



Towards Mainstreaming HIV/AIDS Initiatives

The PWDS-Alliance Experience in
Community Based Care and Support in
Tamil Nadu (1999-2007)



Towards Mainstreaming HIV/ AIDS Initiatives

The PWDS-Alliance Experience in
Community Based Care and Support in
Tamil Nadu (1999-2007)

Palmyrah Workers Development Society

Registered Office:

*Crystal Street, Marthandam 629 165
Kanyakumari District, Tamil Nadu, India
Phone: 04651 270241 · Fax: 04651 270138
E-mail: palmarts@sancharnet.in*

Coordination Centre:

*DATA, 11, Kennet Cross Road, New Ellis Nagar
Madurai 625 010, Tamil Nadu, India
Phone: 0452 2301022, 2603652 · Fax: 0452 2300369
E-mail: datapwds@eth.net*

PWDS-Alliance Project Office:

*Crystal Street, Marthandam 629 165
Kanyakumari District, Tamil Nadu, India
Phone: 04651 273942,273652 · Fax: 04651 270138
E-mail: pwdscore@vsnl.net, pwdscore@sancharnet.in*

Website: www.pwds.org

Acknowledgements

Documentation Support:

Dr. Nandini Murali

Design & Layout:

+G Publishing, Madurai 625 007 · Phone: 0452 2586644

Printing:

LEO Prints, Madurai 625 001 · Phone: 0452 4395755

IN SOLIDARITY—SHG MEMBERS SHOW THE WAY

When Sumathi's husband died of AIDS-related illness, her mother in law ordered Sumathi and her two children to leave the house. She refused their share of the family property as she blamed Sumathi for her son's death. Sumathi sought refuge in her father's home.

Sundari, President of the Anjumozhi SHG in Veerasoodamanipatti village, spoke to the other members about the need to support Sumathi. Assured of their collective support, Sundari invited Sumathi to become a member of the SHG. "Initially I faced a lot of opposition from the group. But I finally helped them to understand why it was important that we offer support for Sumathi," recalls Sundari.

A depressed and diffident Sumathi reluctantly joined as SHG member. The group lent her an interest-free loan of Rs. 6000 to set up a petty shop. Today Sumathi has repaid the loan.

The SHG then organised a meeting of the village elders to highlight Sumathi's denial of a share of the ancestral property. The SHG members launched a complaint with the local Women's Police Station. Thanks to their efforts, Sumathi received her share of the ancestral property—50 cents of land and a portion of the ancestral house.

Today Sumathi is the dynamic president of the Regional Positive Network, Melur. The network that consists of 45 people living with HIV/AIDS was initiated by PACHE Trust, an INGO of the PWDS-Alliance HIV/AIDS care and support programme, in 2003.

Membership in the SHG has given Sumathi a sense of security. "When my daughter came of age, the SHG members responded with gifts and celebrated the occasion as if I were a member of their family. I was touched by their response," says Sumathi.

Such impacts are the result of a planned intervention—the PWDS-Alliance HIV/AIDS community based care and support project to address the growing threat of the HIV epidemic by an enabling, sustainable, and supportive environment towards community based care and support for people living with HIV/AIDS.

While widespread stigma, discrimination and negative attitudes towards people with HIV still exist, there are also several such positive responses as a result of mobilisation and sensitisation of the community through a community based intervention. A participatory approach, capacity building of the community, and linkages with mainstream enables people living with HIV/AIDS to rebuild their lives with dignity and respect.

THE CONTEXT

HIV/AIDS is a leveller that has crossed barriers and boundaries. The first clinical diagnosis of AIDS in modern medicine was in a male homosexual in the US in 1981. In 1986, HIV was detected for the first time in India in commercial sex workers. Since then the infection has demonstrated unprecedented porosity in its prevalence rate not only in the so-called high risk groups but in the general population as well. No one then could have predicted the global impact of HIV/AIDS on individuals, families, and communities.

According to a UNAIDS (2007) estimate, there are 33 million people living with HIV/AIDS in the world, of which children account for 2 million. Of the over 6800 new infections a day, more than 96 percent is in the low and middle income countries. The infection has pushed individuals and families on the brink of disaster and widened the gulf between the rich and the poor. Since then HIV/AIDS has emerged as a global health challenge.

In India, there are 2.5 million people living with HIV/AIDS (NACO, 2006). In recent years, however, the infection has spread rapidly from urban to rural and from the so-called high risk groups to the general population. Besides a significant percentage of infection (98%) occurs between 18-40 years, when individuals are sexually active and economically productive. Thus HIV/AIDS is not merely a health issue but a social issue as well. It is a "human resource crisis" that impacts adversely on the economic, social, and productivity levels.

Currently more than 95 percent of people infected with HIV live in developing countries, with 70 percent in Sub Saharan Africa. "In the breadth and depth of its impact, AIDS has revealed the inner workings of poverty. AIDS creates poverty, AIDS deepens poverty, and AIDS makes poverty hard to escape," said Dr Peter Piot, Executive Director, UNAIDS.

Poverty factors have a direct link with the spread and impact of HIV infection. Rural areas and populations in the low income group are particularly vulnerable. Inadequate income makes people engage in risky behaviours; disease progresses more rapidly when nutrition is inadequate; lack of education and social support; poor health care facilities and denial of human rights leads to increasing isolation and makes people vulnerable to disease and discrimination. Besides related factors like failure of agriculture, disasters, breakdown of social structures, migration, urbanisation, and lack of awareness of diseases, and inadequate access to healthcare compound an already serious situation. Migration in search of income security leads people to engage in high risk behaviour because of absence of normative constraints.

Unlike most diseases that evoke sympathy or support, the most common responses to HIV/AIDS are fear, stigma, isolation, and discrimination. People living with HIV/AIDS are often the target of social violence such as discrimination and human rights abuse. We hear of families losing their sole earning member; of infected persons rejected by families and friends; thrown out of jobs; forced into a burden of secrecy and silence; and denied access to treatment services. Thus the need to prevent discrimination at all levels of society against people living with HIV/AIDS is a vital step in the global response to the epidemic.

Responding to the global development challenge posed by HIV/AIDS, several international agencies have launched major initiatives to address the epidemic.

In India, the National AIDS Control Organisation (NACO) implements the country's national AIDS programme, including formulating policy and implementing prevention and control and care and support programmes. In order to strengthen management of the epidemic at the state levels, the government has established AIDS control societies in 32 states and union territories for effective implementation of NACO programmes. Besides civil society organisations have also emerged as key players in the collective response to the epidemic.

Effective and sustainable responses to HIV/AIDS require a public-private partnership and a partnership between civil society organisations and the community. The PWDS Alliance HIV/AIDS care and support programme in South Tamil Nadu is a pioneering effort that illustrates such a partnership that is community-centric, with total involvement of local communities in strategic planning, activity implementation and evaluation process.

