If anything happens to Rajan life is a big question mark for her always!

The LFC counselors developed a good rapport with the couple, counseled them on prevention aspects and safer sex. They asked his wife to participate in the trainings on nutritive food preparation, OIs and HBC which she did with a lot of interest. In the next follow-up session, one of the sons was brought to the center and counseled. The counselors succeeded in motivating him to get a job immediately.

LFC referred them to World Vision for some financial support. Now Rajan is happy and relaxed from the fear of death. His wife is working as a helper in a nearby school; son is going for daily labor work. World Vision supported him to start a garlic vendor business. Good food and family support improved his health in a better way.

C) Change in the attitude of the service providers:

There is a marked change in the attitude of the service providers, especially those who are working in the Government and private system who were sensitized through this project.

These service providers were able to understand the pain that the communities undergo due to stigma and discrimination, and hence were more sensitive towards their needs. Many of the service providers also started accepting the sexual orientation of the community members and treated them with respect which would not have been possible without this project.



CASE STUDY
Ensuring access to hospital services by fighting
Discrimination:

A client visited the ART centre at Civil Hospital, Thane to see the doctor on 9th Feb 2009. He had continuous fever and vomiting for the past 5 – 6 days. On 6th Feb 2009, ART Dr. Madam Hegde gave in writing that he needs to be admitted and sent him to medical OPD no 24. The Doctor gave the medicine for vomiting and told the client that he would be alright after taking the medicines. On 9th Feb the client returned with the same complaint as he was not feeling well.

The client was once again taken to OPD no.24 to get the letter for admission. Doctor examined the client and said there was no need for admission, gave some medicines and told him to come after 2 days. Doctor was requested to admit the client but again refused. With this issue we met Dr. Hegde and with her suggestion, once again consulted the doctor. He lost his temper and arrogantly said he could not admit this client into this hospital, that whatever medicine he prescribed was sufficient to make the client alright. When doctor was asked to write down what he said, he refused.

This matter was again taken up with Civil Surgeon, Dr. Tambe. The whole case was explained to him and including the circumstances in which client was being denied medical facilities. Dr. Tambe called for the doctor and asked why the client was not admitted, the doctor did not have a reasonable answer. Finally, in the end, the client was admitted and since then this doctor has not denied any PLHIV admission in the hospital.

D) Workplace advocacy

At Ariyalur district, as a follow up of Sarvojana initiatives to address workplace issues, a local work place advocacy committee has been formed to take up issues at the district level on a regular basis.

Of these changes the most significant has been the increased practices of Universal precautions by the lab techs.

Earlier, before our training, there was complete absence of any safe practices in handling the lab waste. The technicians used to dispose of the waste everywhere, putting the patients and themselves to risk. There were no bins to collect waste.

The technicians also feared contracting infections. INP+ through Sarvojana had given intensive one-day training on USP at the instance of District Project Manager, Tiruvallur district. There were many doubts and clarifications in the course of the training and each one of them was cleared.

The DPM who was present at the training had made immediate arrangements to get the kits and utilities. 3 color coded bins, aprons, gloves, appropriate materials, prophylaxis have been regularly given to the lab techs.

The lab technicians reported that they have no fear and do not feel insecure. The lab and its surroundings now wear a hygienic look.

CASE STUDY **Initiative of the PHC nurse**

Government health personnel, when they have the right kind of information and support can take the extra initiative to reach out and help people in need.

A positive woman delivered her baby in the Sirwar PHC. This was the first delivery in the PHC, and although the staffs were willing to do the delivery, they did not have the necessary kits. Samraksha supplied them with the necessary kits. But the PHC staff was not able to give Nevirapine to the child since they were not sure of the dosage. In the meantime, the woman returned to her village.

The PHC doctor and sister took the initiative to find out about the dosage. Through Samraksha, they contacted some specialist doctors, and got the information. The doctor wanted to call the lady back to the centre. But the nurse felt that because the child and the mother were very weak, they should not be asked to comeback immediately to the PHC; rather she would herself go to the village to administer Nevirapine.

This was the first delivery in Sirwar PHC, and the centre is now fully equipped and capable of managing positive deliveries.

E) Capacity Building for the community : The community member's capacities were built through a series of trainings that was planned and implemented as part of the project. These capacity building activities were planned based on the needs expressed by the community. In order to ensure their ownership and commitment to these skills and new learning, community



members were asked to remit a part of this expenditure for this capacity building activity as their contribution. The community members willingly contributed and got their capacity built in HIV programme, counselling skills, care giving, English speaking, and computer skills. This has built the confidence levels of the community which indirectly help them to negotiate for safe behavior.

CASE STUDY

A Little support goes a long way

For the past 10 years, Sultan has been recognized as a Kothi among the community in Bangalore. He was working as clerk in a private school. When he was young, he had feminine feelings but was never able to express it with anyone. Sometimes he used to get a chance to teach dance to the students. At that time, he used to wear saris and female attire which gave him great enjoyment.

One day he saw two men having sex. Curious, he continued watching and this increased his desire to have sex. At about this time, they also spotted Sultan watching them and threatened him... but as sultan had a similar desire, he ignored this and hence they became friends. From that day onwards they used to have group sex and he also got introduced to other homosexuals. At this juncture, Sultan had an interaction with a Satla (Female attire) Kothi. One day, Sultan wore a satla and joined his satla friends for begging. Slowly sultan started practicing as a part-time sex worker after his regular job timings. Then he resigned his job and got into full time sex work.

Earlier, when Sultan worked in a school, he used to go home early and spend some time with his parents. But once he started practicing sex work, he returned home late and hence due to his behavior and late-coming, his parents became suspicious about Sultan's activities.

Hence his parents arranged his marriage with his relative's daughter. Sultan was not happy with this but agreed for the sake of his parents. Within one year of marriage, his wife left him and went to her parent's home as Sultan had no interest in sex.

During this time, Sultan interacted with a new male partner. He left Sultan after having a relationship for about six months. Sultan was aware of Sangama programs but never visited due to fear of identity. He had visited one of the DIC of Sangama for the first time with his friend in 2007. Later, he came to Sangama VCTC and underwent testing for HIV after having a pre test counselling. His report was revealed to him by the VCTC counsellor and he was shocked to hear that he was positive. Sultan had an unmarried younger sister and aged parents. He was confused about changing his behavior and fully concentrated on his health. The project staff introduced him to the FSW and MSM PLHIV support group called 'Sadhane' and he consistently attended meetings. Today he is proud and happy and supporting many PLHIV among the community. He is also managing a pilot project funded by NACO in four districts of Karnataka.

Today he is living with his wife happily. He convinced his wife and tested her for HIV. He is happy that his wife is negative. With the support of the project, Sultan and his wife took the Hepatitis B vaccination and were provided with nutritional supplements. Sultan is also part of PLHIV networks like Arunodaya and KNP+. Now he is self confident and also a model for other PLHIV. He is open about his status and involves in many media and public programs as a PLHIV speaker.

CASE STUDY
From victim to volunteer

Sukumari was born in a family which was too poor even to meet the bare necessities of life. So from an early age, she was forced to start working as a domestic servant in a nearby home. Later, a member of the same family abused her and she got pregnant.

A baby boy was born and the illegal father threatened her of dire consequences if she revealed his identity. So she continued working with the same family. Once again, Sukumari got pregnant through the same person, but, this time around his family members came to know about this and dismissed her from service. A girl baby was born and there was no means to feed her. Sukumari was forced to leave the child in the care of another family. Later the child showed symptoms of recurring ill health though she was looked after well by them. They then took the child for an HIV test and she was tested positive. Later, Sukumari was asked to undertake HIV test and she also tested positive. Then Sukumari was told to look after the child as the family was not interested.

She returned home with the child, without treatment and the child died soon. Sukumari's mother herself immediately made public the news about her daughter's HIV status. The discrimination started soon; the villagers never allowed her to take water from the public tap. At that time, Sukumari came to know about DIC through a person and she started sharing her hardships with the staff. The staff visited her house and talked in detail to her mother which helped her to change her attitude. In the meantime, her son was driven out of the Anganwadis and hearing this, TDNP+ intervened to help her. With the help of the Panchayat President, they conducted many sensitization programmes to dispel negative attitudes and doubts among the people and provide accurate knowledge about HIV transmission. This helped change people's mindset towards PLHIV. Sukumari struck a good rapport with the people and they, in turn, helped her meet her needs. Now Sukumari is taking ART regularly and doing well as a member of an SHG. She voluntarily counsels the newly identified PLHIV and takes part in active politics.

