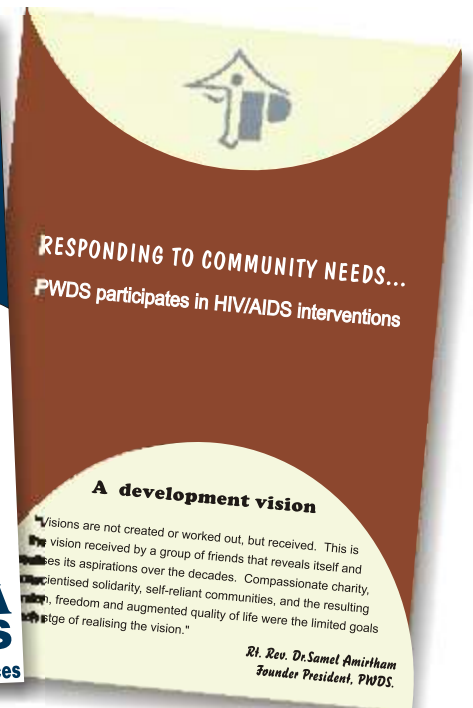
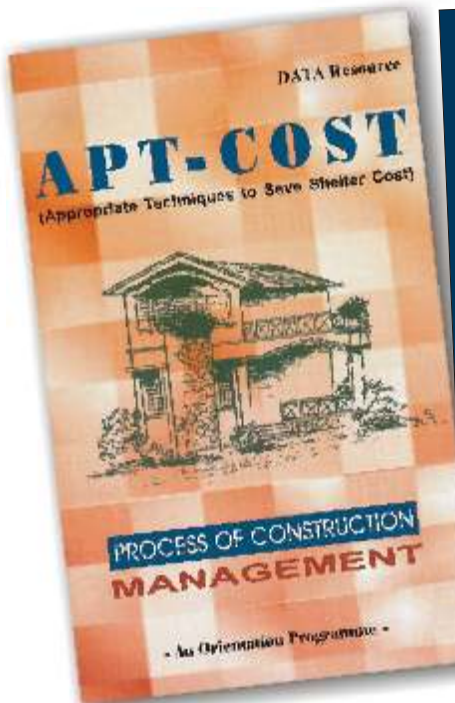
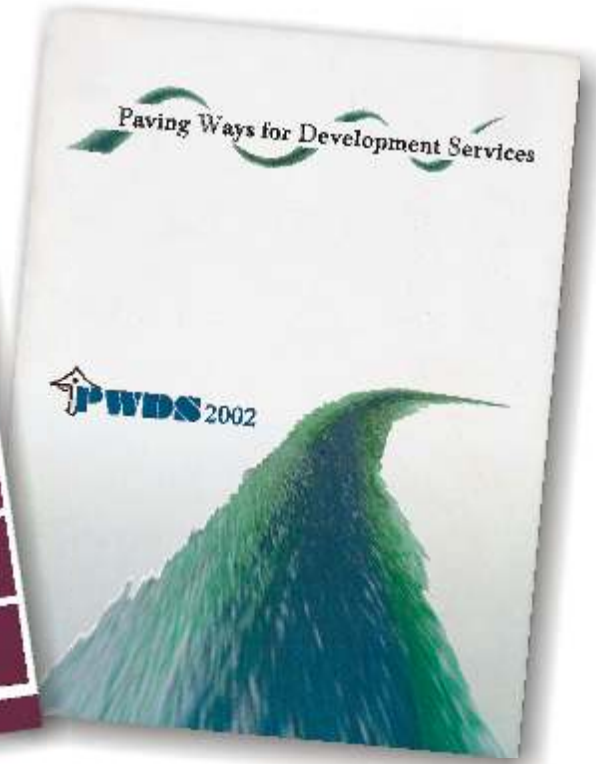


Integration Initiatives





Integration Initiatives and Community Responses

A study to identify and document integration
initiatives in the context of
PWDS - Alliance
HIV/AIDS Care and Support programme.



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The way forward

The learning from development initiatives is that community based support services can be sustained only by linking and integrating them with the mainstream. Past experiences of many interventions that emerged to address people with special needs or to contain diseases like TB and leprosy have also taught us the same lesson. The complexities and consequences of HIV/AIDS, although distinct, do not make it an exception to this development learning.

The recent realisation that HIV/AIDS is to be viewed as a development issue, and addressed with a larger development agenda beyond health related issues is a welcome move towards integration and mainstreaming. Experience also shows that it is essential to build solidarity among the affected people for mutual support and improved bargaining power. But if this mobilisation process lacks a long term perspective for integration, it could also lead to isolation and dependency on temporary support bases and donor grants.

The other learning while working with the community is that people come out with relevant responses when faced with challenges. In fact, the idea for this study on integration emerged in one of the sharing meetings of the care and support programme, where a participant shared the experience of integrating an infected woman in a self-help group. The support from the participating NGOs, staff, SHG members, and the PLHA in sharing their experiences made the study possible. We thank them and the International HIV/AIDS Alliance for their support in this attempt. The limited purpose of this report is to enable programme participants to understand the issues and implications for future planning. We will be happy if others also find the report useful in some way.

The experiences show that integrating affected people with community organisations, integrating health care needs of the affected people with mainstream health care providers, and integrating HIV/AIDS interventions with community development programmes will reduce stigma, facilitate acceptance, promote care and support, and thereby effect prevention and control. In addition, the integration process enables sustenance of services transcending project frame and time.

Although negative responses loaded with stigma and discrimination do exist, there are also many encouraging positive responses. Instead of harping on the negative, building on the positive responses of people seems to be the way forward.

Reji Chandra
Director, PWDS

Palmyrah Workers Development Society (PWDS)
Offering quality support services to sustain community initiatives

PWDS, founded in 1975, is a development support organisation with its registered office at Marthandam, Kanyakumari district, Tamil Nadu, India. PWDS works with community-based organisations aiming at ‘self-management and sustainability.’ Its interventions aim at empowering the community by building people’s organisations, equipping through awareness generation and skill training, and linking them with the mainstream for sustenance. In over two decades of development efforts impacting on wider spheres of activities, PWDS programmes have transcended geographical barriers and traditional frontiers and reached out to thousands of families in 17 districts in the states of Tamil Nadu and Kerala in India.

The International HIV/AIDS Alliance
Supporting community action on AIDS

The International HIV/AIDS Alliance is a UK-based international non-governmental organisation, established in 1993 by a consortium of international donors. Alliance activities reflect its mission of supporting communities in developing countries to play a full and effective role in the global response to HIV/AIDS. Since 1993, Alliance has worked with NGOs and CBOs from across 40 countries in Africa, Asia, Eastern Europe, and Latin America. The Alliance HIV/AIDS prevention and care and orphan support programmes have benefited millions of people.

1. BACKGROUND

In recent years, there has been a growing realisation that HIV/AIDS is not purely a health issue but has significant development implications as well. Development thinking has also undergone a shift from viewing HIV/AIDS as purely a health issue to accepting that it is a larger development issue that should be addressed with a development agenda. Therefore HIV/AIDS cannot be dealt with effectively in isolation, but needs to be addressed through an integrated cross sectional approach sensitive to economic conditions and community norms. Thus irrespective of which sector one belongs, there is an opportunity and need to participate in containing this pandemic.

In the 1990s, two discernable trends could be noticed in the NGO sector in the process of responding to the HIV epidemic: Mainstream development NGOs that took up HIV/AIDS issues as part of community health initiatives and NGOs that specifically addressed HIV issues.

Interestingly, many such NGOs emerged during this period as specialised NGOs in the field of HIV/AIDS. A similar bifurcation was also noticeable in donor agencies, which began to disburse funds to development and HIV funding as two different streams. Perhaps such a priority at the donor level could have also caused the division in the field level to some extent. While accepting the exclusive factors of HIV/AIDS and the need to have such specialised interventions to address these issues, despite its gains over the years, have also been found to be fragmentary and isolated in their approach to a multi-dimensional problem such as HIV/AIDS.

In India, HIV interventions based on prevention and control is not complete because it has been divorced from care of the affected people. With limited access to treatment and care for those living with HIV/AIDS, it has been an uphill task to implement prevention efforts. On the contrary, one observes an alarming trend of rising HIV infection that was earlier confined to high risk groups, now exhibiting porosity by affecting the wider population with low risk behaviour. In the subcontinent as in many other low and middle income areas of the world, a lethal combination of poverty, ignorance about the nature and transmission of HIV/AIDS, low levels of literacy, malnutrition, gender inequalities, and cultural taboos surrounding sex and sexuality fuel the spread of the disease and make control and care difficult. The recent realisation is that to effectively counter this situation, increased and integrated treatment and care efforts must go hand in hand with prevention efforts with the participation of the affected people and community. As a result, community based care and support initiatives emerged as relevant responses.

PWDS - Alliance community based care and support programme

The PWDS-Alliance HIV/AIDS care and support programme with a focus on community based care and support was initiated in 2000. The programme, supported by the UK-based International HIV/AIDS Alliance, currently covers three states in India.

The Tamil Nadu programme spans 13 districts with 20 implementing NGOs as partners, with PWDS as the lead partner coordinating the programme. In the first phase, the project covered eight districts with 14 implementing NGOs. The project works with PLHA and those affected by HIV/AIDS, especially women and children. It has been conceptualised on a vision of capacity building of NGOs in providing low cost community-based care and support for PLHA. It also facilitates NGO partnership and strengthening of community relationships.

The PWDS-Alliance care and support programme works towards an enabling, sustainable, supportive environment towards community based care and support for PLHA, CAA, and FAA in Tamil Nadu.