HIV/AIDS PROGRAMMES FROM A DEVELOPMENT PERSPECTIVE

In recent years, there has been a growing realisation that HIV/AIDS is not purely a health issue but has significant development impacts as well. Development thinking has also undergone a shift from viewing HIV/AIDS purely as a health issue to accepting that it is a larger development issue that needs to 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 community conditions and economic norms.

In India, HIV interventions based on prevention and control is not complete because in the initial years, it was dissociated from care and support of the infected and affected people. With limited access to treatment and care for those living with HIV/AIDS, it was 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 infecting the general population too. Hence to respond effectively to the situation, increased and integrated treatment and care efforts must go hand in hand with prevention efforts with the participation of the affected people and the community reflected in community based care and support initiatives as relevant responses.

Background of the PWDS Alliance HIV/AIDS Care and Support Project

Every threat poses a new challenge. HIV/AIDS is no exception. PWDS, a more than three decades old development organisation, based in Marthandam, Kanyakumari district, works with community based organisations and support service organisations aiming at self-management and sustainability. It is part of the PWDS vision to respond to new challenges and situations and respond to emerging community needs. Also embedded in the PWDS organisational culture is an attitude of being open and adaptable to change in response to contextual demands, while keeping its core values intact.

The core of PWDS development approach is the concept of mainstreaming the concerns and issues of the marginalised through various strategies. PWDS believes in a community based approach in which the key features are its focus on community organisation and community capacity building. The development approach involves a convergence of social and economic goals, integration of rights and capacity; mainstream access and linkages, and policy influence. This is the basis of the MEALS approach: a five step approach that consists of motivate, equip, accompany, link, and sustain community initiatives.

With India being seriously affected in the global crisis of HIV/AIDS, the timing was conducive for PWDS to initiate relevant community responses to the growing threat of HIV/AIDS. In 1999, PWDS initiated an HIV/AIDS prevention and control programme, supported by TNSACS, Chennai. The activities included creating awareness among the general public, providing education for high risk groups, promoting safer sex practices, and referring affected people for care and support services.

The community presence and linkages of PWDS at the grassroots were advantageous in responding to HIV issues with larger implications. It enabled PWDS to perceive the interconnectedness of HIV interventions with other ongoing development programmes. As a development NGO, access to the community and rapport enabled PWDS to respond with a human dimension to social issues and problems such as HIV/AIDS. It also enabled PWDS to view HIV/AIDS from a development framework with a long term perspective.

The International Alliance, a UK-based organisation with its successful experience of HIV/AIDS care and support in Africa, was seeking to replicate its experience in the Indian context. It selected PWDS, to anchor a community based HIV/AIDS care and support with a development perspective. In 2000, PWDS began to implement the HIV/AIDS care and support project

The Alliance made its presence felt in the Indian sub continent with its efforts to promote community based care and support in collaboration with NGOs and CBOs. It identified the states of Tamil Nadu, Andhra Pradesh, and Delhi as priority states to implement a pilot phase of HIV/AIDS care and support project. In each of these states, an NGO was chosen as a lead or primary partner to facilitate a broad range of responses to the epidemic by initiating, implementing, and coordinating the programme in partnership with select NGOs. PWDS was chosen as the lead partner in Tamil Nadu to coordinate the HIV/AIDS care and support project through select NGOs.

The PWDS Alliance HIV/AIDS Care and Support Programme marked a synergy between the technical competence of the International Alliance and the development ideology of PWDS with its sustained and significant presence in the community. Amidst the prevailing scenario of fear and negative messages of HIV/AIDS, and the resulting stigma and discrimination of people with HIV/AIDS, a community based approach that emphasised community participation and ownership; acceptance and compassion; instead of alienation and condemnation towards people with HIV/AIDS seemed as much radical as it was spiritual.

Project Overview

The PWDS-Alliance HIV/AIDS care and support project with a focus on community based care and support was initiated in the southern districts of Tamil Nadu in 2000, when PWDS (Palmyrah Workers Development Society) was selected as a lead partner by the UK-based International HIV/AIDS Alliance to coordinate the programme in Tamil Nadu. It is a partnership between PWDS, the coordinating organisation; the International HIV/AIDS Alliance, the support organisation; and a network of implementing organisations.

The PWDS-Alliance care and support project, supported by Abbott Laboratories, USA; and the International HIV/AIDS Alliance, UK; works with 20 NGOs in Tamil Nadu across 13 districts. The project works towards an enabling, sustainable, and supportive environment towards community based care and support for people living with HIV/AIDS, children and families living and affected by HIV/AIDS. The integrated and comprehensive HIV/AIDS care and support programme is built on a vision of capacity building of NGOs in providing low cost community based care and support for people living with HIV/AIDS.

Objectives

- ☛ Initiate and strengthen community based care and support for people living with AIDS and their families.
- ☛ Initiate and strengthen community based care and support for children affected by AIDS and their families.
- ☛ Link, strengthen, and coordinate the existing services for care and support.
- ☛ Mobilise the community towards care and support.
- ☛ Initiate policy-related interventions towards promoting the integration of care and support and community based activities in Tamil Nadu.

Project Reach In the first phase of the project (1999-2000), the project reach consisted of eight districts in south Tamil Nadu with 14 implementing NGOs (INGOs). Currently the project reaches out to 20,024 people from the low income group living with HIV/AIDS and many thousand of families and children affected by HIV/AIDS in 800 villages in over 13 districts in central and south Tamil Nadu through 20 implementing NGO partners. Since 2008, in a move towards better coordination among other players at the district and state levels, the project now works in ten districts, and works collaboratively in three districts.

Districts	:	13
Partners	:	20
Number of affected people reached	:	20,024
Trained Volunteers	:	783
Trained Home care guides	:	162
Health care providers	:	762
Self help group integration	:	580 PLHA in 360 SHGs
Faith based organisations	:	63
Children's clubs	:	152
Children's support groups	:	96
Coaching centers	:	45
Children's libraries	:	19

Structure of the HIV/AIDS Care and Support Project

The project structure comprises the lead partner (PWDS) to coordinate the project, and the Implementing NGOs (INGOs) who work directly with the infected and affected people. Besides a Project Advisory Committee (PAC) and a Project Committee (PC) were constituted for effective monitoring and implementation.

As guidance for guide future programming, PWDS and the INGOs initiated an attempt to develop a shared understanding of a development perspective in HIV responses. The process involved a participatory approach, sharing of field experiences, and discussions on development perspective in HIV responses.

Palmyrah Workers Development Society (PWDS), founded in 1977, offers development support services to sustain community initiatives. PWDS promotes and works with community based organisations and support service organisations aiming at self-management and sustainability. Its interventions aim at empowering the community by building people's organisations, equipping through awareness generation and linking them with mainstream for sustenance. Currently PWDS coordinates five field projects, and has promoted ten support organisations with mainstream linkages. It works in 17 districts in Tamil Nadu through network programmes with 40 NGOs as partners.