F) Support for Children : Only under this project, support group meetings for children were conducted. They were provided a platform to express their concerns and get mutual support, information on the infection, life skills education, celebrate Christmas and Children's Day. Support is extended to the children, many a times, it is not to the full possible extent due to lack of family support.



CASE STUDY
Relief from an oppressive situation

Lavanya (10 years) is the daughter of late Sivaiah and Nagamma, who were victims to HIV. The child is also infected with HIV and is a school dropout. At present, she is staying with her third brother. Prior to her being with her third brother, she was with her eldest brother, who used to look after her. Her second brother got married to a girl out of their caste and they left the village. Thereafter, the third brother also got married, within relations. Subsequent to this, the eldest brother transferred the responsibility of to his younger brother, and washed his hands from the situation.

After coming to the third brother's house, Lavanya's situation went from bad to worse. Her education was stopped and she was forced to work as a servant in the house. During this period, her health started deteriorating and she used to have fever, diarrhea and vomiting on a regular basis. The family took it in its stride, assuming that these were normal occurrences due to ill health.

During routine home visits by WINS staff, the neighbors of Lavanya approached them and described the treatment meted out to the child by her brother and his wife. WINS staff is thankful to the neighbors and they approached Lavanya's family. They counselled the family members and got the child tested for HIV, where she was found to be positive. They also got to know that she was being deprived of basic education, nutrition and emotional support. They started giving egg and milk every day.

Despite nutrition help and counselling, it is seen that this child has not started any treatment. Her plight is quite deplorable and her situation has to be addressed at the earliest as none of her relatives are willing to accompany her for ART treatment.

CASE STUDY **President's involvement in a case of an HIV Positive**

Bency and her brother, Benson, two HIV positive children in Kerala, whose parents had died of AIDS, received humane treatment (after they were socially ostracized) thanks to the kind gesture of former President of India, Dr.A.P.J. Abdul Kalam. As per his directions, the then Union Minister for Health, Mrs. Sushama Swaraj, took the initiative, and instructed the management of Hindustan Latex Limited (a CPSU under the Ministry of Health and Family Welfare) to provide these children with financial assistance for their education, health care and other connected expenses.

Hindustan Latex Management decided to provide Rs. 60,000/- per annum as financial assistance to these two children for 5 years from 2003 October onwards. The Hindustan Latex stopped the assistance after the said 5 years, and did not extend it, though we represented to them to continue with the assistance.

When it was learnt that Bency was undergoing second line ART treatment at Ward No 3, SAT Hospital, Trivandrum, Kerala, since August 1, 2009, we enquired about details of the treatment with the hospital authorities, fully knowing that there were no trained doctors to administer the second line treatment, and that the hospital had not adhered to certain conditions attached to second line treatment, specified in the NACO guidelines. The hospital authorities refused to divulge any information, and kept the case a confidential matter. We felt the question of confidentiality was not at all relevant in this case, because the issue of Bency was widely reported by the local and national media. The concerned doctor expressed her limitations by saying, "Even I cannot discharge this child, because the Health department, KSACS and NACO are involved in the treatment of this child".

We then, wrote a letter to the President of India, which was released to the media. We received a reply from the President's office stating that the letter had been forwarded to the health ministry for necessary action. That forced the hospital authorities and KSACS to convene a press conference and divulge all relevant information about the treatment.

CASE STUDY
Nutrition and Future Care

Goutham, aged 10 years, is a HIV positive child. Goutham lost his parents to AIDS three years ago. Since then, his grandmother is taking care of his well-being. She is 60 years old and gets an old age pension of only Rs. 200/- per month. Because of Goutham's HIV status, Salamma's other sons have left her. One is a farmer and another works in a private firm. They not only dislike their mother taking care of daughter's child, but, also the child is HIV infected.

Goutham is studying in the 3rd standard and is very regular to the school. He is on ART treatment since 2008. , The sarpanch of the village has been of immense help to them and has supported and admitted the child to school. Initially, there was discrimination from both children and teachers, but the sarpanch took it upon himself to create awareness and provide counselling to the students and teachers, and the community in general.

Goutham, was very weak, unable to walk, and had skin allergies and ulcers in the mouth when CVCTC+ staff met him. He was treated with medicines and food. Now, Goutham is in school and is being provided with mid-day meals. WINS is providing him with nutritional assistance of a 1/2 liter of milk and one egg every day. His grandmother also gets eight kilograms of rice through the public distribution system and her only daughter gives her ten kgs of rice every month. She has learnt to give him locally available protein rich food and he is regular to school, in addition to following his ART treatment.

Goutham requires education, fortified nutrition, protection from discrimination and stigma even after his grandmother's

demise, Such a situation would demand adequate action from the authorities to ensure that the child's future is well looked after.

CASE STUDY
Infected child turned Caregiver

Ponnuswami, a 14 year old child, is afflicted with HIV. His parents have succumbed to this disease and have left him an orphan. He is studying in the 9th standard and staying with his aunt (mother's younger sister). In addition to being HIV positive, his aunt is auditory and verbally challenged as well as mentally unstable. She has a child, whose responsibility is also the prerogative of Ponnuswami. The child has no income of his own and is dependent on the provisions obtained through his parents' ration card and help from relatives.

Ponnuswami has been on ART treatment since 2008. These medicines have to be taken on a regular basis. His aunt's condition is such that Ponnuswami has had to face numerous problems from her side. These included clothes and medical reports being torn and medicines being destroyed. To get out of this situation, Ponnuswami started keeping his medicines with his mother's elder sister, so that he could avail of them when required. This has proved to be an adverse decision for the child, as this lady took offence to the fact that the 35 kgs of rice that Ponnuswami gets on the basis of the ration card of his parents goes to his aunt's house and that she is not benefited in any way.

The child does household work, goes to school and takes care of his aunt and her child. Due to this, he runs short of time and money to go to his elder aunt's house and take the ART medicine on time. This is telling on Ponnuswami's health and he often falls ill.

As can be understood From the above scenario, Ponnuswami is in dire need of care, support and nutrition, though he gets some milk and an egg everyday with the help of WINS till the project ends in December.



CASE STUDY **Care of Infected Children**

Revathi, aged 13 years, is an orphan, who has lost her parents to HIV related illnesses. The child got to know about her HIV positive status, when she was 10 years old. Since then (from 2007), she is on ART treatment. At present, she is studying in the 7th standard in a government school. Revathi is staying with her elder sister, who had an early marriage. After coming to know about Revathi's positive status, her brother-in-law (Revathi's elder sister's husband) has abandoned the family.

Revathi has to face the brunt of anger from her elder sister, as she forgets to take her medicines and food on time. Revathi is also not allowed to play with her sister's child. Considering all these factors, the sister has come to a conclusion that Revathi should be admitted into a hostel.

To this, Revathi's reaction is negative, as she feels quite happy and satisfied from whatever love and affection she is getting from her family. She is apprehensive as to how she would be treated if she is admitted there. Revathi's sister wonders why only egg and milk is given to her and not to her child; she in fact troubles her to keep the house clean and demands that she does some house work, even if she is not well, and in a fit of anger, asks her to leave the house.

WINS team stood by Revathi when she was admitted in the hostel. She learnt that she has supporters who are kind to her and advise her about her well being. Further, it can be clearly stated that the security and bonding that a child receives from his/her home cannot be provided by any residential institution. Considering this point, it has to be ascertained that help from requisite support systems would be significant in the long run.

CASE STUDY
Infected orphans and their care

Murali is 13 year old staying with his sister in his Aunt's house at Thirumanur. Both Murali and his sister are infected with HIV by birth



and their parents died years before. They are studying in the village school and Murali is taking ART from Thanjavur Medical College. But most of the time he doesn't have money to buy his medicines regularly.