The project aims to:

- Mobilise the community towards care and support.
- Initiate and strengthen community based care and support for PLHA and their families.
- Initiate and strengthen community based care and support for CAA and their families.
- Link, strengthen, and coordinate the existing services for care and support.
- Initiate policy-related interventions towards promoting the integration of care and support and community based activities in Tamil Nadu.

The PWDS - HIV/AIDS Alliance provides the following services to people affected by HIV/AIDS:

- Psychosocial Support
- Health Care Services
- VCT
- Food and Nutritional Support
- Economic Support
- Emergency Relief
- Direct Services to CAA
- Referral Services and Linkages
- Capacity Building Activities
- Spiritual Care and Yoga Training
- Kitchen Garden
- Skill Training for Income Generation

Currently, the PWDS-Alliance programme services through the implementing NGOs reaches more than 1000 people living with HIV/AIDS and many thousands of families and children affected by HIV/AIDS. This includes home care, direct and referral services, and linkages with resource and care institutions. The capacity building programmes and sensitisation programme have reached thousands of people like teachers, doctors, religious leaders, health care workers, local leaders, and volunteers.

Emerging Issues and lessons learned

During an Experience Sharing Review Meeting (ESRM), the implementing NGOs voiced their concerns regarding the lack of service facilities available from the mainstream and a number of pertinent ethical issues that frequently cropped up at various stages of their work. Some of these included HIV and marriage, testing, confidentiality, human rights, social responsibility, HIV and gender, poor health care facilities, denial of services, and poverty issues. While accepting the fact that simplistic solutions are not available for such issues faced at the ground, the implementing NGOs reiterated the need to strengthen existing services, initiate alternative facilities, and look for community-based and integrated approaches.

A promising option that emerged was the potential of CBOs to play an enabling role and the need for an integrated approach in providing care and support for PLHA. The INGOs also shared the effectiveness of a few promising integration experiences that emerged in the field as responses to specific needs in certain contexts. The following issues were also expressed as common barriers faced in care and support services for PLHA:

- Stigma and fear of discrimination.
- Resistance and hostility of the community in speaking about HIV/AIDS.
- Non-availability of local testing facilities.
- Inability in many instances to identify PLHA at an early stage.
- Non-cooperation of PLHA.
- Poor health care facilities.

The following are some of the key issues related to community participation, integration attempts, and community-based models that emerged from the experiences shared by the Implementing NGOs:

Care and support as an effective way of prevention: It is not fear and isolation but care and support provided in an atmosphere of acceptance and compassion that controls the spread of infection.

SHGs as agents of change: SHG members sensitised on HIV/AIDS issues work towards creating awareness among other sections of the community. The integration of the affected person in the SHG brings in considerable positive change among the community and affected persons and also serves as a motivation for others to accept and support PLHA.

Advantages of integrated (development) intervention: Community-based NGOs have an advantage, especially in care and support initiatives, over other specialised agencies for HIV/AIDS intervention in accessing the affected people and in responding to their needs in an integrated manner. CBOs and NGOs also have the potential to extend care and support activities as part of community development initiatives.

Integration of affected people with community organisations: While it is undeniable that PLHA need their own associations and networks for mutual support through their solidarity and for policy influences, there are possibilities that such initiatives may lead to ghettoisation that can further intensify feelings of isolation and marginalisation. Integration of PLHA into mainstream organisations/community organisations lessens their 'isolated visibility' while simultaneously enabling them to perform productive and fulfilling roles.

Mainstreaming as a means to provide quality and sustained services:

Lack of appropriate, timely and quality health care services is a major gap in HIV/AIDS care and support. Since generally mainstream health care providers are not cooperative, there is a tendency to create alternative, specialised and isolated services. Thus it is also necessary to improve the quality of self-care and home care. Overemphasising community responsibility and self-help without emphasising the state's responsibility has the danger of diluting the human rights aspect of focussing services from the government as the right of the people in need.

The attempts to initiate institutional services as part of the projects or by affected people and their associations as alternatives could only be a temporary response; despite the unquestionable commitment of such people. Thus integrating the health care needs of affected people, as an integral part of mainstream health care system is important to improve quality, and make timely and sustained service available .

2. INTRODUCTION TO THE STUDY

The experiences during the first phase in community-based approaches in care and support opened up a number of areas for further exploration. While the enabling role and conscious interventions of resource organisations and implementing NGOs cannot be denied in such cases, in many instances, the initiatives were not planned interventions but emerged as spontaneous responses of the implementing NGOs and the community to address a problem in a specific situation. The role of the community, specifically the potentials of SHGs, and the inherent element of sustainability experienced in an integrated approach are promises for developing a future perspective for the programme.

This realisation led to the proposal for a study aiming to identify, understand and document the integration initiatives and to develop a planned intervention based on the experiences. Specifically the study explores the integration process and its impact on HIV/AIDS care and support interventions based on the experiences of the implementing NGOs and the responses of the community to these initiatives. The study is a learning attempt on integration based on the experiences of the INGOs and the community.

Objectives of the study

In general, the proposed study attempts to identify, understand, and document the integration experiences; impact of these initiatives on the affected people, community, and other service providers; and relevance to the HIV/AIDS care and support programme.

Specifically to study:

1. Strategies and approaches used and intervention process initiated.
2. Initiative and responses of INGO, community, affected people and other organisations.
3. The impact on the affected people, community, and other service providers.
4. Facilitating and constraining factor encountered during the process.
5. Resources (human, financial) utilised.
6. Replication / scaling - up possibilities, conditions conducive for scaling - up.

The Methodology

There are four important areas identified for integration initiatives from the experience of the implementing partners:

- ❑ Integrating the affected people with the community / SHG.
- ❑ Integrating HIV/AIDS intervention with community development initiatives.
- ❑ Integrating prevention with care and support.
- ❑ Integrating health care services with mainstream health care providers.

The focus of the study was:

- ❑ Integration of the affected people with the community, specifically with SHGs.
- ❑ Integration of HIV/AIDS interventions with community development initiatives.
- ❑ Linkage building initiatives with a mainstream health care.

However, documenting the experiences of the implementing NGOs, affected people, community, associated institutions, and others involved were considered as important in this learning process.

A three member study team was formed. A guideline for the study in the form of Terms of Reference (TOR) was prepared to guide the team.

The study team selected five INGOs (one-third of the 14 INGOs) based on geographical area, strength of community development programmes, and linkages with community based organisations.

The study team undertook the following steps to collect the information and profiles:

- Studying the experiences of the implementing NGOs from reports, and through focused experience sharing meetings.
- Selecting five implementing NGOs and selecting two SHGs from each selected implementing NGO.
- Visiting the selected INGO and interacting with:
 - SHGs,
 - PLHA,
 - INGO staff,
 - Joint meeting of Alliance project & community development staff.
- Introducing an action plan in the field by the selected INGOs and sharing the experiences.
- Discussing with a selected feed back group from the participating NGOs, affected people, and community organisations.
- Preparing the report.

The intervention plan

An intervention plan was also developed in consultation with the staff by collecting different experiences of implementing NGOs with the following components for integration.

- Enable PLHA in the service area to become members of SHGs.
- Establish working linkages with the local mainstream health care providers for medical care to PLHA and CAA.
- Integration of PWDS-Alliance programmes with the other on going community development programmes of the INGOs / other NGOs working in the geographical area.

The five INGOs participating in the study initiated this process. Staff meetings consisting of all the projects of the two INGOs (CAST and Seva Nilayam) were planned to discuss possible ways of integrating the PWDS-Alliance project with the other ongoing community development programmes of the INGOs concerned. The outcome of these meetings was shared with the other INGOs participating in the study.

Action plan for two months (July & August 2002)

- Listing all the PLHA reached, who are not currently members in an SHG.
- Listing all the SHGs in and around the villages where the PLHA live and also identify the SHGs having less than twenty members.
- Listing private doctors, nursing homes, PHCs and government hospitals nearby.
- Planning for an all staff meeting (all the projects of the NGO) for discussing the integration of PWDS-Alliance project with the community development programmes.
- Review of the intervention.
- Documentation (achievements, experiences, future prospects).

SHG	Community Development	Health
<p>1. Motivating PLHA to be active and participate in the community initiatives through SHGs.</p> <p>2. Frequent visits and sensitising the SHG animators and members of the SHG to accept PLHA as members of the SHG.</p> <p>3. Forming new SHGs with PLHA and other local women in that area.</p> <p>4. Meeting other NGO head and staff to encourage accepting PLHA in their SHGs.</p>	<p>1. Planning with all staff for integration with other CD programmes like micro credit, savings, skill training and self-employment.</p> <p>2. Meeting with the local bodies and district level officers for permanent government support that are available through various schemes.</p> <p>3. Meeting local youth groups, fan association members and other institutions seeking support.</p> <p>4. Promoting of PLHA network.</p> <p>5. Meeting with other nearby NGO heads for integrating with their CD programmes.</p> <p>6. Initiatives for organised local resource mobilisation.</p>	<p>1. Frequent visits and sensitisation of local private doctors for adoption of a few PLHA for free treatment.</p> <p>2. Meeting the Joint Director of health, Head of Government hospitals, doctors from STD departments, approaching PHC doctors for comprehensive and quality care for PLHA.</p> <p>3. Meeting with local village health nurses, maternity assistants, sector health nurses, ANM for special care and follow-up for PLHA.</p> <p>4. Volunteers' training and greater involvement.</p> <p>5. Peer educators' training.</p>

3. LEARNING FROM EXPERIENCES

Integrating PLHA with SHGs

PLHA are enabled to enroll as members in the existing SHGs promoted by the INGOs. In some cases, PLHA are enrolled in SHGs promoted by other NGOs. There are also instances where SHGs are promoted for supporting PLHA, with the PLHA serving as one of the leaders of the SHG.