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 provides technical and financial support to in-country intermediary organisations termed "linking organisations" or "lead partners" that in turn provide financial and or technical support to NGOs and CBOs in their respective countries.

The India HIV/AIDS Alliance (Alliance India) based in New Delhi was established in February 1999 as the country office of the International Alliance. It coordinates and provides support to the Alliance programme of supporting community action on AIDS in India. To achieve these goals, the Alliance supports community action in India through an integrated and comprehensive HIV/AIDS programme in which a key priority is working with children affected by AIDS. All activities supported under the Alliance programme in India operate under the umbrella of the National AIDS Control Organisation (NACO).

Community Based Care and Support for HIV/AIDS

The PWDS-Alliance care and support project for HIV/AIDS aims to mobilise community action for care and support of people infected and affected by HIV/AIDS, with a special focus on women and children. The community based HIV/AIDS care and support programme aims to improve the quality of life of people with HIV/AIDS, their families, and communities by providing comprehensive care that involves a variety of services and resources to address a range of needs— diagnosis, treatment, referral, nursing care, counselling, as well as support for psychological, economic, and social needs.

A community based HIV/AIDS care and support programme bridges the institution and home; between “providers” and “receivers.” It believes in empowering people infected and affected with HIV/AIDS by creating alternatives and thereby increasing their options, and by ensuring appropriate and equal participation by all players.

Its distinctive features include community-based approach; need-based interventions evolving from the community, reaching more people at lower cost, maximising use of existing resources, focus on home-based care and support, greater involvement at all levels of people living with HIV/AIDS and children affected by HIV/AIDS; addressing prevention linked to care; and challenging stigma and discrimination through community mobilization; emphasis on working with existing services, strengthening existing services, recognizing specific gender based needs, greater involvement of people living with HIV/AIDS (GIPA), focusing on both direct services and referrals, collective functioning as a network, strong referrals and linkages, integrated approach, and mainstreaming for sustaining the services.

Timeline

- ☛ **Visits of Alliance Staff** Dr Asha Rao and Mr. Bhaskara Menon, on behalf of International HIV/AIDS Alliance, visited PWDS on September 7, 2000. Dr. Sujith Ghosh, Senior Programme Officer, South Asia, International HIV/AIDS Alliance, and Dr. Tarun Roy, Consultant, visited PWDS in September and November 2000 respectively. The former introduced the project to PWDS staff and discussed the preparation of a plan of action. The latter conducted training sessions for PWDS staff and committee members on November 14-15, 2000.
- ☛ **Formation of a project committee** PWDS formed a project committee in November 2000 to formulate plans for field study and situation analysis.
- ☛ **First meeting of INGOs** The invited INGOs met together for the first time on November 6, 2000, at Kanyakumari, to discuss the HIV/AIDS care and support project and undertake a situation analysis to assess the need of the project in the respective areas.
- ☛ **Consultation and review meeting** NGO representatives convened a consultation and review meeting at CARDS, Tirunelveli, to review the progress of work and discuss the situation analysis report. The report was finalised in November 2000.
- ☛ **Strategy planning workshop** Chief executives of nine INGOs from Tamil Nadu, office bearers and staff of PWDS, and representatives from the Tamil Nadu Government Health Service, AIDS Prevention and Control (APAC), and Kerala AIDS Control Society, participated in the workshop at Thiruvananthapuram, from December 6-11, 2000. Dr. Sujith Ghosh and Divya Bajpai from International Alliance, and Krupa Shinde, India HIV/AIDS Alliance; facilitated the workshop. The focus of the workshop was on the findings of the situation analysis report.
- ☛ **Memorandum of Understanding (MOU)** PWDS and International HIV/AIDS Alliance signed an MOU.
- ☛ **Inauguration of the project** The project was set on the rails in January 2001.
- ☛ **Appointment of staff** Applications were invited through advertisements in leading local and national newspapers. Based on a selection process, L. Edwin Sam, A. Sundar Singh, and K.B. Sudheer were appointed as programme officers to form the staff team at the lead partner level.
- ☛ **Selection of INGOs** One hundred and thirty-five NGOs responded to advertisements in leading local and national newspapers calling for prospective NGOs to participate in the project. Twenty-five NGOs were short listed, of which 14 NGOs were chosen based on a selection criteria. These included relevant aspects such as location, HIV/AIDS service delivery, financial management, working with people living with HIV/AIDS, and presence in other sectors.
- ☛ **Participatory Community Assessment (PCA) Planning Workshop** PWDS-Alliance conducted a PCA workshop on March 7-9, 2001 at the India Alliance Office, New Delhi.

Two representatives each from the three lead partners in India participated. Participants, along with Alliance staff and consultants, prepared a PCA training module.

- ❏ **PCA workshop** Two participants from each of the 14 implementing NGOs (INGOs) attended the PCA workshop from March 19-23, at Kanyakumari. The workshop enabled participants to identify the different care and support needs of people with HIV/AIDS, and children with HIV/AIDS in order to design an effective intervention plan in the respective areas. The Alliance project staff team, and Ms. Alexandra, Consultant, International Alliance, facilitated.
- ❏ **PCA findings review meeting** This meeting on May 31-June 2, 2001, at Courtrallam, was a milestone in the development of the PWDS-Alliance HIV/AIDS care and support project. The 14 INGOs, following the initial preparatory workshop, carried out a PCA spread over a period of two months in their areas of operation. All partners presented individual reports of their findings in the PCA review meeting.
- ❏ **Project Design Workshop** Twenty-eight representatives from the 14 INGOs participated in the project design workshop from June 19-22, 2001, at Thiruvananthapuram. Dr. Tim Lee and Dr. Mandeep Dhaliwal from International Alliance; M. Chulani de Zoysa, consultant; and Krupa Shinde, India Alliance; facilitated. Participants discussed the strategic focus and community based care and support concept of Alliance; the three-year focus of the INGOs; and the PWDS area of focus. Each INGO was enabled to prepare a project with a budget.
- ❏ **Project Design Follow up meeting** Two follow up meetings were organised for the INGOs in Tirunelveli on July 12, 2001; and the other in Madurai on July 15. The components of the proposals and budget were discussed and agreed. The draft agreement was presented, clarified, and finalised.
- ❏ **Inauguration of Project** The project was formally inaugurated on July 17, 2001 at Madurai, with an orientation on project components and financial management.
- ❏ **Mid term Review and Reflection** The mid term review was conducted at Kotavilai Training Centre, PWDS, on August 21, 2001. Dr. Sujith Ghosh and Divya Bajpai from International HIV Alliance, UK; facilitated. The meeting helped to review all the activities implemented during the period and to identify ways to improve future planning.
- ❏ **Experience sharing Review Meeting (ESRM)** The 14 INGOs and the lead partner PWDS came together for an ESRM on November 5-6, 2001, at Pillar Hall, Madurai. The organisations shared their experiences in implementing the care and support programme in its first phase, their successes as well as the obstacles encountered. Participants also discussed various programmatic and administrative aspects of the project.
- ❏ **TNSACS Visit** Dr. Asha Rao, Country Director, India HIV/AIDS Alliance, New Delhi; and Mr. Edwin Sam, Senior Programme Officer, PWDS-Alliance; met Mr. Christudoss Gandhi, IAS, Project Director, TNSACS, on January 17, 2002, to discuss community based care and support project objectives and strategies and to explore ways to cooperate with the existing

government services, especially in health care. Mr. Sebastian Jayaraj, NGO Advisor, TNSACS, also participated.