Once, field workers from Ariyalur District Network for positive people visited Murali's school and requested the teachers to lend a hand to get his medicine regularly. Teachers started to help him. At that time Perambalur HUT, an NGO came forward to help Murali. They with his aunt's permission shifted him to a management school where they promised free education. His ART is transferred to Perambalur ART center and he has started studying in the new school. However, after 6 months, he had some disputes with some of his schoolmates which ended in a suicide attempt by swallowing 30 tablets. By the grace of God, he escaped from the critical condition. The school management took disciplinary action and relieved him from the school. Murali returned to his village, discontinued not only with his studies but his treatment also.

At this time he had some infection, itching, and sores all over the body. Field workers from Ariyalur Network once again took him to Thanjavur Medical college. Murali has started attending meetings and training conducted by the network. The training on Opportunistic Infection conducted by DLN under Sarvojana Project gave him a lot of information related to his health problems. He took treatment for OI infection and started ART again from Thanjavur Medical College. Now he is studying in the village school again.

G) Community empowerment and ownership : The community members were empowered enough to make safe

choices regarding their behavior, support another community member when there is any violation of their rights, raise their voice whenever their own rights were violated, started seeking the support of other members thus started showing their solidarity for the community group. They started to take ownership of their life and also this project, which makes it possible to sustain the momentum that was set off by the project over these four years.

CASE STUDY

Empowered decision:

The client is a young lady, her name is Manisha (not the actual name of Client). At the age of 15 she got married. After one and half years of marriage her husband started getting sick and Manisha's life revolved around caring for her husband. Days passed by and she got pregnant. She opted to test for HIV and her test result declared that she was HIV positive. She had to manage her husband's illness on the one hand, and her baby on the other. After a few months, her husband died, and her in-laws family started to blame her for his death.

At the age of 19, she was widowed and a single parent. After knowing her HIV status, she started ayurvedic medicines to gain weight and to be strong and healthy and completed one year's course. She has been maintaining her positive status for the past 12 years. After her husband's demise, she lived with her parents for many years. Now, her daughter is grown up and she returned to her in-laws place. She is doing all the work and serving them, but getting no support. She chose not to re-marry and spend her life alone.

After many years, she is in love with a person called Ashok (not the actual name). Ashok also loves Manisha very much. He knows about her positive status, yet, he wants to marry her. He is

supporting her treatment and is willing to be with her till the end and to take care of her. Manisha says she was restricting him, thinking he could get infected if he lives or talks with her. After consultation with Humsafar, she changed her stance and now says he can talk with her or love her, but would not prefer to marry him because **“I am HIV positive and will it be right to get married with Ashok and make him positive?”**

CASE STUDY
Courage in the face of a threat

On August 10th, 2009 The Humsafar Trust TG staff was taking the Ambernath train. She entered the compartment and stood near the window where there were two people. As she entered the train, they started shouting and ordered her to get inside. She thought they might be a policeman which is why they were ordering her, yet, she asked them who they were to tell her to go inside. She asked “are you police?” but the people didn't respond. She then realized that they might be thieves / thugs who have come into the compartment. She was scared but mustered the courage to speak with them boldly. When the train reached Ulhasnagar station, she held both their hands and pushed them on platform. Suddenly, one man bit her hand; she screamed for help, many commuters gathered around and started beating them. When the policemen reached the spot, the thugs were handed over to them. Police thanked Humsafar Trust staff and appreciated the TG's courage.

CASE STUDY
Aspiring community member motivated by leader of the community group formed at CVCTC+:

Divya is a HIV Positive transgender, born and brought up in a very decent family in Tamil Nadu. Before getting into the Hijra

community, Divya completed her college from Mumbai. Later, she started staying with her Guru and doing Basti and Mangti. She was so involved in her work that she was unable to take care of herself. Suddenly she became weak and her Guru immediately took her to hospital to check her CD4 count, which was found to be only 70. She completed her baseline Investigations and started the ART treatment regularly and ultimately her CD4 count rose up to 152. Divya wanted to continue her studies but after such an incident she was not able to. Divya's guru knew that she wanted to continue her studies and prove her identity in society; she encouraged her to continue studying. From then onwards, Divya worked as well as kept up with her studies. She has now completed her D.E.D Exam in Tamil Nadu and stood first in the State. She came back to her guru with the result and applied for further studies. Now Divya is working in Hyderabad as a professor with reputed college.



CASE STUDY
Start Young :

This is about an Incident during Worlds AIDS Day campaign on December 2nd, 2008 at Bhiwandi. The rally was organized by FPAI

(Family Planning Association of India) along with B.ed college students and we were invited by FPAI to join this procession. We went with our staff members, peer educators and Drop- ins to participate in the rally and show our solidarity. At the time of the rally, the students were teasing our group members. Their unruly behavior was ignored by us for some time, but when it went beyond limits, then The Humsafar Trust members complained about this incident to FPAI. But when we realized that no action was taken, we directly approached B.ed College and complained about this to the Principal. Principal called all the students and asked us to identify those who made fun of us. Once we identified them without fear, these students apologized to us for their indecent behavior.

CASE STUDY

Holistic care for a PLHIV:

Maya, (Name changed) a 29 year old illiterate woman infected with HIV lives in Villupuram district. Her husband died 5 years ago due to AIDS. She has a 7 year old daughter who is also positive. Both of them are on ART for the last 2 years.



After her husband's death, she shifted to her parent's house and depended completely on them. But her family is not happy with them staying in their house due to their positive status. They discriminated them by not allowing them to involve with others or attend any family functions. Maya was mentally depressed by all this but, knew no way out of this strangulation than to suffer. Once she came to know about life focus Center at Tambaram, she visited and shared her experiences with the counselors. The counselors suggested bringing one of the family members along with her during the follow up visit. But the family members were not ready to accept that suggestion.

The counselors referred Maya to the Villupuram DLN and she became a member of one SHG. There, she learned some craftwork such as mat weaving and making agarbatis. Now, she earns Rs. 30/- from the SHG for her daily needs.

With the help of LFC staff, her daughter got accommodation in a hostel near Kancheepuram where she receives educational as well as medical support, free of cost.

Now Maya lives happily without much stigma and discrimination and not depending on others for her immediate needs. She regularly visits the LFC to participate in trainings on nutrition, OI treatment, HBC and to discuss and share her life with the counselors.

CASE STUDY
TAKING ON THE POLICE UNAFRAID:

Aparna :

I was working near Dombivilli station. One person took me to a place where sex work happened. We had sex and after that

when I took the condom to dispose it, he held my hand and told me that he was a police man and since I had sex with him, I either had to give him money or go to the police station. I boldly told him "If you want to take me to a police station, let us go, but definitely I will first tell that you asked for money. If you refuse, then I will definitely give this condom which has your sperm. If you are eating food and throw it, that very food will curse you; similarly, if you use me and then threaten me, we also have courage to stand against such things. Then he became scared, apologized to me and said he would not do such things and would not come here again.

CASE STUDY
OPENING UP AND LIVING LIFE FULLY:

My name is Saleem, but I am called by the name, 'Shanu' by the community. I want to share some of my life experiences. It is something that happened two years ago. It happened in Dombivilli station near Thane which is the cruising point for MSM activities. We all meet there. I went to watch a movie. I came back to take the train on the 3rd platform. I saw a person and signaled to him. He caught hold of me and started scolding me. Just at that time the train came, but he continued to beat me. Two men tried to help me and stopped him. One of them brought the police. But before that he pushed me on the floor and was beating me. They arrested him and took him to the police station. After some time, his parents came and requested me to leave him. They discussed with the police about some settlement and after completing my medicals for my bleeding wounds, the police gave me Rs. 200/- and asked me not to talk about this to anybody.

I was worried about what my family would say I gave a false address. I missed the train and spent the whole night in the station. The next day I took the train in the morning. A similar incident happened to my friends and they also took those culprits to the police. I request gay and MSM to have the guts to take action against such people. I think these days the MSM groups have grown and are not afraid to express their views and ensure that they are also human beings. I learnt that being an MSM, one should not be ashamed about one's orientation, and should not be worried to express about it to family members. Gays and MSM are taking the steps to complain to police due to advocacy efforts which was not there earlier.



H) Opportunity to advocate for the community : The CVCTC+ helped people access its services without any reluctance and helped the partners to identify key issues that affect the community. Most of the issues were due to the attitude shown towards the community by the service providers, Government officers, and police people. There were also instances where the NGOs tried to bring their personal agenda into the HIV prevention

and control programme and were stopped from doing so.