The process of integration with SHG mainly involves orientation of the SHG members to HIV/AIDS issues, sensitising the NGO staff and the community, and motivating PLHA. This orientation and preparation phase at the level of NGO staff, community, and PLHA helps to address stigma and prevention as part of the process, and leads to care and support. The infected person is also willing to reveal the status openly, as there are signals of acceptance from the SHG members and in a few cases, from the larger community itself. The acceptance of the infected person and family by the SHG influences on the larger community in the village to understand the issue of HIV/AIDS and become more sensitive to the needs of the affected people. The attitude and the manner in which staff and SHG members treat the PLHA also exert a demonstration effect on the community.

Organising an SHG around a PLHA has also created impact in many ways. The leadership role given to the PLHA in the group gives a sense of satisfaction and purpose for the PLHA. In general, SHG membership empowers the PLHA in all aspects and improves access to care and support and to resources.

Before enrolling themselves as SHG members, most women living with HIV/AIDS had suicidal tendencies; felt rejected and stigmatised by the community; apprehensive and anxious about their children's future; hesitant to undergo treatment for opportunistic infections; and fearful that AIDS was a “killer” disease.

After membership in SHGs, however, women living with HIV/AIDS showed an increased desire to live; increased leadership qualities; an acceptance that HIV/AIDS is also a disease like other diseases; improved health seeking behaviour; increased levels of acceptance leading to happiness; better economic returns due to work opportunities that were made available; and opportunities to avail loans, and opportunities for skill training. In many cases, the SHGs function as guardians for PLHA and CAA, with SHGs even adopting HIV orphans and taking care of the food and education needs.

A few interesting cases were also shared in the process like a PLHA supported by an SHG in selling clothes for income generation; formal linkages created with private health care providers; working linkages created with the government primary health centre; collaboration in the field between the community development programmes; and HIV/AIDS care and support programme.

Linkage process with the health care system

- There are successful experiences with government services like Primary Health Centres, taluk and district level hospitals and private doctors. The initial hesitancy from doctors and paramedical staff is diluted in a spontaneous process of sensitisation that happens in the interaction with the INGO staff. The attitude and the manner in which staff treat the PLHA also exert a demonstration effect on the service providers in many instances. The PHC staff collaborates with the INGO staff in extending services to PLHA.
- Many private doctors are motivated to treat opportunistic infections at concessional charges. A few doctors are motivated on a charity basis to help one or two PLHA who are poor, and thus treat opportunistic infections at concessional charges or free of charge. This model is then shown to the other doctors of that area that motivates the latter to accept it. More than the charity or welfare concern, it is the change in the mindset of the doctors and the staff to accept the PLHA for treatment in the clinic that leads to a process towards access to health care from mainstream health care providers. In a few instances, private doctors have consented to treat more than ten PLHA on a regular basis for opportunistic infections.

- This process also involves a sensitisation process for the persons involved. Prior to INGO efforts to reach out to health care providers about the special needs and concerns of PLHA, many doctors were insensitive. Isolation, discrimination and denial of treatment to PLHA were common. Even doctors willing to treat PLHA, were fearful of being branded as “AIDS doctors/AIDS clinics” by other patients who come to the clinic for treatment. However, there has been a significant decrease in such responses following persistent advocacy of INGOs for the rights of PLHA to access quality treatment and care.
- Doctors are invited as resource persons for the NGO programmes and to serve in programme advisory committees. The care and support staff of CAST request for permission to speak about their programme to health care providers such as doctors and paramedical staff of local PHCs. Such a non threatening approach frequently has the audience wanting to know more about specific programme details and showing interest to participate has a better impact than a confrontationist stance implicit in sensitisation programmes.
- Formal working arrangements have emerged in a few projects. CSR has established a linkage with Annammal Hospital, a local private hospital in Kanyakumary district, to provide treatment for PLHA. The doctor concerned volunteered to treat them free of charge. Similarly, CAST has established a linkage with a local primary health centre to provide treatment for PLHA.

Interventions in health care services : Doctors as members of care and support project advisory committee

Dohnavur Fellowship Hospital in Tirunelveli District is located seven kms from the CAST project office. It is a 40-bed hospital that provides cost effective treatment for low income groups. The trustees of the hospital initially started an orphanage. The hospital is staffed by a team of three doctors and paramedical staff. The latter are from the orphanage. Dr. Karunya(55), who grew up in the orphanage, heads the medical team.

Initially, a few persons infected with HIV came to the hospital for treatment when they were unaware of their HIV status. The hospital treated them at nominal charges. However, following the intervention of the CAST Care & Support team, the hospital provides treatment for opportunistic infections for people living with HIV/AIDS free of charge. Besides they provide treatment without isolating people living with HIV/AIDS from the other patients.

The CAST care and support team and the hospital staff have built a rapport with each other. Dr. Karunya is a member of the CAST care and support project advisory committee.

Dr. Abdul Sheik Ali and his wife Dr. Abitha Begum run Sugam hospital, a 15-bed hospital in Kalakad block in Tirunelveli district. The hospital is located half a kilometre from the CAST Project office. Initially, the hospital provided treatment for people whose HIV status was not known. Once it was confirmed, they were referred elsewhere for treatment. However, following the intervention of the CAST care and support team, the hospital provides treatment for opportunistic infections at concessional rates (50%). Besides maintaining confidentiality, the hospital also admits PLHA as in-patients, if required. Dr. Ali is confident that doing so will not have negative impacts on the image of the hospital. He is also a member of the CAST care and support project advisory committee.

The CSR care and support staff team established a linkage with a local private hospital, Annamal Hospital, Kuzhiturai, Kanyakumari district. Dr. Jayalal, a general surgeon, and his wife Dr. Sheela Jayalal, a gynaecologist, run this 40-bed hospital. Dr. Jayalal had been interested in medical service for the poor even as a student. Later when he began practising, he treated PLHA free of charge. However, he was unable to provide follow up services.

The CSR care and support staff team requested Dr. Jayalal to provide treatment free of charge to PLHA in their project area. Dr. Jayalal enthusiastically responded to their request. While treating at least ten PLHA free of charge, he does not hesitate to do so even if the number of such patients who need his services are higher than expected. Dr. Jayalal is a member of the CSR project advisory committee and also trains PLHA, CAA, peer educators, and volunteers.

Picking up the threads of her life

Kamalam (33) is a poor semi literate HIV widow who lives in Tiruvambalapuram village with her two children – a 14-year-old boy and a 12-year-old girl. Her mother died early and she and her two male siblings were brought up by their grandmother.

In 2001, Kamalam's husband began to develop symptoms such as unexplained fever and weight loss. The local doctors suspected malaria but tests proved negative. After what seemed an endless round of clinics in search of a diagnosis, her husband was referred for an HIV test at neighbouring Valiyoor.

Kamalam's husband tested positive for HIV. Thereafter he was referred to the TB Sanatorium, Chennai, as he began to develop opportunistic infections such as persistent fever, and cough. He died within three months of diagnosis after a 20-day stay at the hospital. Kamalam was under enormous financial distress having sold the family's land holdings to meet her husband's medical expenses.

She claims to have spent more than Rs. 2 lakhs for medical treatment by selling a piece of agricultural land and borrowing from money lenders.

Meanwhile her life began a downward spiral, and she had to support her children with a low-paying job as an agricultural labourer. To make matters worse, she separated from her husband's family following a property dispute. Her parental family were not resourceful enough to take care of her and her two children.

While Kamalam's life seemed apparently gloomy and uncertain, field staff from INGO offered her an opportunity to rebuild her life. Building on her lived experience with HIV, Kamalam received a comprehensive orientation on HIV/ AIDS, modes of transmission and risk factors. Enthused by the possibilities of reaching out to similar women in distress following AIDS - related deaths of their husbands, Kamalam enrolled as a peer educator. She draws a monthly allowance of Rs.300 and also gets nutritious food and medicines free of charge.

Meanwhile, the INGO staff motivated Kamalam to enrol herself as a member of the SHG. Impressed by the possibilities of the SHG being a source of economic, social and emotional support, Kamalam became an SHG member. She says she feels “strengthened and happy” ever since.

We're there for you!

The members of the SHG in Thottavillai village in Tirunelveli district wait for us under a peepul tree. The place is arid and climatic conditions hardly conducive for agricultural activities. Most of the women in the village roll *beedis* to supplement their meagre family income. “But we will not allow our children to do so,” asserts Jeyarani, one of the SHG members.

Selvi (27) is the secretary of the SHG. However, her outward exuberance camouflages the pain and turmoil she experiences as she copes with being an HIV widow with three children.

Ambitions of a job in the Middle East, lured Selvi's husband, a fishing trawler driver, to Mumbai enroute to the land of plenty and prosperity. Following the sojourn in Mumbai, he began to develop symptoms of persistent unexplained fever and diarrhoea. After a futile round of doctors in search of a definitive diagnosis, his HIV status was confirmed in 2000. He died of AIDS-related causes six months following the initial diagnosis. Selvi recalls that his last days were traumatic and indeed as painful for her as a caregiver as it was for him.

Selvi's parents do not permit their daughter to come home as she chose to elope and get married. “ They welcome my children, though. My father still does not even talk to me. My mother sympathises with me, but poor lady, what can she do? She is under my father's control,” says Selvi.

Selvi's wheel of misfortune turned full circle, when she too tested positive for HIV. On hearing this, her husband's family, migrated to another village as they feared the burden of caring for her would be foisted on them. Realising that giving in to despondency would not help matters, Selvi with great effort, decided to pull herself together. She owed it, she says, both to herself and her three young boys. Helping her in her resolve was the unconditional support offered by the RED staff. "Meeting the RED staff was a godsend for me. They gave me the courage and strength to face life. I learnt how a positive approach to life can make all the difference," says Selvi.