- ☞ **YRG CARE Visit** Dr. Asha Rao and Mr. Edwin Sam met Dr. Suniti Solomon, Director, YRG CARE, in Chennai, on January 16, 2002, to mutually share their activities and experiences. They also discussed possible means of collaboration between the technically proficient YRG CARE and the development experience of PWDS in community based care and support.
- ☞ **APAC Visit** Dr. Asha Rao and Mr. Edwin Sam met Dr. Bimal Charles, Director, APAC, on January 17, 2002, to discuss the HIV scenario in Tamil Nadu and identify mutual areas of collaboration.
- ☞ **Selection of INGOs (Second Cycle)** In a review meeting in November 2001, PWDS-Alliance decided on a geographical scale-up to the following five additional districts: Coimbatore, Erode, Karur, Namakkal, and Trichy. The selection committee short listed potential organizations based on criteria such as FCRA, society registration, experience in HIV/AIDS, past track record, capacity of staff, and availability of efficient management systems. The following eight INGOs were selected in April-May 2002: Anbalayam, Trichy; Imayam, Coimbatore; HEALDS, Namakkal; SSH, Dindugul; CARE, Erode; Gramium, Karur; NMCT, Coimbatore; and WORD, Namakkal.
- ☞ **Mid Term Review** This workshop reviewed all the care and support project activities conducted from January to July 2002. Participants also identified areas and issues to be considered in the annual review and replanning.
- ☞ **Project Advisory Committee (PAC) Meeting** The first PAC meeting of PWDS-Alliance Care and Support project was held in Madurai on October 12, 2002. Representatives from YRG CARE, Chennai; TNSACS; Government Rajaji Hospital Madurai; PWDS; and PWDS-Alliance participated. All participants expressed the need for a forum or coordination efforts beyond project frames and grant requirements.
- ☞ **Review and Replanning 2002** PWDS-Alliance and India Alliance conducted an R&R (Review of activities in 2002 and Replanning for 2003). Representatives of India Alliance, INGO heads, and care and support project coordinators participated in the INGO review. The INGO staff made presentations on the important activities, significant achievements, comparative analysis of the pre and post project trends and future concerns. Participants also identified capacity building training required for INGOs. The Replanning for 2003 was based on the discussions of the preceding days. Participants prepared the draft work plan and budget using participatory processes. They reached a consensus to discuss these in the R&R meeting for Alliance India in November 2003.
- ☞ **National Thematic Meeting** India HIV/AIDS Alliance conducted a national thematic meeting and workshop on "Children Affected with AIDS" on December 16-19, at New Delhi. The three-day workshop consisted of poster presentations, presentations by Tamil Nadu, Andhra Pradesh, and New Delhi, skill building sessions, and a final plenary session. One representative

form each INGO and three from PWDS represented Tamil Nadu. A cultural troupe consisting of INGO staff and volunteers presented a much-acclaimed 20-minute cultural programme. The INGOs also presented posters and case studies on issues related to children affected with AIDS.

- ☛ **External Relations Meeting** Twenty-seven participants attended the external relations meeting on December 28, 2002, in Madurai. Its objectives were to involve service organisations such as Rotary and Lions Clubs in community based HIV/AIDS care and support; create a link between the government, NGOs, and institutional care organizations; an integration between the various projects of the same NGO; integration with general health stream and the development sector; and networking of NGOs involved in HIV/AIDS. A planning committee was formed that included representatives from NGOs, health care sector, industry, and development organizations.
- ☛ **State Level Care and Support Seminar** PWDS-Alliance organised a two-day state level HIV/AIDS care and support seminar on October 14-15, 2003, in Madurai. Over 165 representatives from 65 organisations participated. The seminar was an attempt to converge all major players in the HIV sector in Tamil Nadu on a common platform to share experiences and identify possible areas for coordinated efforts.
- ☛ **State Level Review Meeting of Child Centered Programming (CCP)** A state level review meeting on Child Centered Programming (CCP) was held on September 2, 2004 in Madurai. Representatives from the INGOs and PWDS-Alliance care and support staff team participated. The meeting presented progress made in CCP, discussed problems, challenges and lessons learnt in CCP, identified gaps and possible solutions to enhance CCP. Kate Harrison, Senior Programme Officer, child Centered Programmes, International Alliance, was the resource person. Participants arrived at a common understanding of CCP based on the objectives, reach, approaches, activities, success, challenges, lessons learnt and future plans of CCP with reference to PWDS-Alliance care and support programme. Stigma and discrimination, bereavement, child-headed households, and policy decisions pertaining to children affected by AIDS were some of the issues discussed.
- ☛ **Step Forward Team Visit** the team from Abbott Laboratories, USA, consisting of Jeff Richardson, Reeta Roy, and Craig Bendor, visited Seva Nilayam, Blossom, AIRD-V, CBH, and CSR (PWDS-Alliance INGOs), and also held discussions with the director, board members of PWDS, and the care and support staff team on September 9-11, 2004.
- ☛ **Volunteers Convention** Ten volunteers, one staff from each INGO, and lead partner staff participated in a Volunteers Convention on December 13-14, 2004 in Kanyakumari. It provided a platform for volunteers from 20 projects to share their experiences that provided an insight into their involvement in care and support initiatives that reinforced their role as volunteers and motivated them. Two hundred and twenty people participated. The special guests included HH Balaprajapathy Adigalar, religious leader; James R, Daniel, Principal, Scott Christian College, Nagercoil; Delphin, Municipal chairman; Dr Raviraj Williams, Consultant; Anand Kurup, India Alliance; Joseph Yesudian, secretary, PWDS; and Reji Chandra, Director, PWDS. The session on basic facts on HIV/AIDS facilitated by Dr Williams helped participants

to clarify doubts, myths and misconceptions about HIV/AIDS. Participants were happy that their services were recognized and expressed a desire for such conventions at least once a year.