Though we need to continue our efforts in strengthening the community, the efforts taken this far was feasible because of the strong linkages created with the community and the trust that was built with them over years of works done by the partners.



CASE STUDY

Forceful eviction of sex workers and Legal Intervention (Advocacy)

In August 2006, 39 FSWs were thrown out of their legally occupied homes in Bangladesh Colony in Kozhikkode by the moralists with the tacit support of the local Marxists and the police. Since the agitation would have caused imprisonment to many community members, we moved the High Court of Kerala seeking direction from the State DGP to give police protection to the evicted sex workers to re-enter their homes, and to conscientize the entire police force in the State about the legal status and rights of sex workers. The Court gave an order in our favor.

But the implementation is still pending due to lack of support from the local people and a section of top brass in the police, against whom we are contemplating contempt proceedings. Regarding the order to provide awareness sessions to the police force about the rights of sex workers, the government has entered into an agreement with the Kerala State AIDS Control Society (KSACS) to impart this awareness.

The lesson learnt is that sex workers are still being used by mainstream society and its agencies for the ends of mainstream society only. So, when the real issue of discrimination crops up, the mainstream society and its agencies turn a blind eye towards the issue. In this case, no other NGO, human rights activists the media, politicians or KSACS came to the help of sex workers except FIRM.

CASE STUDY

Fight against Stigma and Discrimination to an HIV positive (Advocacy)

Ashok K. Nair, an HIV positive, met with an accident that saw his left leg broken at three places. Though he was rushed to a leading private hospital, which was nearby, the hospital management discharged him, without giving the necessary treatment, once his HIV status was revealed. He was rushed to the government-run medical college hospital, where he got apt and timely treatment without discrimination. We managed to press in the service of the media into the incident. The incident was widely reported by the media.

We moved the National Human rights Commission (NHRC) on the second day itself. The NHRC asked the Kerala State AIDS Control Society (KSACS) to enquire and report. The KSACS reported that there was no case of discrimination.

The very process of enquiry, conducted by KSACS, was discriminatory, in the sense, that the KSACS met the hospital management, who are offenders in this case, at their hospital and Summoned the victim to KSACS office and denied the witness his right to adduce evidence. The NHRC dismissed the case, against which we have moved a Writ Petition before the Kerala High Court, making both the NHRC and the KSACS as respondents.

But what helped the KSACS to file a false report was the statement given by Ashok K. Nair that since he was drunk and fell unconscious, he was not aware whether any discrimination was meted out to him at the private hospital. Ashok K. Nair gave the statement to KSACS without informing us. In fact, KSACS lured him with some offers. He fell into the trap. After they got the statement from Ashok K. Nair, the KSACS backtracked from their offers. Though Ashok later repented for his action, and gave a signed statement to us, which was rushed to the NHRC, the fact is that the damage has been done.

The experience gained from the incident, which we carefully handled, was that it is easy to cajole community members by offering them small favors without the intention to give/restore what is rightfully due to them. The KSACS, supposed to fight against stigma and discrimination of PLHIV, was acting, at the behest of influential politicians, to favor the private hospital management and save its face. This happens when government agencies work as the bridge at crucial and critical junctures.

CASE STUDY

Fight against discrimination towards HIV positives (THE PAMBADY ISSUE) The MDLP school management in Kottayam and the Parent Teachers Association threw out 5 HIV positive children, who were residents of an orphanage, in Kerala, in December 2006, purely because of their HIV status.

FIRM organized a celebrity visit by taking along the National Award Winner (for film acting) Mr. Suresh Gopi, who had been associating with the efforts to reduce stigma and discrimination towards PLHIV, and organized awareness classes. When those efforts did not produce the expected results, FIRM moved the High Court of Kerala (WPC No: 19860 / 2007 (s). The Court ordered on July 17, 2007, that the children be readmitted to the same school.

Next year, the issue cropped up again against the very same students by the very same management. While FIRM was discussing with lawyers about the legal action to be taken, the orphanage requested the school management for transfer of the children from the said school, thereby blocking legal entry into the issue. The experience learnt is that any effort to fight stigma and discrimination can be thwarted by interested parties, so long as the affected community members are at the mercy of the mainstream society that stigmatizes the community members.

CASE STUDY

Advocacy by the Peer Counselor

A positive woman was diagnosed with uterus prolapsed and came to the district hospital. However the doctor was not willing to perform the surgery. She kept putting it off, and furthered the delay by continuously prescribing different tests.

The peer counsellor placed at the district hospital heard about this, and tried speaking with the doctor, but to no avail. So he brought the matter to the attention of the District Surgeon. The District Surgeon took immediate action by personally visiting the patient and instructing the doctor to perform the surgery. He also publicly affirmed that the hospital was open to performing any necessary surgeries on positive people, and would not send them away.

This effort at timely advocacy by the peer counsellor has ensured that there have been very few problems with positive people seeking services at the district hospital, over the last few years.



1) Acceptance by family members: In many cases, the intervention by the Sarvojana team has helped many people from the community gain acceptance from their families, who were opposed to them at the start of the intervention. This was possible only because of family counselling services, education on HIV, clarifying their myths and misconceptions, and facilitative group sharing exercises by the project team.

CASE STUDY

Groups as a setting for disclosing about HIV

Public disclosure about HIV status can be a powerful tool for galvanizing the community to pledge support for people living with HIV, especially in an atmosphere, where the groups are already starting to think in a sympathetic way about PLHIV.

In one of the perspective building sessions, Hanumanthappa, a participant spoke about being accepting of people with HIV.

According to him, "All of you say you have to be accepting. Even these people from Samraksha have come to say the same thing. But who has done it. I have actually done it. I am supporting my brother who has HIV, I give him food and shelter"

Hearing about this, the entire group was moved. They came forward to support Hanumanthappa and his family, and vowed that they would support any other person who is living with HIV in their village. To this day, people in the village are very supportive of PLHIV. Youth bring them to clinics on their motorbikes, they help them access services, and support them in other daily routine activities.

CASE STUDY

Testimonial sharing by positive person to inspire change in another's family During a group education session, one positive woman shared that her elder son had started acting in a very discriminatory way towards her. He kept complaining that her illness had stigmatized him, and he felt ashamed of himself when he went to work, and had to listen to the comments of his co-workers. She shared that despite some people from the Samraksha centre trying to talk to his son, he had not really changed.

On hearing this, another participant in the group volunteered to help. He was a school teacher and positive for HIV. He sought out and spoke to the son, and shared his own story. He spoke about how he too had to listen to so many comments about his status, but had learnt to overcome them, and sometimes even educate other people using his own example. Many people, near and dear ones had hurt him; but, why was the son hurting his own mother.

This sharing of a personal story inspired change in the son, who is now very supportive to his mother.



J) Respect for the community members :

The community members were respected and the level of stigma, discrimination and violence on them by people in the immediate environment (PIE) has reduced drastically. In some areas, the local community even started getting advice from the community members for their issues. In some cases the CVCTC+ was considered as a centre where people who need support can get guidance and advice. The counselors from the CVCTC+ centres were well-received and respected in the ART and CCC whenever they referred people to those centres. Thus the respect for the community among the general community and other service providers has considerably increased, which is what was envisaged when this proposal was developed.

CASE STUDY

Positive Living

Mr. J and Mrs. L are HIV positive. He is twenty five years and old she is twenty. They were referred to us by our outreach worker.

He had OI's, inflammation on the neck and fever. She was pregnant with their second baby when they visited the CVCTC+. They visited to clear his doubts about the reason for his inflammation, which was troubling him, so often; that he would like to get some blood tests and investigations to get rid of the problem.

The counsellor told them that he wanted to talk separately to both of them. She said that she could clear all possible doubts in her capacity and then they could also get the tests done. Mr. J said, "you can talk to us together and my wife or I would not mind you saying anything to us". But the counsellor insisted that she would prefer a separate conversation with them and then a joint session which was agreeable to them.