Fortunately for Selvi, other factors began to work in her favour. A local SHG, in an inspirational show of solidarity and compassion, decided to promote another SHG to provide space for Selvi to be integrated as a member.

Today Selvi revels in her new found status as an SHG member who is also the secretary of her group. She says her new role has enabled her "to feel strengthened, and boosted her self-esteem and self-confidence." Selvi remarks that the other members often say, "You are one of us. We are there for you." Ironically, Selvi's husband was hostile to her becoming a member of an SHG and did not allow her to do so as long as he was alive.

Integrating with community development programmes

“The all staff integration meeting could be considered a milestone because for the first time all departments in the organisation came together to discuss an issue and bring out shared perspectives and understandings to generate possible solutions towards an integrated approach to HIV/AIDS care and support. It has facilitated a rapport among all the departments. Earlier we used to be compartmentalised and were unaware directly of many of the activities of the other departments,” expressed a Seva Nilayam Staff after the joint staff meeting as part of the integration process.

The concerns related to the integration of HIV care and support and community development programme were formulated into questions first and then staff discussed them. The following questions were discussed:

- What are the kinds of community development programmes with which HIV interventions can be integrated?
- How is it possible to integrate the different programmes that come from different donor restricted project frames and objectives?
- Is it possible to integrate diverse / separatist development approaches or priorities with HIV care and support?
- What will be the implication of this process in the organisational structure or the changes to be effected in the organisational structure and culture to achieve this?

Rediscovering meaning

Mary (31), a trained nurse, is an HIV widow with two children a six-year-old boy and a five-year-old girl. She lives in a village in Kanyakumari district in Tamil Nadu. Her husband worked as a cook in a Mumbai hotel for 15 years.

A year after marriage, he developed symptoms such as unexplained fever, weight loss, skin lesions, and diarrhoea. Mary says that neither she nor her husband had heard of HIV/AIDS. When his HIV positive status was confirmed, local hospitals refused to treat him. His family, fearing that she would neglect her husband if she knew his HIV status, with-held the test results from her. “Instead they told me it was blood cancer. Can you believe it?” asks Mary. Initially the family gave her Rs.10,000 for medical expenses but thereafter there was no help forthcoming. Mary was shocked to discover her husband's HIV test report while rummaging through family trunks for hospital bills.

Her parental family were hesitant to be openly accepting and supportive of her as they were seeking a matrimonial alliance for their younger daughter. “They didn't want prospective marriage proposals to be turned away because of the stigma of 'AIDS family',” says Mary. Mary’s husband died of AIDS-related causes in 2000. His family refused to bury him in the family cemetery, as they feared he would “pollute” it.

Later, having developed symptoms of opportunistic infection, Mary underwent an HIV test. Not surprisingly, she tested positive. Her husband's family's antagonism towards her intensified when they heard about her HIV status. She was made to feel unwelcome and unwanted in the family, her visits were met with hostility and anger. On the few occasions they relented, she was subject to degrading practices such as being forced to eat in separate utensils earmarked for her. The family members would not lend her their clothes. They also forbid the other children in the family from playing with Mary's children.

Meanwhile Mary met the staff of the INGO who gave her hopes of making her life more meaningful by creating avenues of economic, social and psychological support. The first step in Mary's journey to empowerment began with her acquiring adequate information about the nature of HIV/AIDS, modes of transmission, and prevention and care. Today Mary works as a peer educator who reaches out to many others like her.

Two years back, Mary, motivated by the staff, decided to become a member of a local SHG. The group consists of 20 members, each of whom contributes a monthly amount of Rs. 20. Mary regards her involvement in the SHG as a momentous event in her life. “Earlier I was withdrawn and depressed and just didn't want to live. But look at me today... I'm so confident and positive in my approach to life. It's all due to the support my SHG members give me,” remarks a jubilant Mary.

The SHG members have lent Mary interest-free loans three times for Rs. 5,000, Rs. 2,500 and Rs. 2,000 respectively. She used the loans to meet expenses related to electrification of her house and repay debts incurred as a result of her husband's medical treatment. The SHG members are unconditionally fond of her and ensure that she and her children eat nutritious food. They also look after the children when Mary is away on work. The members have taken the initiative to tie up with a local flower vendor for whom Mary strings flowers. Some of the SHG members help Mary so that she is able to string flowers that earn her a reasonable income.

Mary's mother-in-law and sister-in-law also became members of an SHG in their village. According to Mary, this has brought about a transformation in their attitudes towards her. Their earlier hostility and discriminatory attitudes towards her have been replaced with acceptance and support. They are also happy at the support the SHG extends towards her. Mary attributes this attitudinal change to the awareness and sensitisation programmes on HIV/AIDS conducted for SHG members.

Mary has many sources of support and sustenance. The local church supports her children's education. The local youth clubs supply them with books, and uniforms free of charge. Four SHGs and a youth club have provided her with a tailoring machine. Mary is open and accepting of her status as a woman living with HIV/AIDS. Initially she was angry with God for having given her an incurable disease. But that helplessness and dismay has yielded to a mature acceptance of very trying circumstances. "If God closes one door, he opens up many other alternatives," muses Mary. Mary's older child has tested negative and the younger child's HIV status is not known.

In general the following suggestions emerged related to integration :

- The management policy needs to be integration-sensitive and should realise the need for integration not only at the field activity level but also at the organisational level. Functioning as discrete departments in a way leads to a sort of compartmentalisation and fragmented approach at the field level. Even though there are justifications for such a division, attempts to integrate at various possible levels helps to achieve better results, optimise resource utilisation, and strengthen cooperation among staff.
- There is the ever-present danger of showcasing PLHA and CAA, and integration with the other programmes may increase this tendency. Therefore caution should be exercised in doing so. Limiting visitors, organising visits and interactions through some other programme activities for the PLHA are recommended. Visits have the danger of singling out PLHA as objects of curiosity. HIV project staff are also sometimes taken away by over enthusiasm to showcasing PLHA for the programme cause.
- Loans to PLHA for income generation activities through SHGs and services through village health schemes are possible. It is very difficult for PLHA to access credit from mainstream finance institutions or join insurance schemes if their status is known. CBO integration is helpful since credit is accessed by the group with the group identity. Integration of PLHA with the special loan schemes of federations is another option available to establish access to resources/services to PLHA and affected families.

From isolation to care and support

Vimala (27) is a semi literate HIV widow with two children - a five-year-old boy and a three-year-old girl. She lives in village near Marthandam. Her husband worked as a vendor in a teashop in Mumbai. Vimala says her husband was infected before marriage, although his HIV status was confirmed only after marriage, when he developed symptoms such as unexplained fever, weight loss, and diarrhoea. Her husband died within a year of diagnosis. While Vimala's daughter has tested negative, she fears that her son may be HIV positive because of symptoms such as unexplained weight loss.

Vimala recalls that initially when she and her husband came to know of their HIV status, they wanted to choose the easy way out by committing suicide along with their children. To make matters worse, the entire community began to isolate, and discriminate against them when they heard of their HIV status. Vimala cites painful instances of isolation, hostility and ostracism.

For example, she says that their HIV status received adverse publicity throughout the village through announcements in the regional language newspaper, refusal of treatment by the doctors at the primary health centre, and a prominent board displayed at the village river prohibiting the couple from bathing in its water as they would “contaminate the water” and infect others.

Her children were not allowed to play with other children and their families isolated them by forcing them to live in an out house in the main compound. Vimala's life took on a change for the better when she came into contact with the INGO staff. Today she is a peer educator and a PLHA volunteer who imparts awareness and HIV/AIDS education for SHGs, and people infected, and affected.

Vimala is today a member in a local SHG which has 20 members. The SHG members have lent Vimala an interest-free loan of Rs.2000. Vimala tries to support her family through weaving palm baskets and mats. She also rears cattle, goats, and poultry to sustain the income. The local church, although initially hostile and ignorant, is today one of her staunchest supporters. Among the many forms of help extended to her include support for her children's school education.

From isolation to care and support, it certainly has been a turbulent journey for Vimala.

- PLHA home visits through village health groups, and DOTS (Directly Observed Treatment Services) teams, and ANC/MCH mobile clinics are effective. Such visits do not arouse suspicion, as these are part of ongoing community health projects. On the contrary, PLHA home visits by special HIV teams exclusively for HIV purpose creates adverse publicity by inadvertently making obvious the HIV positive status of the person(s) visited. Affected people and families feel uncomfortable about these visits.
- All NGO staff, SHGs, and federations to be trained in attitude and behaviour change towards PLHA. Such programmes create acceptance among members to enroll PLHA as members in community development programmes and subsequently integrating them in SHGs and federations.
- Joint programme review of all departments including TB and HIV is necessary. The most obvious impact of such a measure is based on the positive correlation that exists between HIV and TB. Besides, such an all inclusive department meeting would generate need based responses that would integrate PLHA into the services provided by the organisation.
- Integrating HIV/AIDS care and support concerns in all programmes can be effected through talking about HIV issues to staff of other projects, sensitising them to HIV issues, and inputs in some form on HIV/AIDS in all training programmes. Training for development staff on health issues is vital because this helps to understand HIV/AIDS as a health issue and as a development issue as well. Such a move is a step towards integrating HIV/AIDS issues with the ongoing community development work of the institution, and creating a rapport between community development and care and support. In its absence, development staff and HIV programme staff work in compartments and even tend to be hostile and antagonistic to each other as they are unable to find a meeting ground.

Silver Linings

Nancy (26) is an HIV widow and the mother of three children – two boys, six years and four and a half years, and a one-year-old girl. Her husband was employed in a cotton mill in Mumbai. He used to visit his hometown once in three months. About two years back, her husband complained of unexplained fever, persistent cough, skin eruptions, and joint aches. After a seemingly endless search for diagnosis, his HIV status was confirmed. From then on it was a steady decline in health. Nancy provided care and support at home. He died a few months later.