- ☛ **Support Group Formation Orientation Meeting with INGO** Coordinators from the 20 INGOs and LP staff participated in the meeting on April 19, 2005. The objective was to orient INGO staff to facilitate the formation of 100 children's support groups in the community and to equip the community to guide the children's support groups.
- ☛ **Tamil Nadu Consortium Core Group Meeting** PWDS-Alliance participated at the meeting at TNSACS office, Chennai, on April 19, 2005. Participants discussed with Futures Group, contracted by NACO to prepare an action plan for NACP III. They also reviewed the draft of the Madurai district plan and discussed the surveillance draft report for 2004.
- ☛ **Leadership Training for Select Children** Two children from each INGO participated in the training on April 26-28, 2005, at Madurai. LP staff and staff of Gramium, SSH, CAST, and NMCT were the resource persons. The objective was to build the leadership capacity of children who contribute their time and skills for the development of children affected with AIDS and other vulnerable children in their areas.
- ☛ **Seminar on Children Affected by AIDS** In order to have a better perspective and provide a platform for different stakeholders PWDS-alliance organized a two-day seminar on HIV/AIDS and children on February 17-18, 2006, at Kanyakumari .

The two-day seminar was attended by representatives from different organisations involved in HIV/AIDS, NGOs working among children, children and staff representatives from the Implementing NGOs who shared their experiences. The highlight of the seminar was the child-centered approach. Children were an integral part of the seminar as equal participants. They staged cultural programmes and also shared their experiences as vulnerable segment of the population regarding the realities of living with HIV/AIDS.

The seminar consisted of thematic presentations (Impact of HIV/AIDS on children, child-centered programming, different experiences on children's programmes) sharing of experiences, (affected children and NGO representatives) and group discussion on HIV/AIDS and children—emerging key issues and responses.

- ☛ **Exposure visit from Centre for World Solidarity, Hyderabad:** A 17-member team headed by Ms. Kalamani visited PWDS–Alliance on April 10 - 15, 2006, to understand the practice of Mainstreaming HIV/AIDS. The team visited SSH, PACHE, Seva Nilayam and SRDPE; they also had a meeting with INGO coordinators at Kanyakumari.
- ☛ **Visit of India Alliance Staff** Sunil Nanda and Mr. Narendra's visit: Mr. Sunil Nanda, Programmes Director; and Mr. Narendra, Senior Programme Officer (M&E), India HIV/AIDS Alliance; visited PWDS on April 24 and 25, 2006. The team had a meeting with Mr. Reji Chandra, PWDS Director; and visited SSH and Arulagam on 24th, and PACHE Trust on 25th.

- ☛ **HIV/AIDS workshop jointly organised by UNICEF and TNSACS** Mr. D.T. Reji Chandra participated in the workshop on responding to the needs of children affected by HIV/AIDS jointly organised by UNICEF and TNSACS on August 10, 2006.
- ☛ **One-day workshop on Health Insurance Scheme for people living with HIV/AIDS organised by TNSACS** Mr. D.T. Reji Chandra participated in the one day workshop organised by TNSACS during September 19, 06 at Chennai. He made a presentation on the NEERA Health Insurance scheme initiated by PWDS jointly with New India Assurance. Mr. Sunil Nandraj from WHO, New Delhi, representatives from Insurance companies, Representatives from Key players in Tamilnadu and PLHA network representatives were the participants
- ☛ **Advocacy Meeting with Key players in Tamil Nadu and Networks of positive people** Dr. Christopher participated in the advocacy meeting with key players in Tamilnadu and network representatives of people with HIV/AIDS, organised by TNSACS on October 3, 2006. Based on the issues raised by various key players in Tamilnadu, participants arrived at a consensus to influence the following groups for advocacy aspects: Health care providers, police, media, politicians, and corporates. Strategies for taking up the issues of PLHA and children to the above groups were discussed in different group sessions. Participants collectively agreed that the TNSACS will take the lead role in advocacy issues with the support of other key players and positive networks.
- ☛ **Meeting of Initiative of HIV/AIDS Net partners** Mr. D.T.Reji Chandra participated in threes meeting of Initiative of HIV/AIDS Net partners and made presentations on looking at HIV/AIDS with a development Perspective, Networking, and governance and code of ethics. The Initiative of HIV/AIDS Net (IHN) is a network of 117 NGOs working for HIV/AIDS in Tamilnadu.
- ☛ **Consultative meeting for gap identification in HIV/AIDS programmes in Tamilnadu** Dr. Christopher and Mr. Thomas K. Varghese participated in the meeting organised by APAC, Chennai on July 4, 2006
- ☛ **National Pediatric ART Programme meeting** Mr. Thomas Varghese participated in the meeting organised by NACO and TNSACS at Chennai on October 7, 06.
- ☛ **NGO Capacity Assessment:** PWDS-Alliance conducted a rapid assessment of the 20 INGOs to assess their capacities and performance during January and February 07.
- ☛ **White paper on Community Based Care and Support:** Dr. Patil, consultant, India Alliance, was involved in conducting the review. Mr. Narendra, SPO from India Alliance, accompanied the consultant. The team visited SRDPE, AIRD-V, and CSR, interacted with the stakeholders, staff and community members. The process study was carried out during February 19 – 23, 07
- ☛ **Training on Life skills:** Two children and one staff from each of the 20 INGOs participated in the training held on April 25-27, 2007. Mr. Sunder Singh, Samuel Kumar, Mr. Muthuselvan and Ms. Nancy facilitated the workshop.

- ☛ **Workshop on Advocacy:** Five chief functionaries and five project coordinators from ten selected INGOs participated in the workshop held during April 25-27, 2007. Mr. Stanzin Dawa, Programme Officer – Advocacy, India HIV/AIDS Alliance, facilitated.
- ☛ **India HIV/AIDS Alliance Team field visit:** The Alliance India team consisting of Mr.Pankaj Anand, SPO Knowledge Management; Ms. Vaishakhi Chaturvedi, Documentation Officer; and Ms. Padma Buggineni, Policy Officer; visited CAST, CBH, SEDCO and AIRD-V during June 4 & 5, 07. Mr. Thomas K.Varghese, Programme Officer, Documentation, accompanied the team.
- ☛ **Visit for Nutrition Study in Tamilnadu by Alliance India:** Dr. Naidu, consultant for Nutrition study, visited NMCT, SSH, PACHE and AIRD-V and had interviews and discussions with the key stakeholders and staff during June 5 – 7, 07. Mr. Samuel Kumar and Mr. Sunder Singh, Programme Officers accompanied him.
- ☛ **Abbott Team’s Visit to SSH and PACHE:** Mr. Reji Chandra, Director, PWDS, Mr. Sunder Singh and Mr. Thomas accompanied the Abbott Team consisting of Mr. Jeff Richardson, Ms. Reeta Roy, Ms. Linn Veltema, and Mr. Craig Bender to SSH and PACHE on July 15 & 16, 07.
- ☛ **Meeting with Abbott Team:** A meeting of PWDS-Alliance team and the Abbott Team was held at DATA Hall, Madurai on July 17, 07, to discuss future strategies for the care and support programme.
- ☛ **Photographic Visit to PACHE:** Mr. Samuel Kumar accompanied Mr. Craig Bender from Abbott Team to PACHE Trust, Melur, on July 17, 07 for photo documenting some of the life styles of people living with HIV/AIDS and the impact of the project.
- ☛ **Alliance Consultant’s Visit to PACHE and SRDPE:** Mr. Christophe Cornu, consultant from Alliance India, visited PACHE and SRDPE on September 17 & 18, 07, to collect and document the experiences and processes of Community based care and support for preparing a handbook. Mr. Thomas Varghese and Mr. Samuel Kumar accompanied the consultant during the visit.
- ☛ **Children support group consolidation meeting, Coimbatore on November 5 & 6.** Ms.Priya Mohanty, Programme officer from India HIV/AIDS Alliance, facilitated Project Coordinators from 20 INGOs, and children from NMCT and Imayam participated.
- ☛ **November 12- 15 – Alliance team visit for Study on local self-governing institutions, Civil Society Organisations (CSOs), Resource mobilisation and IGP.**