The counsellor introduced himself. Mr.J said he worked in a tea shop at Reniugunta. He said he was sick for the last three months, but was unable to recover despite treatment. He said he took the advice of our Outreach worker and had reached CVCTC+. He was very scared because he was getting fever very often, a swelling that never subsided. He informed about TB symptoms, and tests and treatment, later HIV counselling protocols, tests and treatment.

Mr. J. confided that his brother was positive and his wife was not willing to care for him. So, he had to take care of his brother, who was in AIDS Stage, and on his death bed, his mother was very old and his wife a home maker was unable to help his brother. He cleaned his brother's puss, blood with naked hands, and as he was a tea maker his skin was ruptured and expressed that he might have had an exposure to virus through him. He broke down after he explained all this. He was worried that his brother had passed away recently and said that he is sick now and would end up like his brother.

He got to know the advantage of early detection and he gave consent for HIV test, knowing the implications fully well.

The counsellor spoke to his wife; she was worried about her husband's health (inflammation). She said he was fine when she was pregnant for the first time. She gave her details; she was illiterate and was married for the past three years. She had known her husband to be a responsible person. He used to stay home when he had no work; he drank only occasionally, and did not visit other women. Asked whether she had, any risky behavior, she said, she was injected only once in her life for Polio. She was crying that they had lost her husband's brother recently and that her husband was also falling sick very often. She was given confidence that she can manage the disease with all available medicines and support. She consented for HIV testing. Both took the HIV test.

He asked the counsellor before he left "tell us how and what we can do now". After the basic information, the next day, both looked prepared to receive the test result. He was told that he was HIV positive. He received a shock, looked disbelievingly, and kept mum. "How can I live, will I get medicines"- these were some of his worst fears. After that he was given medical advice. Step by step, he took TB treatment to reduce the swelling. When asked whether he was willing to share his results with any one he wanted to do so with his wife; he was worried about his wife's test results. The counsellor told him that she could not disclose her HIV test results without obtaining her consent.

His wife was equally shocked and she wept. She was assured that early testing would do her good, as she had time to take care. She was willing to share her positive result with her husband.

She enquired about the complications. The doctor confirmed TB test results; they showed their HIV test results to the doctor. They were given tablets for ulcers, and swelling. They preferred to hide their results from their old mother; they wanted an assurance that the outreach worker would not reveal their status to their mother.

As a follow up she was referred to PPTCT centre. She was admitted in the hospital and administered Nevirapine. The older child is 3 ½ years old and HIV negative, the second child is under 18 months and tests cannot be done now. He visits the Centre for Hemoglobin tests every month and pays Rs.20/- as donation to PNP+. He is able to lead a normal life with ART.

CASE STUDY

Sensitization of the PIE

K. Danalakshmi is twenty three years old, her husband divorced her after two years of marriage, by the time, she was pregnant, and was attending ANC check up at a government clinic and was referred to the PPTCT centre . Her test results showed she was positive. Her only relative disowned her, soon after the news. She became a maid servant to many families.

As soon as she joined hospital for delivery, the separate ward in the hospital made her neighbors know that she was positive, including her only relative, her sister in law, who confirmed the news, and this information, reached her house owners. The house owner said only one thing "vacate my house". She insisted, and this was told to her when she was still in the hospital. She knew only the CVCTC+ phone number, and spoke about her plight.

Even before she could arrive home, from the hospital with the baby, the CVCTC+ team spoke to the owner, introduced themselves, and gently asked her why she did not want her back. The house owner replied, “we need to use the same pathway, there are no drain pipes and the waste water from her house might be a risk. She would touch all the things in my house, and even walls could get contaminated”. So she said she would prefer her to vacate and that she could get the house white washed



and make it virus free. After she came out with all her fears and misconceptions, the counsellor and the team attempted to clarify all her myths against facts one by one. Virus and its potency were explained to her. So she was able to clear all her doubts and permitted Dhanalakshmi to come back with her child and come home with dignity. She continues to live in the same house even now.

CASE STUDY

Surgical need attended:

The counselor received a phone call from Rekha and her husband saying that they were positive and would like to visit the CVCTC+ for testing their children.

Children were ten and eight, and healthy; the parents and children received pre test counselling.

Rekha liked the CVCTC+. Her mother's brother was fighting with their family. She approached for suggestions and slowly understood that she could also be healthy, but she had severe white discharge. She received treatment three times, but did not get any relief; she had severe abdominal pain, and was bleeding too. She went to the Government Maternity hospital for STD treatment all by herself taking the advice of ART centre doctor. She had treatment adherence, but the doctor did not do PV Examination because she was HIV positive.

They prolonged her treatment. They said they could not operate on her because she is a Known AIDS case, and junior doctors flatly refused to be kind to her. But then she persisted and met Senior doctor too. Even there, she was not treated kindly, "You are taking ART, we cannot do a surgery", The (senior doctor) too referred to her as an AIDS patient!

But CVCTC+ team without losing hope met the Superintendent of the Hospital Dr. Bharati, with the help of WINS Secretary. She was kind and explained about her immunity status, gave her a new set of medicines and treated her condition. She said her condition may not improve despite surgery. She took her advice, and, now she is free from abdominal pain and feels better even though she still has white discharge. She now runs a shop.

Panchayat Resolutions on anti discrimination

Another significant change brought about by the consortium; with specific reference to village leaders has been their determination to fight against discrimination of PLHIV and their families.

Nearly 27 Panchayat leaders from Ariyalur district have been sensitized and they have been fully convinced on the ill effects of discrimination against PLHIV. These leaders have come forward to pass Panchayat resolutions in their Gram Sabha.



CASE STUDY

Restoration of Property Rights of PLHIV:

There are community rooted mechanisms to address grievances, which if tapped in the appropriate manner, can help in the just and equitable resolution of the issue.

Basamma, a young widow, had faced many problems in her husband's family after his death and therefore chose to live separately. She was a volunteer in Samraksha's programmes. Her brothers-in-law started using this opportunity to cheat her out of her property. Her husband had dues from many people in the village, and the brothers started claiming the dues as their own.

Basamma got to hear of this and sought a way to address this problem. Discussion with the community team, and other volunteers helped to get some ideas. She sought the support of the Dalit Seva Sangha in her village, and personally went and spoke to the leader and disclosed that she was HIV positive, and therefore being cheated. The leaders went to speak to the family, and brought the issue into the community realm through discussion. Through this forum, they were able to restore to Basamma what was her due from her brothers-in-law. Some land, which was to be hers, and had been usurped by them after a watershed project was developed nearby, was also restored to her.

CASE STUDY

Community support in child upbringing:



Communities can be an enormous resource and support for the care and upbringing of children affected by HIV. Individual members in the community can and do take the required initiative to provide all kinds of support, including material support.

In one of the group discussions during a perspective building process, Yalappa shared that his daughter and son-in-law had died of AIDS. His two grandchildren were also positive, and he was looking after them. Yalappa became emotional during his sharing, and spoke about his difficulties in managing the two children. He said that although he had stretched his resources and ensured that the children got the right treatment and medicines, he was just not able to make sure they had good nutritious food, and did not know what could be done in the prevailing situation.



Yalappa's story moved one of his neighbors to such an extent, that from that day onwards, the neighbor sends a share of whatever vegetables and other food they cook in their house to Yalappa's grandchildren. Any special occasion food is always given to these children.

CASE STUDY

Small acts of acceptance have great impact

Small acts of acceptance can be very encouraging for people living with HIV, and can inspire them to be agents of change.

Lakshmamma, a widow with two children was shunned by all the people in her village because of her HIV status, and her husband's death. The villagers not only isolated her, but also actively discouraged anyone from supporting her or even talking to her. During the perspective building process, one of the team members visited her and spent some time with her. When she was leaving the house, Lakshmamma's neighbor stopped her and asked her what she was doing there. This opened up an opportunity to discuss with the neighbor about Lakshmamma's condition, and give them some basic information on HIV.

After listening to this, the neighbor had a change of mind, and the very next day there was a cradle ceremony in the neighbor's house to which they invited Lakshmamma and her children. This encouraged Lakshmamma to come forward and share her story at the concluding session of the perspective building process. She spoke of her illness, her husband's death and the discrimination faced in the community. She spoke of how overjoyed she was to receive the invitation to a function in the neighboring house. Lakshmamma's story inspired the community enormously, and they welcomed her back into their fold.