Like most women coping with AIDS-related deaths, Nancy initially knew nothing about the disease. However, life has been a great teacher. When she realised that she too was developing symptoms such as unexplained fever and cough, Nancy, spurred by well wishers, realised the need to get herself tested for HIV. The result that she too was HIV positive, she says, was something she expected to happen.

Nancy's story has silver linings. Her immediate family and the larger community are supportive of her in many ways. Her mother in law is an agricultural labourer and works hard to support Nancy and her children. Her husband's brother and his wife provide economic support such as food and clothing. In addition, the local SHG is supportive and help her in her times of need. In 1999, Nancy enrolled herself in an SHG, which has 20 members. The SHG has extended a loan to Nancy on flexible repayment terms to enable her repay the debts incurred due to her husband's medical expenses.

Nancy earns Rs.10-20 every day by rolling *beedis*. However, she finds it difficult as her compromised immune system makes her vulnerable to health hazards inherent in the job. The INGO operating in the area, has offered her an alternative source of livelihood in making dolls from plant fibres.

“For the sake of my child!”

Sudha (28) is an HIV widow with a five-year-old son. Her husband was a migrant labourer who worked in a cotton spinning mill in Mumbai. In 1999, he began to be troubled with persistent fever and unexplained weight loss. Shortly thereafter his HIV positive status was confirmed. He died of AIDS-related causes within two months.

Sudha's in laws isolated her following the death of her husband. There was no significant support from her parents too. The field staff of the INGO met Sudha. In 1996, she joined SHG. The SHG members have rented a house for Sudha from one of the villagers for a nominal rent. Thanks to their efforts, Sudha today has a roof over her head. Sudha wants to lead an independent life and is determined to “live for the sake of my child.”

- Exposure visits for SHG members sensitise people to the special needs, concerns, dreams and aspirations of people living with HIV/AIDS. It also helps to clear myths and misconceptions about the disease and the affected people.
- Enable PLHA to access government schemes for widows, senior citizens, girl children, and orphans. Enabling the affected persons to access such schemes establish sustained linkages for support.
- Schooling and job opportunities for the infected and affected persons and opportunities for education for children need to be explored for sustaining the care services. In an attempt to integrate HIV/AIDS care and support programmes with the other programmes of the institution, IGP training is a move towards economic self-reliance of PLHA.
- PLHA who are reluctant to join SHGs must be counselled about the potential benefits of SHG membership. The psychological, emotional, social, and economic impacts of SHG membership must be highlighted to PLHA who, in many cases, may be unaware of such acceptance and possibilities for support.
- Staff of INGO could act as a bridge between PLHA and SHGs. The INGO can play a facilitating intermediary role in aligning the needs and concerns of PLHA with the operations of SHGs so as to effect maximum benefit for the PLHA and a sense of satisfaction and fulfillment to the SHGs in supporting a worthy cause.

Helping others to help themselves

Amala (29), a high school drop out, is an HIV widow with two children—an eight-year-old girl and a one-year-old boy. She was married in 1992 and moved to Mumbai where her husband was a taxi driver.

Amala recalls that her life in Mumbai was comfortable and there was no apparent cause for complaint. In 1997, her husband developed jaundice and recurrent unexplained fever. As preliminary investigations were inconclusive, the local doctor asked him to get tested for HIV. Amala recalls that for a long time her husband and his family did not disclose the results of the test to her. She was wondering what the mystery illness was all about. Finally the plucky woman gathered enough courage and managed to meet the treating doctor without the family's knowledge. It was then that she learnt that her husband was HIV positive.

The burden of taking care of her husband fell entirely on Amala. Her family refused to offer any form of support either financial or psychological. Amala says that she pawned her 20 sovereigns of gold to raise money for her husband's treatment. Besides the family became openly hostile to her and blamed her for being the source of infection. Their son, of course, was absolved of all responsibility in contracting the infection.

After her husband's death due to AIDS-related causes, Amala moved to her village in Tirunelveli district. Today, she lives with her parents, who are a source of support and sustenance. Amala recalls the harassment by her in-law in coercing her to undergo the HIV test. “They would not give me milk and food to feed my hungry children. But they were willing to spend on my HIV test just to throw me out of the house if I tested positive. Is there any justice in this?” she asks. She says that they even plan to deprive her and her children of their property rights too.

Amala tested HIV positive in 2000. She has enrolled her two children in a boarding school being run by Christian missionaries. She, however, has chosen not to reveal her HIV status to the school authorities.

Amala met the field staff of CAST through an employee, related to her. Thanks to their counselling and intervention, she saw alternatives that would enable her to live life meaningfully and with a sense of purpose. Amala is currently an SHG coordinator in CAST and also coordinates an HIV/AIDS awareness programme. Lack of geographical proximity deters her from becoming a member in any of the local SHGs. Amala says she finds a lot of meaning and satisfaction in her work. “My work gives me a lot of joy. When I see others going through similar problems, I feel that I am not alone. Helping them in whatever way I can means a lot to me,” says Amala as she smiles through her tears.

- PLHA loans based on their savings would infuse an element of 'fairness' in SHG loan lending and counter the charge of other SHG members and the community that PLHA are often singled out for 'special' treatment. Hence it is necessary to evolve a consensus among SHG members. Another way to counter the charge that special treatment is meted to PLHA, is to arrive at an agreement among SHG members based on commonly agreed upon criteria regarding PLHA membership in an SHG. Wives of PLHA could be also inducted as SHG members. This is a strategy to integrate HIV with community development initiatives. Contrary to an open door policy of membership in SHG for PLHA, this is an attempt to introduce specific criteria for PLHA membership in SHG.
- The SHG membership fee for women living with HIV/AIDS needs to be waived. Due to economic constraints, PLHA find it difficult to comply with SHG membership rules such as a mandatory membership fee. Keeping in mind the low income group to which most PLHA belong and the financial constraints they face, flexibility in SHG membership would facilitate a quicker process of integrating them with SHGs.
- INGO staff to create HIV/AIDS awareness in mass meetings. Such awareness meetings facilitate integration of PLHA in the community / SHG by creating a positive accepting environment that is conducive to the local community to accept PLHA without reserve.
- Fostering the concept of integration among health care workers is a move towards integrating HIV with the mainstream healthcare system. The INGO experience highlights the need for integrated health care programmes. On the contrary, isolated HIV programmes are associated with increased risk of stigma and discrimination.

Much better than it used to be

Prema (30) an HIV widow with a twelve-year-old daughter lives in Sitharapatti village in Theni district. She is an agricultural labourer and earns Rs.25 every day.

Around two years back, Prema's husband, a trucker, developed continuous fever and cough that was resistant to treatment. Shortly thereafter he was diagnosed HIV positive. Following the diagnosis, he quit his job and was re-employed in Seva Nilayam as a lorry driver. He died of AIDS-related causes in 2000. Prema recalls that she was ignorant of HIV/AIDS.

Prema tested positive six months back. She was enthusiastic about the possibilities of becoming a member in one of the local SHGs. However, initially, none of the local SHGs were willing to accept her. Over a period of time, thanks to greater awareness of the disease, a local SHG was willing to accept her as a member. The group has 19 members. Prema, like the other members, pays Rs.40 as monthly subscription. The SHG has lent her loans two times at a nominal interest rate: Rs. 5,000 to buy cows and Rs. 3000 to buy sheep. Prema says that the SHG membership has enabled her to make ends meet. Besides the support extended by the SHG, Seva Nilayam supports her daughter's education by supplying note books and school uniform.

Prema recalls that her husband's family isolated her after their son's death, blaming her for being the source of infection and the cause of their son's death. She says she feels hurt and pained at these false and unjust accusation but chooses to remain silent. Prema's daughter has not been tested. Despite the hardships and struggles of being a woman living with HIV, Prema remarks that acceptance levels in community of people living with HIV are much better due to greater awareness.

- Motivate Primary Health Centres to be involved in care and support activities. This is a move towards integrating prevention with care and establish linkages with local health care for sustained support. In an attempt to integrate PLHA with mainstream health care system, sensitisation of the health care providers fosters attitudinal change such as greater acceptance and willingness to provide treatment and care for PLHA. Involving local doctors in care and support advisory committee helps in the attempt to integrate HIV services with mainstream health care system. This strategy would serve to make the health care providers aware of care and support issues and possible solutions in which they could play a role.
- School teachers who are sensitised to HIV/AIDS issues are more likely to be responsive to the needs, hopes, dreams and aspirations of CAA. Such teachers are empowered to counter stigma and discrimination CAA may experience in school. Sensitising the parents of other children in the school is also achieved through such teachers.
- Promoting NGO networks and PLHA networks for policy influences and human right issues is necessary. The collective bargaining power that results from networking is often influential in policy initiatives.

A few critical concerns also emerged such as: Why should PLHA be singled out for 'special' treatment? There are also other people who are poor and vulnerable in the villages. While poverty is the issue, why single HIV for 'special' treatment? Thus there is a need to look at issues in the larger contexts of health and poverty, rather than regarding it as an HIV issue.

When PLHA die, how does the group retrieve the loan(s)? This may lead to the collapse of the group or a burden on the group members who are poor.

Lives in hope

Meena (29) is a homemaker and has a two-and-a-half-year old daughter. Her husband works at a local confectionery shop in Theni district, earning about Rs. 80 every day. About a year back, he was diagnosed HIV positive. Since then life for the once-happy and prosperous couple has never been the same.

Articulate and confident, Meena, despite the harrowing life she leads as a woman affected with AIDS, retains her sense of composure and equanimity. She is well informed about health issues. She attributes her heightened sense of awareness to being an avid reader of popular magazines, newspapers and TV shows. “In fact, when initial tests were inconclusive, it was I who gently suggested to the doctor about the possibility of HIV,” she recalls.