Best Practices

In recent years, there has been a shift in development thinking from viewing HIV/AIDS as purely a health issue to that of a larger development issue that needs to be addressed with a development agenda. Poverty, low levels of literacy, gender inequalities, stigma and discrimination, poor health care facilities, and denial of human rights lead to increasing isolation and make people vulnerable to disease and discrimination. Hence it is necessary to address the cause while also responding to the immediate needs of the infected and affected people. In a resource poor setting, while responding to the threat of HIV/AIDS through specific interventions, it is also equally important to reform, improve, and strengthen (health care) systems and to empower people to manage.

The distinctive features of the PWDS-Alliance care and support project are its community based approach, emphasis on working with existing services, strengthening of existing services, focus on both services and referrals, collective functioning as network, integrated approach and mainstreaming for sustaining services. The project interventions stem from the PWDS development approach: the MEALS Approach (**M**otivate **E**quip **A**ccompany **L**ink and **S**ustain) that illustrate a blend of self help, alternatives, and mainstreaming strategies.

Building community consciousness, not just service delivery

The community based approach essentially believes in building on already existing capacities and infrastructure. The community mobilisation process was effective with the active participation of community based organisations such as Self Help Groups (SHGs), youth clubs, fan clubs, service organisations, volunteers, local health care providers, faith-based organisations, and community development NGOs.

There have been several instances of positive responses from the community as a result. These include home based care, support for food, education, shelter, scholarship support for affected children, integration of infected/affected persons in SHGs, and access to healthcare and medicine. Such responses enabled care and support at the family and community levels with effective collaboration from the government, private sector, and NGOs.

Based on such experiences during the initial and subsequent phases of the programme, one sees several instances of community responses. These emerged through the involvement of various sectors of the larger community such as SHG members, volunteers, healthcare

providers, people living with HIV/AIDS, and community leaders that resulted in tangible improvement in the lives of people living with HIV/AIDS.

There were instances of integration of people living with HIV into SHGs, local resource mobilisation, establishing referrals and linkages with healthcare institutions, forming community support structures such as Children's Clubs, and Children's Support Groups, and providing nutritional supplements to people living with HIV/AIDS. These interventions underscore the impact of a community based care and support project in creating a shift in people's mindsets, improved participation of the community, formation of community structures, and strengthening existing community structures.

A Chain of Links

“People living with HIV/AIDS who are linked with NGOs who work in HIV/AIDS lead a better life,” says V. Jeya Singh Mani (38), peer educator, NMCT, and field worker, COODU.

Mani was diagnosed HIV positive in 1995. He was linked with NMCT by the doctors in Coimbatore Medical Hospital. Depressed and suicidal, Mani felt revitalised and hopeful thanks to the counselling provided by the care and support staff at NMCT. He decided to create awareness about HIV/AIDS in the community, especially among young people, and therefore joined NMCT as a peer educator.

Mani has experienced several beneficial changes in his life because of his association with NMCT. He has been linked with private practitioners in Coimbatore for treatment of opportunistic infections. He has also been linked with COODU (Community Organisation for Oppressed and Depressed Upliftment) where he works as a field educator earning a monthly salary of Rs. 4000.

Mani is also involved in several activities to mobilise resources for people with HIV/AIDS. A positive speaker, he talks to college students and unmarried young men about his personal story and also creates awareness on HIV/AIDS issues. These groups of people in turn collect money for people with HIV/AIDS. Mani then uses it for educational support and to buy clothes for children infected/affected by HIV/AIDS. Mani also links people living with HIV/AIDS with NGOs to create possibilities of job opportunities for them.

To Serve With Love

Justice Joseph, former Assistant Sessions Judge, Madras High Court, is on a mission: To better the lives of people affected/infected by HIV/AIDS. Central to Justice Joseph's passionate activism is his belief that a personal approach makes all the difference to people living with HIV/AIDS as they are often "shunned and shunted by society." "When I personally visit such people, they feel accepted and loved," says Justice Joseph. According to him, it boosts their self-confidence and self-esteem too.

Justice Joseph recalls a village teacher telling him about an emaciated person in Valiyoor who was on the brink of death. He cycled to visit the sick person and gave him money for immediate medical assistance. "I suspected he had AIDS. I immediately asked AIRD Valiyoor to rush a team to the village. But the patient died before they reached. The team then counseled his wife and children (the latter are non infected) and also enabled her to find a suitable employment," recalls Justice Joseph. The incident strengthened his resolve to better the lives of people infected and affected by HIV/AIDS.

"If I daily don't visit a family affected by HIV/AIDS, I can't sleep," admits Justice Joseph. Everyday he cycles across remote hamlets in and around Valiyoor in Tirunelveli district.

Justice Joseph's involvement with HIV/AIDS was accidental. "I first came to know about people living with HIV/AIDS through AIRD, Valiyoor. Their problems and suffering motivated me to do my bit for them. AIRD staff talked to me about HIV/AIDS and cleared myths and misconceptions about the disease," he explains.

Justice Joseph contributes money on a monthly basis to 20 families and has also adopted ten families affected by HIV/AIDS in Tamil Nadu. He visits them regularly, counsels, helps them get civil supplies cards, old age pension, and other basic needs. In addition, he talks about the needs and problems of people living with HIV/AIDS at church gathering, at Lok Adalat (Free legal aid services) where he is the presiding judge, at meetings of Vincent De Paul Society of which he is the president, and to legal and police officials. In addition he has motivated several community members—retired officials—to reach out to people with HIV/AIDS.

Over the years, Justice Joseph feels that stigma and discrimination towards people with HIV/AIDS has significantly decreased. "Earlier people were either hostile or apathetic. Now even if many are not openly accepting, they don't condemn these people either," he observes.

Justice Joseph feels that his involvement in the cause is a means of "repaying for the abundance in my life. It gives me the greatest satisfaction. If there is personal commitment to the cause, resources will surely emerge," believes Justice Joseph.