This experience also helped the other women in the SHG understand how everyone could be at risk of HIV, and how so many people among themselves, as well as their young people could be at risk. The women have been actively referring people for testing.



K) CVCTC+ as service hubs:

As we have mentioned, more community members and the people from the immediate environment started accessing the services of the CVCTC+ due to its service quality, high level of adherence to confidentiality, its links with different services and the respect they command in different health care settings. Thus CVCTC+ centres were seen not just as HIV specific service centres but as a community development centres by providing counseling for different problems of the local people. Many women from the local self help groups have accessed the services of the centres and taken advice regularly for their local issues, and how to proceed with them.

Challenges with CVCTC+

Irrespective of the achievements we have discussed above, and difference it made to the community, there were also some key challenges that we faced in establishment and operationalizing these CVCTC+ centres. We would like to discuss some key challenges here, so that it would be helpful for any organization wanting to set up similar community based service centres:

i. Low motivation level of the communities:

The community's motivation does not remain at the same level. It goes up and down which affects the work adversely. The chief reason being opposition from the local people in the immediate environment. This low level of motivation has reduced the voluntary participation of members in the activities of the CVCTC+, getting mobilized to the centre with community identity and accessing services. Much effort has been mobilized by all the partners in order to get the community's involvement through periodic discussions, educating and counselling them.

ii. Selecting the location for the CVCTC+:

Where the centres are located in a rented building, the owners of the building were not very interested to let out space to organizations working for HIV programmes. Although they were motivated by our efforts, the hesitation shown by PIE resulted in revoking their decisions and not renewing the rental agreement. The specific reason mentioned by them is that the community members are disturbing their neighborhood. The partners have taken many efforts to overcome these concerns and maintain the centres in the same location.

iii. Limited human resource:

The project was planned with very limited human resources especially for the outreach activities. The project recruited very few ORW, as per plan, who were not sufficient to achieve the target in terms of outreach and service delivery. This was later handled by establishing linkages with other outreach workers under other HIV programmes implemented by other organizations.

iv. Limited change in the attitude of HCP:

The healthcare providers were not completely supportive to the programme and the community as a whole, even though they started providing treatment to them. While confidentiality was given the top priority in CVCTC+ centres, confidentiality seemed to be more of an unfamiliar word in the government health care settings. The efforts made by the project over the years has helped bring recognition to the community, but, not changed the service delivery mechanism or the attitude of the service providers. Women face greater level of stigma and discrimination irrespective of the level of work that we have done over these years.

CASE STUDY

Persistent Stigma and Discrimination in Health care setting :

Munemma, 25 years, was half dead, groaning, struggling hard for breath. Flies and worms had infested all over her body. She was lying right on the corridors of the Outpatient Department, for twenty four hours. Everyone sped past her- doctors, nurses, and the next morning, sweepers had dragged her and dumped her near the entrance of the hospital. Not a single person bothered to find out whether she was alive or not.

The next day Muneeswari, staff of CVCTC+ went to the ART centre for her monthly medical review. She noticed that there was a body lying uncared for, and saw an ART book next to her. She tried to talk to her and wake her up, but she was unable to utter a word and there was no movement at all.

Muneeswari was baffled and upset when people "spat" on her, while she was still breathing. She rushed with her PLHIV friends, Pushpa and Aruna, to clean her and arrange clothes for her, but, by the time she could reach her with a stretcher to take her to the casualty ward (within half-an-hour) she was dead.

She requested the duty doctor to visit and declare that she was dead. She intimated the Police outpost that the patient was a destitute, and that the body had to be kept in the hospital as no one knew of her whereabouts. Efforts could be made to find out about her background as they had the ART Medical Register. In the meantime, the Sanitary Inspector and worker had to be called. When the news of death reached them, the sanitary worker was furious, used foul language and refused to budge an inch. She shouted saying "these destitute women go and sleep around and get AIDS and they burden us all the time" "why can't these prostitutes die elsewhere, they are taking our lives away." Muneeswari and others could not bear this and asked her to stop her theatrical outpouring and asked whether she could do her duty as was required of her. She called the Sanitary Inspector and reported the matter to him.

Muneeswari had to remind him that the treatment meted out to this poor woman was unjust and that the worker refused to do her duty of removing the dead body because she was an AIDS patient. In addition, she found fault with women, who showed some concern towards her; she demanded an apology for the verbal abuse that she hurled at them.

All PLHIV gathered and protested that she could not use derogatory terms. She was firm and told the supervisor that she would not allow transporting the corpse till she apologized for her bad behavior. Instead of reprimanding her, he started accusing. Muneeswari that he Would report her to the police station if she obstructed removal of the corpse. He went on to say that they were not scared even if the issue was taken to the media or to the Hospital Authorities. So, Muneeswari and others reported the same to the SVRR Hospital authorities and to the Media. Even though the media recorded the entire episode, it did not get the attention it deserved.

So, WINS decided to boycott World AIDS Day and informed the District AIDS control Officer that WINS was against participating in mere slogan shouting rallies, and claiming that Universal Access to Human rights for destitute women was not a reality.

V. Exploitation of the community by stakeholders :

The stakeholders of the programme like the SACS officials, medical officers and some members of the networks exploited the community for various reasons. The lack of access to resources, poor literacy level and lack of power to make informed choices by the community members made it possible for the stakeholders to exploit them. The project challenged this in many cases, but was not able to completely put a stop to all such instances happening due to lack of a legal mechanism to bring these people to books.

VI. Blocking empowerment of community members by policy makers: The CVCTC+ project envisages formation of CBOs. One of the CBOs thus formed was 'FRIENDS', a CBO of MSM in Trivandrum. The community members lacked motivation. When we succeeded in motivating them, their primary interest was about who should be selected as the office bearers.

Though we motivated them to register the CBO formally, it was limping right from the beginning. When we enquired about that, Some community members told us that many of them were closely associating with various projects of KSACS, and that the KSACS did not want any CBO to be registered without their participation. Though the NACO Phase-III mentions about the transfer of projects to the CBOs, the KSACS still wants the CBOs to be under their control and thwarts any attempt or move by the community members to form their own CBOs. Even if the community members succeed in registering their CBO without the assistance of KSACS, the KSACS would undermine the activities of that CBO by using the carrot and stick policy.

The experience shared is that the mainstream society, including the KSACS, wants the sex workers to be solely the medium to prevent transmission of HIV among the society. The real issue of empowerment of the community members still remains in the cold storage.



CASE STUDY

The issue of petroleum jelly as condom lubricant

It is a well known fact that only water-based lubricants are to be used in latex-based condoms. (Oil based lubricants can be used in polyurethane-based condoms). But, it was brought to our notice that a project of KSACS was supplying petroleum jelly as lubricants to the MSM. A few MSM had approached us expressing willingness to adduce evidence. We sought specific information from the KSACS under the Right to Information Act. The KSACS replied that they had not allowed any project to supply petroleum jelly.

When we contacted the MSM who had approached us expressing their willingness to adduce evidence, they back tracked. They told us that they had been forced to back track since the KSACS officials had hinted at their ouster from the project. In fact, their identities were revealed to KSACS by some other community members who accompanied them the day they had informed us about the practice of supplying petroleum jelly. The experience is that bad practices like supplying petroleum jelly are still very much alive, for reasons not known. But attempts to tackle them, legally, would be nullified using the community members themselves.

VII) Use & misuse of Media to portray community:

FIRM associated with Compton Foundation, USA, and the Tata Institute of Social Sciences, Mumbai, to make two separate documentaries, one each on the sex workers(based on the Bangladesh Colony eviction issue) and on F2M transgender.

Ms. Alexa from Compton Foundation, USA, approached FIRM for creative association in making a film on the issue of eviction of sex workers in the Bangladesh Colony. She said that there would be participation of the sex workers at different stages of production, including at the editing stage where their suggestions would be considered. FIRM had made it clear that they did not want the community members to be treated as objects of a film, to which Alexa agreed, fully. FIRM could not have entered into a legally valid agreement with the Foundation, for that involved many complexities that needed sanction from the State and Central governments.