Her husband's family refused to believe the test results, as they were sure that their son was not sexually active outside marriage. Meanwhile, Meena and her husband, desperate for a cure, spent around Rs. 40,000 on local systems of medicine such as Siddha, besides prolonged treatment at CMC, Vellore.

Meena's parental family is a source of sustained financial and psychological support. Both she and her daughter have tested negative. Prior to his being diagnosed as HIV positive, Meena and her husband were running a flourishing side business selling tea and snacks to the local people. Meena recalls those prosperous times rather wistfully. However, the moment the locals got to know of his suspected HIV status, they tacitly stopped patronising the shop. Meena tearfully recalls that while there is no open antagonism or hostility, it is all too evident in acts of boycott such as this, which make it more difficult for them.

She says soon after confirmation of her husband's HIV status, sales began to decline steadily. Today, she says the shop is practically non-existent.

Around six months back, the idea of enrolling in one of the local SHGs enthused Meena. Fortunately, the Veera Nagammal SHG members were sensitive and responsive to her special needs and concerns as a woman affected by HIV. Overcoming initial opposition from some of the members, they willingly inducted her as an SHG member. There are 16 members in this SHG, each of whom, including Meena, pays Rs. 40 as monthly subscription. The group has lent her Rs. 5000 on easy repayment to enable her start a small trade.

Meanwhile Meena's husband pushes himself to go to work, to support his family. Fearing dismissal, he has told his employer that he suffers from TB. The couple have already spent Rs. 70,000 on treatment. Since her young child needs her around constantly, Meena is unable to take up a job. According to her, until the child becomes less dependent, home-based work would be the best option.

Meena says, that “When I should be enjoying life, I'm burdened with difficulties. I lead a life of sexual abstinence and I know I cannot have another child. Earlier the loss of my first born due to accidental drowning was painful. Little did I know that worse sorrows were in store for me.”

Meanwhile Meena prays for her husband's health and lives in the hope that a cure would soon be discovered for the disease.

For this determined woman, life's battles have to be fought until the very end.

- Induction of PLHA in SHG and immediate loan disbursement arouse suspicion among outsiders about their HIV status. This may affect confidentiality if the PLHA is not willing to reveal her HIV positive status.
- How does one address the confidentiality issue when PLHA have to reveal their status in most cases to become members in SHGs ? The need to understand HIV issues from a poverty perspective was also emphasised.
- Other issues that emerged include initial resistance and hostility of SHGs towards accepting PLHA as members; disapproval of SHG members towards loan criteria being waived for PLHA; resistance and animosity of community development staff towards attempts to integrate PLHA in SHGs, insensitivity leading to denial of treatment by medical and paramedical personnel; and the inability to perceive staff of various departments in an organisation as integrated parts of a whole.

Reaching out to a new way of life

Muthu (29) is a semi literate HIV widow with a seven-year-old son. Her husband was an itinerant cloth merchant. Following the appearance of symptoms such as unexplained fever and swollen lymph nodes, her husband tested positive in 2000. Her husband died of AIDS-related causes last 2001. A short while later, she too tested positive for HIV.

Muthu, like many of the other women, was ignorant about HIV/AIDS and its ramifications. Her husband's family isolated her and are openly hostile and antagonistic to her after their son's death. While her parental family accept her HIV status and feel for her, Muthu does not want to burden them as she has five younger sisters and family finances are strained.

In 2000, Muthu enrolled in the local SHG. She says being an SHG member “gives me a sense of fellowship and kinship with the other women. I feel less lonely. I know that there are people who really care for me.” The SHG has loaned her Rs. 1,000 to meet domestic expenses. Meanwhile Muthu has undergone training in various home-based industries. She looks forward to a source of sustainable livelihood.

For this woman believes that life must go on...

Implementation of action plan

The five INGOs identified the following key points pertaining to integration for future consideration:

1. Integration of PLHA with SHG
2. Integration with primary health centre
3. Improved role of private doctors
4. Joint staff meetings of different programmes in NGOs
5. Field level coordination between community development and HIV/AIDS programmes
6. Formation of advisory committees
7. Networking of NGOs and PLHA
8. Linkage with government agencies / institutions / corporate houses.

1. SHG integration

Constraints:

- lack of awareness among SHG members about HIV/AIDS;
- rigid rules and regulations regarding membership in SHGs;
- migration of PLHA;
- stigma and discriminatory attitudes towards PLHA;
- problem of self-acceptance among PLHA;
- breach of confidentiality experienced by PLHA;
- difficulty in repayment of loans by PLHA; and
- low ratings of SHGs due to defaulting PLHA members.

Advantages:

- decrease in stigma and discriminatory attitudes towards PLHA;
- economic and psychosocial support for PLHA provided by SHG members;
- community participation;
- increase in self-esteem and a positive attitude experienced by PLHA; and
- access to resources.

2. Primary Health Centres

Constraints:

- shortage or non-availability of essential medicines;
- lack of cooperation among health centre staff;
- lack of facilities;
- adverse publicity for PLHA; and
- resistance and hostility among medical staff in treating PLHA.

Advantages:

- easy accessibility;
- cost effective; and
- decrease in PLHA resorting to quacks.

3. Private doctors

Constraints:

- expensive;
- stigma and discriminatory attitudes towards PLHA;
- excessive claims of cure; and
- risk of private doctors being branded as “HIV doctors”.

Advantages:

- immediate treatment for opportunistic infections;
- provision of free medicines;
- quality treatment and medicines; and
- counselling service.

4. Joint staff meetings

Constraints:

- dilutes objective-driven meetings;
- time consuming;
- lack of cooperation among staff ;
- differing priorities of staff;
- duplication of work; and
- issues relating to confidentiality.

Advantages:

- coming together and sharing of experiences;
- informative and broadening of perspectives;
- opportunity for field level coordination; and
- cooperation in creating access to resources and services.

5. Field level coordination with community development

Constraints:

- divergent concepts;
- lack of cooperation;
- too much of work; and
- dilutes focus programme.

Advantages:

- decrease in stigma and discrimination;
- increased community participation; and
- economic and psychosocial support.

6. Formation of advisory committee

Constraints:

- time consuming;
- resistance from existing members; and
- lack of involvement of members / low levels of commitment.

7. Networking

Constraints:

- greater visibility leading to stigma;
- discrimination and isolation of members;
- lack of clarity in leadership roles;
- financial constraints;
- difficulties in coordination; and
- corruption and self-interest.

Advantages:

- common platform for sharing and learning from experiences;
- resource mobilisation;
- linkage with other NGOs;
- peer support; and
- collective strength and bargaining power.

8. Linkages with government agencies/institutions

Constraints:

- non acceptance;
- hostility and resistance;
- rigid rules and regulations; and
- non cooperation from agencies/institutions.

Advantages:

- economic support;
- resources;
- sustainability; and
- policy influences.

**PWDS - ALLIANCE HIV/AIDS CARE AND SUPPORT PROJECT
REACH THROUGH THE INTEGRATION PROCESS**

No.	Implementing NGOs	PLHA's integrated	Total SHGs promoted	SHG in HIV/AIDS Response	Doctors involved in Care	Hospitals involved in Care	Direct beneficiaries	Indirect beneficiaries
1	AIRD-R	8	199	40	14	6	139	5721
2	AIRD-V	15	10	10	8	8	740	8400
3	Blossom	2	400	25	9	8	222	2250
4	CAST	17	276	20	10	4	36	5000
5	CBH	16	90	16	8	8	120	240
6	Chevaliar	20	20	13	28	12	336	2840
7	CSR	36	58	32	5	8	36	189
8	Pache Trust	19	-	79	11	6	321	3500
9	RED	11	163	11	6	4	220	1100
10	SEDCO	11	324	10	12	9	264	976
11	Seva Nilayam	13	241	21	4	7	324	29757
12	SRDPE	15	298	32	6	5	195	1500
13	Anbalayam	16	4	4	15	-	65	-
14	CARE	2	250	5	5	5	124	375
15	Gramium	2	589	6	4	8	102	320
16	Imayam	22	207	-	9	9	424	2200
17	NMCT	7	150	3	14	10	27	2400
18	SSH	17	90	10	10	9	215	1727
19	WORD	-	52	-	5	6	84	385
Total		249	3421	337	183	132	3994	68880

Even though PACHE has not promoted any SHGs, they have utilised the facilities of SHGs promoted by other NGOs. SEDCO has promoted two SHGs exclusively for PLHAs.

4. CONCLUSIONS AND FUTURE OPTIONS

1. Strategies and approaches used–intervention process initiated

PLHA are enrolled as members in SHGs through an orientation and sensitisation process of all people involved. This process addresses stigma and isolation, care and support, and acceptance and prevention.

Integration with SHG provides an opportunity to interact with community development staff, integrate HIV/AIDS intervention with community development initiatives, open access to many economic and social services to the affected people, and project HIV issues as a development agenda. Enrolling PLHA in existing SHGs of the INGO, in SHGs promoted by other NGOs working in that geographical area, and promoting new SHG for the PLHA with opportunities for leadership roles are some of the options.

Instead of approaching community organisations or service providers with a sensitisation plan, introducing the programme and inviting others to participate in the programme, helps to build linkages and working relationships, especially with the health care providers.

Community-based approaches in development are essentially integrated, and transcend sector boundaries. HIV/AIDS interventions initiated as part of the community development programmes or as a component of community health programmes are more effective in establishing contact with the affected people, maintaining confidentiality, and addressing various needs of the affected people which cut across different (development) sectors.

“Our experience tells us that integrated HIV/AIDS health programmes are the need of the hour. On the contrary, isolated HIV/AIDS programmes are associated with increased risk of stigma and discrimination.”