Fistful of Rice Scheme

While across the globe, the poorest people are at the receiving end of the epidemic, they are also the pivot of positive responses to the epidemic. Several community responses such as the “fistful of rice” scheme and SHG adoption of infected and affected children are instances of positive community responses through mobilisation of the community.

In Theni district of South Tamil Nadu, people spontaneously came up with a novel way to help people with HIV/AIDS: with a ‘fistful of rice.’ While preparing the family meal, each woman throws places a handful of rice into a bowl. These bowls are brought to the weekly meeting of the local self help group, where the rice is collected. Society for Rural Development and Protection of the Environment (SRDPE), an Implementing NGO, distributes the rice to those who need it. Each self-help group contributes six to ten kilograms of rice a month. This practice has also been introduced into the wider community. Besides involving them in supporting affected families, it also provides an opportunity for implementing NGOs to raise awareness about HIV/AIDS. “In a way this practice benefits the giver and receiver,” said an INGO staff member.

“Behind one fistful of rice is a very strong development dialogue,” says Reji Chandra, Director, PWDS. “We cannot live without charity, but that alone is not a solution to poverty. With HIV we do need an emergency strategy, but we should also see this as an opportunity for a more long-term sustainable response – for example, the development of health infrastructure.”

Over the years, the rice scheme has expanded to other districts as several Implementing NGOs introduced it in the larger community. Although the fistful of rice scheme apparently looks like a charity or welfare approach, it is in reality a community sensitisation process and a component of local resource mobilisation. Although the amount of rice collected by the scheme can be collected by other means, the community sensitisation that ensues has a ripple effect. The number of families or people who contribute to the scheme is an indicator of the quantum of sensitisation in the community.

Integrating People Living with HIV/AIDS in SHGs

Another instance of a best practice is integration of people living with HIV/AIDS into self help groups. During the initial stages of the care and support project, although some of the initiatives were planned; several important initiatives emerged as spontaneous responses from the community and the Implementing NGOs. One such initiative is integration of people living with HIV/AIDS as SHG members and the other, adopting children affected by HIV/AIDS (orphans and vulnerable children) by SHG members.

In another instance, an SHG member, on seeing a woman infected with HIV said, “When I see her, I only feel for her. There is no fear of HIV/AIDS.” Subsequently, the woman motivated the other SHG members, who then unanimously expressed a desire that the infected member become a member of their SHG.

As part of the initiatives of the care and support project, several people living with HIV/AIDS enrolled themselves as members of SHGs promoted by the INGOs. The process of integrating people living with HIV/AIDS into SHGs involves raising awareness of HIV/AIDS issues among self help group members, sensitising NGO staff and the community, and motivating people with HIV/AIDS to join SHGs. This orientation and preparation phase therefore addresses stigma and prevention and care as an integral part of the process, and the outcome is improved care and support of affected people. Membership in SHGs increases self-esteem of people living with HIV/AIDS and greatly improves their access to credit and other income generation options and to community resources.

There are also instances where SHGs are formed specifically in order to support people living with HIV/AIDS. When Isakkiammal (32), tested positive for HIV, the staff of RED, an Implementing NGO, offered her unconditional support and counselled her to rebuild her life. A local SHG, the Katteriperumal SHG, was adequately sensitised to the needs and issues of people with HIV/AIDS. In solidarity, and compassion, the group decided to promote another SHG to provide space for Isakki to be integrated into it as a member. Shortly thereafter Isakki rose to be the secretary of her group and says she feels “strengthened and more self-confident.”

CBOs as a source of support

Aligning the needs and concerns of people living with HIV/AIDS with the operations of SHGs not only benefits people living with HIV/AIDS; it also enables SHG members to be valued for their much-needed support. In several instances, SHG members, fan clubs, youth clubs, service organisations, and faith-based organisations directly support people living with HIV/AIDS and affected children. A relative of an HIV positive SHG member said, “I have two children. If she dies, I will take care of her three children and bring them up as my own.”

In another instance, one sees a reinvention of popular customs and traditions in the context of HIV/AIDS. It is customary in villages, for people to offer their first salary to temples or churches. However, a young woman from a village, the daughter of an SHG member, who recently got a job, offered her first month's salary to a woman in the village affected by HIV.

The ongoing awareness and sensitisation programmes for the community, and a positive approach towards HIV/AIDS among the infected people themselves resulted in considerable decrease in social stigma and self-stigma. Such attitudinal shifts led to decreased instances of discriminatory behaviour and greater community acceptance. Today thanks to several awareness and sensitisation programmes on HIV/AIDS and sex and sexuality, several community members tend to view HIV/AIDS as another condition that can be treated and controlled, although not cured. “A person with HIV/AIDS is just like any of us; not different,” recalled Jyothi (40) SHG member.

Such responses based on greater community involvement and collective functioning have the potential of replication in the community and sensitise the whole village. Community based interventions effect attitudinal shifts and thereby reduce stigma, facilitate care and support, and effect prevention and control. In addition, these strategies help the community to participate and own the programme and sustain programme initiatives.

The Good Samaritans of Annai Theresa Self Help Group

Annai Theresa SHG in Coimbatore is an SHG with a difference. Unlike most self-help groups, the Annai Theresa group consists of members from the middle income group. Several of them are in government service, while others manage IGP units. Their husbands too are reasonably well employed either in the government or run small independent businesses successfully.

The Annai Theresa SHG consisting of 17 women was formed in 2006. Each member contributes Rs. 100 every month as membership fee. Thus savings and credit was not the primary motive, although internal lending takes place within the group. The group was formed primarily to help sections of the community who needed some form of support to improve the quality of their lives.

The members say that they were inspired by Imayam Care and Support staff Raman, who spoke to them about the needs and concerns of children infected and affected by HIV/AIDS. Hence when the group was formed, each member contributed Rs. 500 towards educational material (pencil, pen, school bag, and stationery) for 25 children. The members also gifted the girls with cosmetics and trinkets. They also provided the children with a sumptuous lunch. "In fact we inaugurated the SHG activities with this initiative," say the SHG members.

Jyoti, the representative in the group, says that even the choice of the name Annai Theresa indicates their motive to work for the greater common good. "We are sure that Annai Theresa (Mother Teresa) will guide us in our desire to serve those in need. We want to help others who need such services. We are determined to do whatever is possible for us," say the altruistic members of Annai Theresa SHG.

Annai Theresa SHG illustrates an innovative form of community organisation and collective response to larger social issues such as HIV/AIDS.

A Religious Leader with Social Consciousness

When Panimalar (40), organised a trip to Melmaruvathur Temple near Chennai for 40 people living with HIV/AIDS and 20 children infected/affected with HIV/AIDS, it was as meaningful for her as for the group. She blessed them each with a Shakthi Mala and a dollar of the Goddess, sanctified by special pooja.