But, after the shoot was over, and after all relevant documents were given to her, Alexa flew to USA, and informed us that she will have to do all the post-shoot work in the USA, and that she was not to take the suggestions of FIRM or sex workers while editing the film. FIRM wrote to Compton Foundation, quoting mails from Alexa which were contrary to her new stand, and asked the sex workers also to take up the matter directly. The film is yet to be screened.

The experience gave us a rude shock, vis-à-vis the attitude of so-called activists, that we have said 'NO' to another researcher from a US-university who came to do a study on the very same issue.

The film on an F2M transgender was thought of when we realized that, even those who work among the sexual minorities treat the sexual act of a transgender as a purely bodily act, resulting in a F2M transgender being wrongly labeled a lesbian, and hinting at that person's female identity, which that person disowns. That is because we fail to understand the mind of a F2M transgender when that person, who believes that he is a man trapped in a woman's body, thinks that it is the man in him that makes sex with a woman, positioning him in a pure heterosexual context.

The film-XXwhy- addresses the issue in clinically precise manner. The film had its premiere show in Toronto, Canada. The film got rave reviews within and abroad, and initiated a new look at the sexual and other identities of an F2M transgender.

My experience with Sarvojana

One of the key objectives of this booklet is to share our experience in running this project for the past four years and to allow the community members share their experiences in being a partner, as a service provider, as a staff member and also as a beneficiary who accessed any of the services that provided in this programme. In order to maintain confidentiality of the community members who have shared their experiences with us, we have not mentioned their names, or changed their names. Any resemblance of name to the name(s) mentioned in this sharing is only coincidence.

TESTIMONY

Enabled through one's own pain to reach out to others :

I am from Kerala, Trichur. My family comprises of my mother, father & one brother who is married. I don't want to get married as in our country a man can marry only a woman. I am a homosexual and I love men. Hence I can't get married to a man in our country. One year ago, my mother passed away. I started moving with my boy friend where I got the opportunity to meet more men like me, share our problems with regard to HIV, STI, family problems, which made me realize that I am not alone and that there are lots of people like me. I moved to Bangalore and started working where I met more people like me, male, female, Hijra, sex workers, transgender, lesbians etc., When I started discussion and sharing with them, I realized the difficulties that I faced in my life are miniscule compared to other people like Hijra groups.

When I met a few of them and discussed their issues, they shared about difficulties like undergoing surgery, wounds becoming septic. Similarly for a lesbian girl, she wanted to live with a woman, but she could not have her breasts removed as it was very expensive and she faced more problems as compared to me. So I decided not to concentrate on my problems, but devote time to listen to others' issues. I joined FIRM where I was given the role of an ORW, trained and given an opportunity to work among sex workers, MSM and lesbians. However, in Kerala there is no lesbian group; they migrate to Bangalore as there is no platform for them here.

People are afraid to go near people with HIV as they think that they will get infected by going near them. I continue to work with them and also educate others. The project should continue its service and provide more training. I want to say this to the community, "Kindly don't cry about your problem. If you have a problem it will be there, but start looking at other people who are suffering, so kindly come out openly about your status. Don't think about what society will think about you, but think about how you will look at society"

TESTIMONY

Right information helps reduce stigma and discrimination :

My name is Sarala. I am residing at Koovathur in Ariyalur district. When my husband died everybody in the village came to know about the reason of his death-AIDS! Nobody attended the funeral and we were not allowed to cremate him in the public cemetery. Hence we cremated him in our own land. Nobody in the village permitted me to do any work, talk to me or played with my children. I was also not aware about the disease then. I visited the district network, availed counselling and learned more about HIV and AIDS.

At that time our DLN (Ariyalur) planned to conduct a home-based care training programme supported by Sarvojana. I requested my aunt to join with me. She was not interested but came along to give me company. She has learned more details about the disease and its care. After the training there is a noticeable change in her attitude and behavior. She started supporting me more and shared her training experience with other relatives also.

When my daughter attained puberty, we had to conduct some rituals/ceremony. On that occasion all my relatives cooperated and attended the function. Now many people admit that while they had some fears about the disease earlier, they do not any more. So Sarala is living without stigma and discrimination.

TESTIMONY

An Aravani's story of struggle and success:

I am Guddiya. I am living in Bombay. I am part of the Hijra community and working with them. I am happy and also concerned about people's fear of HIV. There is no treatment, we all were scared. One RMP doctor was helping with treatment of our community. When someone becomes very sick, he suggests a blood test; if someone is tested positive, that person is thrown out of the house, because of the fear that others will get infected too. The myth was so powerful that people believed that if we even inhale their gas, we may get infected, so my guru sent them out. After the death of my guru, I was given that position. After 5 years I became sick and even after taking treatment for malaria, typhoid, jaundice was not doing well. So my blood was tested and I was found positive. I admitted myself to JJ hospital, where I was given treatment for TB and my CD4 count was 300.

Now, whenever I come to know that someone is sick, I meet them, arrange for treatment, and if found positive we take care for increasing the CD4 count.

There was one TG who was not doing well but avoided me. I asked another friend to check her status and tell me, She was found to be positive. I took her to JJ hospital, tested her CD4 and it was very poor, only 70. She took DOTS for two months and later started ART. After that she completed her studies, opted for a transfer to another ART centre and is working as a professor. Now I educate people on HIV/AIDS, how to avoid the infection, how to be safe, if they get infected, how to live their lives positively. I am living for them.

TESTIMONY

The dark connections between sexual abuse and sex work

I am _____ and I am sharing my story. I was 5 when my family was not in a position to take care of me, so they got me enrolled in a hostel. There were many children in the hostel. Once the school was closed for two days, and most of the boys went home, that time some senior class guys were drunk and they ragged me and raped me. I lost lots of blood and fainted. Hence they themselves brought a doctor and gave me treatment. Once the school started, I informed the school administration about this and they sent those students out. They asked me whether I wanted to continue my studies I said, "yes" and hence I completed my education up to Std. 7.

When my father was sick, my mother brought me to Mumbai. I was very interested to play with girls, and I continued my studies and also took care of house work. While doing my 10th std, I met another boy friend, who was an MSM. He introduced me to more members, took me to parties, and even suggested that

I involve in sex work to earn money which I did and started earning money. After few years, I was having Rs. 50,000. Once my mother asked for some help for my sister's marriage. I gave her that 50 k and told her not to ask where that money came from. She also did not ask. My sister got married and she left.

I failed in 10th and started to work, I continued to do sex work and earned money, and spent that. After a few years, my mother asked me whether we can perform my marriage or my younger brother's. I told her that I did not want to get married, but she did not agree to perform my brothers marriage before mine. So I agreed and everything was decided and arranged. Six days prior to my marriage, I ran away from home. My brother knew where I would be so he traced me and begged me to come back and get married; I told him what I was. But he insisted on my mother, father and family. So I agreed and got married. I had a daughter after that marriage and lived with my wife. But after 3 -4 four years I was having financial problems, so one of my friend suggested to me to get back to sex work. Though it was suggested by him, it was I who took that decision.

I engaged in sex work and started earning more money. At this time, I met another boyfriend who loved me very much. I committed a grave mistake; I had sex without using a condom. He left me and gave me HIV as well. After that I tested myself and was found to be reactive; informed this to my mother, she was also upset. I informed that I earned the money that I gave to my sister's marriage only through sex work. She was very upset but said she will take care of me as it was me who helped her during her critical situations. My relatives also started accepting me.

TESTIMONY

Empowerment in action :

Priya – WINS (Tirupathi): I am working as a peer counsellor in the CVCTC+ in Tirupathi. My husband passed away due to HIV and during that time I got in touch with WINS. I don't know anything about HIV, I know about AIDS and that if people get AIDS they will die. I attended a support group meeting for women and children. That's when I came to know about HIV and that children are also getting infected. My husband was positive, but I am negative. From that meeting I felt that I should start working for this issue. I started volunteering for WINS and in this project they have given me the position of a peer counsellor in the Sadhane CVCTC+ in the Sarvojana Project.

I was provided trainings and it improved my skills. I was educated only up to Std. 7. After joining this project, I improved my skills and am doing my degree and am in my third year. I learnt counselling skills here and am providing counselling services to people depending on their needs. My suggestion to people would be that what ever infection one has, whether HIV or STI, they should be treated as normal human beings who also have wishes, skills and capabilities. I was selected from Andhra Pradesh to participate in the 17th International Conference at Mexico. I was very nervous to talk with people there as I knew only my native tongue, Telugu.