- Seva Nilayam Staff

2. Initiatives, roles, responses of INGO, community, affected people, and any other organisations / people involved in the process

The INGOs act as a bridge between the PLHA and the community through their multiple roles that include enrolling PLHA as members in existing SHGs; evolving an SHG for PLHA; and enrolling PLHA as members in SHGs promoted by other NGOs; availing services from the primary health centers, and creating awareness about HIV/AIDS care and support among local private medical practitioners and involving the latter in the care and support advisory committee of the INGO.

The initiative, in most of the cases, has come from the INGO staff as a way of providing support to the PLHA. It was difficult in the beginning as the community was suspicious and often doubted if the NGO staff were also infected. Stigma and isolation are common responses of the community to people living with HIV/AIDS. Initially, even priests and religious leaders were hostile and refused to meet the field workers and SHGs. For earlier, knowledge of HIV/AIDS although present, was disseminated around 'a fear approach' or not internalised correctly. As a result, non-acceptance was implicit. However, due to awareness and sensitisation programmes, interacting with SHGs is now a lot easier. All SHGs who were earlier hostile are now open and accepting people living with HIV/AIDS. Demonstrating the accepting behaviour of the staff has an impact. SHG members voluntarily initiate activities to help women members living with HIV/AIDS. SHGs also take on responsibilities of care for women living with HIV/AIDS. After intervention, sympathy has given way to a genuine desire to help as one person to another.

“There is no fear of HIV/AIDS; when I see her I only feel for her.”

“I have two children. If she dies, I will take care of her three children and bring up all of them as my own”

“We will support her in what ever ways possible.”

These are some of the voices of SHG members about PLHA in their groups.

A young woman, daughter of an SHG member, from one of the villages, who got a job recently, has volunteered to give her first month's salary to an affected woman in the village. It is customary to offer the first month's salary to the church / temple in this village.

“It takes a lot of effort to promote an SHG. We find it difficult when our care and support colleagues just ask us to enroll a PLHA as a member,” expressed a community development worker.

“We need to go with a strategy and with patience to convince the people. Once this is done people respond so positively.”

A few SHGs have introduced the practice of collecting rice for families affected by HIV/AIDS. Each SHG member contributes a small quantity of rice every day before cooking for her family and gives it to the group on a weekly basis. This practice is introduced among the general public too. Besides involving the general public to support the affected families, this also provides an opportunity to interact and in the process remove some of the myths created about HIV among the public.

“In a way, this practice benefits the giver and the receiver,” said an INGO field staff. More than the contribution of rice by public the process leads to a sensitisation process and helps to reduce stigma and the misunderstanding about the disease.

Prior to INGO efforts to reach out to health care providers about the special needs and concerns of PLHA, many doctors were either insensitive or concerned about their public image and that of the hospital. Isolation, discrimination, and denial of treatment were common among the government and private sector care providers. However, there has been a significant decrease in such negative responses following persistent lobbying of INGOs with health care practitioners and general public about the nature of the infection and for the rights of PLHA to access quality treatment and care.

3. The impact of the intervention on the affected people, community, and other service providers.

After integration in SHGs, there are positive impacts on the PLHA and community. As for PLHA, many of them validate the observation that SHG membership builds their self-esteem and self-confidence.

The experiences of PLHA include an increased desire to live; a positive attitude about life; increased levels of acceptance leading to happiness; security, improved health seeking behaviour, increased leadership qualities; better economic returns due to work opportunities that were made available; and opportunities for skill training, and to avail loans.

The community expressed that the process of integration helped them to realise that HIV/AIDS is also a disease like other diseases, to accept the infected person as a co-member and offer need-based help. In general, the SHGs willingly function as guardians for PLHA.

Doctors volunteer to treat many PLHA after a linkage is established. The general acceptance by SHGs and health care providers of the area helps to create awareness among the general public about HIV and PLHA that leads to reduced stigma. A clear relationship is established between care and support, stigma, and prevention aspects. This is effective when one starts from care and support, where the other aspects come as part of the process.

Following the intervention efforts of CSR, an implementing NGO, ten PLHA in CSR's operational area have been linked to a local hospital for treatment free of charge. The doctor concerned volunteered to treat them free of charge.

The integrated staff meeting at CAST and Seva Nilayam was a milestone because for the first time all departments in the organisation came together to discuss HIV/AIDS integration and bring their shared perspectives and understanding to generate possible solutions towards an integrated

approach for HIV/AIDS care and support. The meeting has facilitated a rapport among all departments in the organisation. Earlier the departments were compartmentalised and staff were unaware of the activities of the other departments.

Prior to the intervention, staff encountered widespread lack of acceptance of PLHA, stigma, isolation, discrimination, and fear about HIV/AIDS. However, sensitisation and awareness programmes have resulted in an attitudinal change among the people, who now volunteer to help PLHA.

4. Difficulties encountered during the process with facilitating and constraining factors.

Initially, the community questioned the special treatment meted out to PLHA. Since there are many families living under poverty conditions in rural areas, the special focus on PLHA is a matter of debate among the community. There is resistance and hostility of SHGs towards accepting PLHA as members in the initial stages. Some SHG members question the need to waive the loan criteria of an SHG in order to accommodate PLHA. Resistance and animosity of community development staff towards attempts to integrate PLHA in SHGs occurs if the process is not well planned or fails to initiate an orientation process before integration. On the other hand, integration of PLHA into the SHG impacts on wider spheres like sensitising the staff, SHG members, the larger community, and also leads to the possibility of integrating with the community development programmes.

Donor priorities and requirements, specific project frames and monitoring tools introduced by various donors as part of the project management process, the departmental functioning of different projects within an organisation, and a fragmented project approach are some of the constraining factors in integrating HIV/AIDS interventions with community development programmes.

Insensitivity of the health care providers leading to denial of treatment by medical and paramedical personnel, the fear that HIV/AIDS treatment may lead to decreased patient turn over are constraining factors in the health care sector.

5. Resources (human, financial) utilised

In most cases, the interventions “happened” as a spontaneous response to a specific need. A large amount of human and financial resources were mobilised from local sources in the form of kind and human support. This resource mobilisation for a specific need also involves a sensitisation process. In all the integration attempts, stigma, care and support, and prevention aspects come in one by one. The support in the form of INGO, staff, and resource teams for training are all there as the basic structure on which all these initiatives happen and with a positive community response.

6. Replication/scaling-up possibilities

“ There is a need for NGOs to work towards creating a positive accepting environment that is conducive for the local community to accept people living with HIV/AIDS without reserve. The government and NGOs should work concertedly to make this a reality.”

- INGO staff

There is scope for replicating these experiences in improved and more effective ways. Enabling the PLHA already involved in the process to form collectives or networks can help to replicate these experiences in a large scale. NGO networks, those working in HIV areas and other community development NGOs, could pave the way for scaling up in an effective way. The integration of HIV/AIDS care and support concerns with the community development programmes as one of the components opens the way to cut across all sectors of intervention, address all dimensions of HIV/AIDS, and create wider impact in the community.

Working with reliable and competent partners, with space for experimentation and innovation within the project frame is essential. Confidence in partners' reliability and implementing ability seem to be more important than the monitoring of strict adherence to the planned and agreed upon project frame and activities.

People interact in specific contexts; they are aware of what is available, they know what works. So learning from them; working with them; and starting from what is there seems to be the best approach. Instead of focusing on negatives, identifying positive responses of the people; recognising them, strengthening and replicating such experiences in scale looks to be a potential option. "Initiating integration interventions and learning from community responses" seems to be the way forward.

Improving mainstream services, establishing linkages, promoting NGO and PLHA networks for collective functioning, and enabling the community for appropriate responses through integration initiatives seems to be the agenda for the future.

5. ANNEXURES

1. Meetings / Visit Schedules

1. Planning Meeting, March 20, 2002: At the first planning meeting at DATA, the team reviewed the draft TOR. Roles and responsibilities were clarified and each of the three members was assigned specific responsibilities.

2. INGO visits, March 24-27, 2002: The team visited the following three INGOs and interacted with SHGs, PLHA and INGO staff.

- Rural Education for Development, (RED), Idayankudi
- Centre for Social Reconstruction (CSR), Nagercoil
- Community Action for Social Transformation (CAST), Cheranmahadevi.

3. Introduction of the study, March 27, 2002: The study team introduced the study details to the staff team and INGOs at an Experience Sharing Review Meeting (ESRM) at Kanyakumari. The participants also shared their experiences.

4. Planning Meeting, April 3, 2002: At this meeting in DATA, the study team finalised the visit to Seva Nilayam and Andipatti on April 4. The team also circulated the draft of the earlier visit and discussed it. The team planned a joint staff meeting of the programme coordinators and SHG members of the five INGOs for a joint meeting at DATA on April 25, 2002.

5. INGO visits, April 4, 2002: The study team visited Seva Nilayam, Andipatti; and Society for Rural Development and Protection of Environment (SRDPE), Theni; and interacted with SHGs, PLHA and INGO staff.

6. Joint Staff Meeting, April 25, 2002: At this meeting in DATA, the programme co-coordinators and the staff of SHG programmes of the five INGOs discussed various strategies involved in their integration initiatives.

7. Integrating the PWDS-Alliance project with the other ongoing community development programmes of the INGOs concerned: The study team visited Seva Nilayam on July 26, 2002, and CAST on August 10, 2002, to discuss and explore strategies for integrating the PWDS-Alliance project with the other ongoing community development programmes of the INGOs concerned.

8. INGO meeting following implementation of action plan, October 19, 2002: The five INGOs met at DATA following implementation of the action plan to discuss key issues related to integration.

2. INGO Profiles

1. Centre for Social Reconstruction (CSR): CSR is a development organisation based in Nagercoil, Kanyakumari district. Established in 1974, CSR operates in Tuticorin and Kanyakumari districts.

The organisation's major activities include women's development, promoting SHGs, enabling the community to initiate and manage IGP activities, skill training; implementing programmes to eradicate child labour, school enrolment programme for drop outs, STD and HIV/AIDS awareness and control programmes.

CSR also implements HIV/AIDS awareness programmes from 1995; Women in Prostitution (WIP) Intervention programme from 1997; and PWDS-Alliance community based care and support programme from 2001.

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Nagercoil - 629 002, Kanyakumari District.
Ph: 04652-225969 email: csrnagar@yahoo.com

2. Rural Education and Development (RED): This Tirunelveli-based development organisation, established in 1975, operates in 62 villages in Tirunelveli district.

The organisation works for the socio economic rehabilitation of women, children, rural artisans, dalits, PLHA, CAA and FAA. It promotes micro enterprises and micro credit systems and attempts to create viable models for their replication. The major activities include community pre-school education, micro credit, community based enterprises, self-employment training, and HIV/AIDS care and support. RED has been involved in the community based care and support programme since 2001.

Contact Person: Mr. T. Muthunayagam
Address: 102, Peter Street, Idayangudi Post,
Tirunelveli District - 627 651.
Ph: 04637 - 571462

3. Community Action for Social Transformation (CAST): Established in 1984, CAST operates in nearly 250 villages in the following five blocks of Tirunelveli district: Kalakad, Cheranmahadevi, Nanguneri, Tenkasi, and Radhapuram.

The major activities include women's empowerment programmes, child development, AIDS prevention and control, natural resources management, networking, and HIV/AIDS care and support. The phenomenon of migrant labourers in the region, most of whom migrate to Mumbai in search of livelihood opportunities has made this area particularly prone to spiralling rates of HIV infection.

CAST implements the Tourism and Women in Prostitution intervention project from 1998; HIV/AIDS awareness programme among *beedi* (local cigar) rolling women; cultural team for HIV/AIDS awareness programme, and community based care and support from 2001.

Contact Person: Mrs. P. Sushila Pandyan
Address: Poothathankudieruppu, Thiruviruthanpulli Post (via)
Cheranmahadevi, Tirunelveli District - 627 414.
Ph: 04634 - 463355

4. Seva Nilayam Society: This is a collaborative effort with the UK-based Ryder Cheshire Foundation. The organisation was established in 1963 by the British-born Dora Mary Scarlett, a social worker. Seva Nilayam's community outreach programme covers 70 villages in Aundipatti, Kadamalaikundu, Myladumparai, and Theni blocks.

The programmes, geared towards assisting the local community to achieve improved health and socio economic status includes the following: women development programmes; IG programmes; skill training; family counselling centre; female infanticide control; NGO capacity building; medical care; community based primary health care; community based anaemia control; community based RCH; AIDS awareness; and community based HIV/AIDS care and support.

Seva Nilayam implements AIDS awareness programmes from 1998, and community based care and support programme from 2001.

Contact Person: Mr. A. Vijayaraman, Director
Address: Rajathani Post, Aundipatti Taluk, Theni.
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5. Society for Rural Development and Protection of Environment (SRDPE): This Theni-based development organisation was established in 1993. The organisation's development approach is based on people's participation and community involvement.

The activities focus on health, gender, social and economic upliftment. The major programmes include women's development; vocational training for REDP and skill training; HIV/AIDS intervention; environmental sanitation; social action; and community-based HIV/AIDS care and support.

SRDPE implements the women in prostitution intervention programme from 2001, and community based care and support programme from 2001.

Contact Person: Mr. P. Murugan, Director
Address: 1588, Periyakulam Road, Allinagaram,
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3. SHG Profiles

As part of the study and documentation, ten SHGs were covered to collect integration experiences. These SHGs are already existing ones, newly formed for accommodating PLHA, or SHGs of other NGOs working in that geographical area. The SHG members also participated in the process of the study by sharing their experiences in admitting a member into their group or working with PLHA as group leaders.

1. Grama Munnettra Mahalir Suya Udavi Kuzhu is an SHG promoted by CAST in Puthoor village, Kalakad Block in Tirunelveli district. Formed in March 1999, the SHG headed by S.Prema, has 20 members. Each member pays a monthly subscription of Rs. 50-100. The SHG has a total savings of Rs. 65,000 and lends to its members at a rate of 2% interest.

H (25) is a PLHA who has been a member of this SHG since its inception. The SHG members are supportive and empathetic towards her. They took charge of the funeral arrangements of her husband who died of AIDS. An SHG member says, “Her children are our children. We will look after them after her death.”

Another SHG member’s daughter, says, “I will give my first month's salary to her family.”

2. Rani Jhansi SHG is promoted by CAST in Puthugramam village in Cheranmahadevi block in Tirunelveli district. Formed in 1996, the SHG has 20 members. Each member pays a monthly subscription of Rs. 50 and the SHG has a total savings of more than Rs. 50,000.

K (28), a PLHA joined the SHG following the intervention of the CAST care and support staff team. The SHG members have rented a house for her from one of the villagers for a nominal rent. The members who are supportive of her say, “ We have no fear of being infected when we interact with her. She is one of us.”

- 3. Kanmani SHG** is promoted by RED in Radhapuram block in Tiruvambalapuram village in Idyankudy. The SHG with a strength of 20 members was formed in 2000. Each member pays a monthly subscription of Rs. 50 and the total savings of the group is around Rs, 20,000.

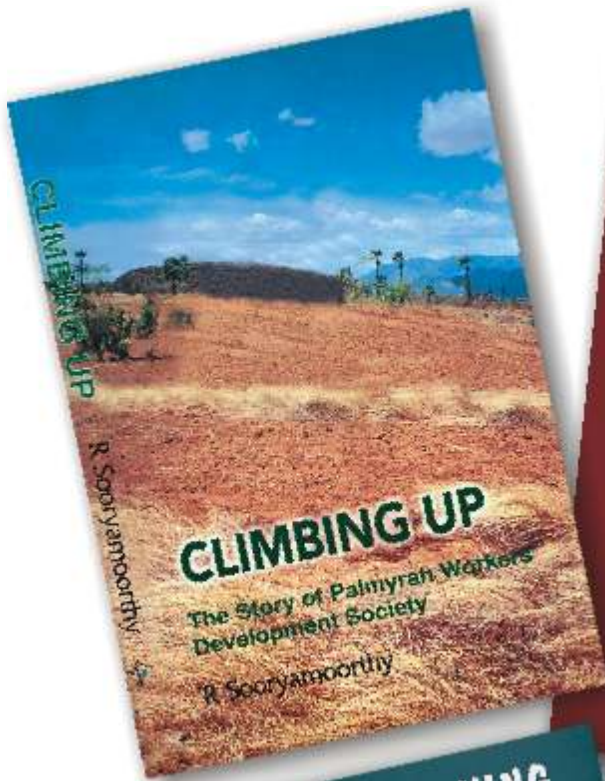
The RED care and support staff team sensitised the SHG members to HIV/AIDS issues. M, a PLHA, who was receptive to the idea of becoming an SHG member, enrolled herself in the group. The members accept her without reserve and are supportive of her. She says “she feels strengthened and happy ever since she became an SHG member.”

- 4. Katteruperumal Suya Udavi Kuzhu** is promoted by RED in Radhapuram block in Thottavilai village in Tirunelveli district. Formed in 2002, the SHG has 13 members. Each member pays a monthly subscription of Rs. 51.

The RED staff initiated steps to form an SHG for a PLHA (27). All the members are sensitised to HIV/AIDS issues. The affected person is the secretary of the SHG. She says her new role has enabled her “to feel strengthened, and boosted her self-esteem and self-confidence.” She remarks that the other members often say, “You are one of us. We are there for you.”

- 5. Surya SHG** in Thettivilai village, Melpuram Block, Kanyakumari district, was started in 2001 with the support of START, an NGO working in the area. CSR, an implementing partner of the PWDS- Alliance programme approached the NGO and the SHG to enrol an infected person from that area. The SHG currently provides the following support and services to PLHA: labour contribution for house construction for the PLHA, giving vegetables and coconuts regularly, educational support and dresses to CAA, interest free credit, and home based care.

6. **Pitchy**, an SHG promoted with the support of Nala Oli, an NGO in Kanyakumari district, functions in Kappukadu village, Kanyakumari district from 1999. The SHG with the motivation and sensitisation process of CSR has an HIV positive woman in the group as a member. The group has provided a sewing machine and also supplies vegetables and coconuts regularly. The group members also help in making dresses and selling them as an income generating activity for her. The group members also help to access timely treatment.
7. **Veerachinnammal** SHG was started in 2001 with the support of Seva Nilayam and functions in Sitharapatti village, Theni district. The SHG has enrolled an HIV positive woman in the group and provides a loan for goat rearing.
8. **Veeranagammal** SHG also functions from 2001 with an HIV positive woman as a member. In addition to the other regular services by the SHG, a loan was extended to the HIV positive person to set up a petty shop in the village.
9. SRDPE, Theni was successful in integrating many HIV positive persons in SHGs. **The Malaimathi** SHG extends support in the form of loans, EDP training, rice collection from the members, and treatment for opportunistic infections.
10. **The Pall Nila** group provides support for treatment, EDP training, rice, and loans with reduced interest.





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A development vision

"Visions are not created or worked out, but received. This is the vision received by a group of friends, that reveals itself and realises its aspirations over the decades. Compassionate charity, conscientised solidarity, self - reliant communities, and the resulting liberation, freedom and augmented quality of life were the limited goals at each stage of realising the vision."

- **The Rt. Rev. Dr. Samuel Amirtham**
Founder President, PWDS

support services to sustain community initiatives