However, I spoke in Telugu in a small group discussion, which was translated to them in English. That was a great experience which I cannot forget. I became confident that my skills had improved to talk to a big group in a different language and I also traveled by flight. It was a great achievement for me. I think that I should live for other people, and that is the objective of my life.

TESTIMONY

It's not about me, it's about all humans:

I am from Kerala from the organization _____. 12 of us MSM were staying in a house together. I got the opportunity to join this project and learnt many things here. I told my friends about the medical camp that was being organized, and they said that I can also take the HIV test as part of. So we all decided to test ourselves. 3 among us from our group tested positive; we were shocked as to how we were going to face this issue, inform our families and friends, and cope with life. After this earth-shattering experience, my life has changed; if 3 out of my 12 friends are positive, how many people would be positive in the community. When I thought about that question, I learnt that I should only have safe sex and I should dedicate my life for HIV prevention, not just for MSM, FSW and TG, but to prevent infection to all. My behavior has also changed since then. I thought that since I was exposed to sex education, I had not become infected.

So, now, I educate people and also provide emotional support to the gay community. Other services are provided by the state except this. Hence we want to build them as a group and impart education and provide emotional support. I took a pledge that nobody should get infected and that's why I am living today. Infected people feel that they have done something wrong and that's why they are infected. I still feel that there is no platform where we get right information.

TESTIMONY

Empowerment & advocacy through sangams:

I am Radha from Tamil Nadu. I became a sex worker early on. When I was at home, the police took me and told me that they were filing a case for 'soliciting in public'. But when they filed case on two members and asked me to sign a case, I refused to sign. The sangam people also came and advocated that I was at home and did not solicit anybody.

They asked for money and I gave the money I had saved. The sangam members also gave me money and helped. Why I did not want the case to be filed was that I have two daughters and do not want their life to be spoilt. I can earn money; similarly the sangam members also helped me on time. They saved me. I will continue to work for them and do any sacrifices. In our sangam, earlier nobody respected us, but, now even the general people come and ask us for help as well as the police, to help to solve some problems. This recognition is mainly because of the sangam. We have learned and benefited a lot in the sangam, I was not very literate and did not even know how to write my name, but now I read and write well. Savings is very helpful for our future; hence people should have the habit of saving.

TESTIMONY

Gay & positive and a leader by example:

I am Sundar and I am HIV positive and living healthily for the past 17 years. I was diagnosed for HIV in 1993. I started SWAM organization, which works for MSM, Gay and TG and PLHIV. It's a 17 year old organization. We have lots of support from donors such as FHI, TANSACS, and APAC. Fifteen years ago MSM were a hidden population while only TG was visible, and were not recognized due to the strong cultural background. However, at present the media has raised our issues and the government has given recognition for MSM. 40% are yet to be recognized. I used to think that community people did not have talents earlier.

Now the scenario has changed- TG & MSM have talents, are permitted to study, and attend colleges. Community people are coming up and standing on their own. They are also taken into the mainstream community. I request the family members to accept the gay and MSM and not to hate and/or discriminate them. Be sensitive and sensitize others to accept the community.

Each family member should show acceptance and you should understand that we are a democratic country where all have equal rights.

TESTIMONY

Annamal: (TN) – a 'positive' grandmother and still going strong!

I started my life in a decent family. After getting married, my husband passed away. I liked someone and ran away with him. He disowned me and I was left with the child. When I joined work to fend for my child and myself, I was pressurized to have sex. This is how I started engaging in sex-work. I had to face violence from rowdies; they would knock at my door and when others asked about it, they would say that I was the one who called them! Men are interested only in having free sex but not willing to pay any money.

One of my friends working in an NGO helped me and with her support I went to get tested for HIV. I was found to be positive. It was very painful. I had three daughters and I could not die leaving them alone. I was so scared that I may die, or be thrown out of house by the house owner. I did not have adequate and accurate knowledge about HIV. So when I shared with my friend about this, she said that I need not worry, and that I would live long. She took me to her house, shared the food that I ate, used my soap. I became confident and started to do some household work, field work, and kept myself occupied. As a result, my health improved and even if I told people that I was HIV infected, they did not believe me. I volunteered myself for this project.

SIAAP was the organization that helped me. They did not pay me; however, they helped me to handle my issues with my neighbors, the police and related problems. They trained me on different aspects; now I am well trained in counselling and have helped many people avoid the suicidal thought.

Recently I helped a TG who was scared and thought of committing suicide. Later she took care of her life. Similarly a girl was not taken care by the family and was discriminated by them. After counselling her family, and her husband, they are now living together. I have achieved a lot. My daughters are married, I have grand children. I have not disclosed my status to my sons-in-law as I was scared that my daughters may be thrown out of their marital homes. One daughter is yet to be married. After her marriage, I will disclose my status to them and will do service to others.

Reaching out to the wife of an MSM :

My name is Ramu. I identify myself as a 'Double Decker'. I have two elder sisters and am the last son in my family. I work in an export company I am married to a woman, even though I am least interested in women and marriage. Out of the force of my parents, I had to agree to get married. When I have sex with my wife, I think of guys in my mind and have sex. Often feel bad about my situation.

I have engaged in sex work for the past 8 years. Sometimes, I have sex even without condoms. I consume alcohol everyday and sometimes have sex under its influence. I did not know much about HIV and STI and how to use condoms properly in my early days. While having sex with guys, mostly I prefer to have anal sex [receptive].

Some months back, I had pain, itching and oozing in my anal region. Initially, I took some home remedies and self-medication and did not care much about this. But, the pain did not subside. I was apprehensive about getting information from other [MSM] as they might spread rumors within the community.

At the same time, I was reluctant to go to the hospital, for fear of being identified by other [MSM] coming there. So, I had to undergo a lot of mental agony alone without knowing any remedy.

Then, with the help of other community members, I met Sinu [SWAM] in Tambaram. I explained my problem to him. He gave me their office address and invited me to visit. As per his advice, I visited the office. He gave me more information about types of STI, modes of transmission, HIV, and connection between STI and HIV.

He also took me to the Govt. hospital where I was tested for STI and HIV. I felt so relaxed after getting tested. After 3 days, when I went back for the testing result, I was informed by the counsellor about my positive STI status. Sinu advised me to bring my wife for testing. At first, I felt reluctant to bring her, but somehow managed to; fortunately, she tested negative for both STI and HIV. I have started taking medicines for STI. Personally, Sinu helped me to get a decent job. Now I am earning well, practicing safe sex and not engaging in sex work.

TESTIMONY

Is 'nirvan' really nirvana?

My name is Vinitha. I have studied up to Std. 8. I knew that I was a kothi when I was 10 years old. I have four sisters and am the last son in my family. I have been working in Koyambedu market from the age of 10. Since, I have feminine mannerisms my family forced me to behave 'properly' like man, but I was not able to. So, I came out of my family and had to struggle a lot for my survival. I engaged in sex work and earned a lot of money. Once every week, I used to meet my mother and would help her with some money. I have been in sex work for the past ten years.

If there was some problem among the 'community' [Aravanis] they would tell me, "Become like me". [Meaning - non-emasculated transgender would be looked down upon by emasculated TG and often verbally abused/forced to go for emasculation]. Since, I was hurt by that, I saved some money for nirvana [emasculation]. I also started taking hormones for the past 6 months. To get permission for the same, I went to meet my mother but, she was not at all ready to accept my decision.

With this background, I volunteered for counseling help offered in a CBO. The Counselor gave me a lot of information in relation to pros and cons of Nirvan. He also gave me some live examples about complications in post-nirvan period. He asked me to think through before taking any decision. Also, the Counselor spoke to my mother about my decision, with my consent. My mother suggested me not to opt for Nirvan, but, I was not ready to accept her words. Further, my mother told me that I should not go for Nirvan till her death. Finally, the counselor spoke with both me and my mother in a joint session. He advised me to also consider my mother's feelings. He also gave his personal opinion about nirvan. Finally, after witnessing some complications faced by my Aravani friends in post-nirvan period, I withdrew my decision of Nirvan. And, now I am happy with whatever I am.