“I cried before the Goddess. I wondered why these people had to suffer so much, often for no fault of theirs. I prayed for strength to enable them face life with courage,” recalls Panimalar (40), head of the Melmaruvathur Adi Parasakthi Mandram (a religious sect of followers of Goddess Parasakthi at Melmaruvathur) at Nondikovilpatti village in Melur. A member of the Roja SHG formed in 2003, Panimalar is also a trained counsellor in HIV/AIDS.

Panimalar admits that initially she and the 300-member Melmaruvathur Adi Parasakthi Mandram were hostile and towards people living with HIV/AIDS. “Initially when PACHE Trust staff approached us to talk about HIV/AIDS, we were upset and told them that we were a religious group and refused to be associated with people living with HIV/AIDS. The women of the SHG of which am a member also had similar views,” explains Panimalar. She, however, says that the care and support staff of PACHE trust were persistent in their efforts. “They gradually built a rapport with us through frequent visits, awareness and sensitisation programmes that motivated us to do our bit for people living with HIV AIDS,” recalls Panimalar.

The turning point was meeting Rama (26) an HIV positive person who visited Melmaruvathur Temple. Panimalar brought her to PACHE Trust, Melur. “Initially meeting people living with HIV/AIDS was upsetting. I was affected by their suffering and distress. I even recall talking about this with Panchavarnam, another volunteer who said I would soon be able to handle these feelings,” says Panimalar.

Today the Melmaruvathur Adi Parasakthi Mandram spearheads various activities to improve the lives of people living with HIV/AIDS. These include weekly prayers and pooja (on every Friday), prayers on special days such as full moon and new moon, regular prayer meetings, clothes and food, food on religious festivals such as Pongal, and Aadi Pooram. In addition, they provide counseling and spiritual support, and provide educational support for 35 children affected by HIV/AIDS. Panimalar also guides the activities of the Om Shakthi Children’s Club. The Children’s Club functions from the premises provided by the Adi Parasakthi Mandram free of charge.

The involvement of religious groups in addressing social issues is an indicator of community support for people living with HIV/AIDS.

Awareness on Healthcare

The care and support programme provides the following referrals and linkages as part of its services: Opportunistic infection referrals, VCTC referrals, ART referrals, care and support referrals, network referrals, free legal aid services, and referrals to local NGOs and positive speakers' networks.

Lack of appropriate, timely, and quality health care services is a major gap in treatment and management of HIV/AIDS. In the initial years, due to widespread stigma and discrimination, and ignorance about treatment options mainstream healthcare providers were unwilling to treat people living with HIV/AIDS. This led to alternative, specialized, and isolated services alongside widespread quackery.

The Implementing NGOs were unanimous that magico-religious cures for HIV/AIDS were widespread in the project area. AIDS was believed to be the result of a possession syndrome or a visitation by '*Mohini piasu*' (possession by a female spirit) from Mumbai! Hence people with HIV/AIDS spent exorbitant money, often approaching '*kodangis*' or village healers who fleeced them as he promised to exorcise the ghost! The widespread stigma and discrimination among the community, healthcare providers, and self-stigma among the infected people was another factor that led people to resort to quackery in search of a 'cure' for HIV/AIDS.

Through strategies such as home visits, involvement of the community through volunteers and home care guides, community awareness and sensitisation programmes for healthcare providers, the care and support team effected attitudinal changes in the community. These strategies resulted in bringing together people infected with HIV/AIDS and healthcare providers on a common platform.

Greater Participation of Healthcare Providers

In the initial years of the care and support programme, widespread ignorance about HIV/AIDS led to denial of treatment by healthcare providers. The discriminatory attitude was widespread because healthcare providers were not fearful of the HIV infection per se; but being branded as "AIDS doctors" and the repercussions on their professional status and prospects. The initial hesitancy of doctors and paramedical staff in treating people with HIV was diluted in a spontaneous process of sensitisation during interaction with Implementing NGO staff.

Over the years, the community sensitisation process has also encouraged healthcare doctors to be open and accepting in providing treatment and services to people infected with HIV/AIDS.

There is now greater awareness among healthcare providers themselves about current clinical management of Sexually Transmitted Infections (STI) and HIV/AIDS. They attribute

the shift in approach to the sensitisation programmes for general practitioners organized by the government and several other agencies. In 2006, India Alliance organised a workshop on treatment and management of paediatric AIDS in Coimbatore in which private practitioners and local pediatricians also participated.

Similarly, PACHE Trust, in collaboration with the Indian Medical Association (IMA) Melur, organises Continuous Medical Education (CME) programmes on current advances in treatment options in HIV/AIDS for general practitioners in Melur once in six months.

As a result of such ongoing sensitisation efforts, many private practitioners are now motivated to treat opportunistic infections at concessional rates or free of charge. In addition to the charity or welfare approach, it is the change in the mindset of health care providers that enables people living with HIV/AIDS to access mainstream healthcare services.

Dr. Krishnan, general secretary of the IMA Melur Branch, recalls that prior to 1996-97, most doctors and hospitals refused or were unwilling to treat people living with HIV/AIDS. He, however, attributes the high levels of acceptance and non-discriminatory medical treatment for people with HIV/AIDS provided by general practitioners in Melur to the efforts in sensitising the medical community and the regular updates on treatment options for STI and HIV/AIDS at the CME programmes.

Such responses highlight that prior to the efforts of the Implementing NGOs to reach out to healthcare providers, isolation, discrimination, and denial of treatment were common. There has been a significant decrease, however, in such responses following persistent advocacy by the Implementing NGOs for the rights of people living with HIV/AIDS to access quality treatment. "We've sensitised health care providers, the infected people, and the community.... It will vibrate," says C. Raman, Coordinator, Care and Support Project, PACHE Trust.

A New Life for Anandan

At the Roja Kootam Children's Support Club organised by NMCT, Anandan (12) is a natural leader. He talks to other children who are also HIV positive like him about the problems which children who are HIV positive face. Together they decide how to face the situation. He is also a member of the Roja Kootam cultural troop. "I'm on ART," says Anandan as he shows me his medical chart. He also shows me the skin rashes on his hands—an opportunistic infection for which he is being treated.

Anandan's parents died of AIDS-related illness and he is being brought up by his grandmother, Krishnaveni (64). Residents of Bhavani, Anandan and his grandmother shifted to Coimbatore as they found it impossible to live in Bhavani. Anandan wondered why children suddenly refused to play with him.

"Nobody visited us after Anandan's parents died... parents refused to let their children play with Anandan, and the school authorities ordered to take him away from the school," recalls Krishnaveni. To escape such isolation and discriminatory practices, the family fled to Coimbatore to live with an uncle.

Anandan was referred to NMCT, a Coimbatore-based INGO, by the doctors at the Coimbatore General Hospital. Anandan receives the following support from NMCT: educational support (including for his brother who is HIV negative), nutritious food and medical support through local sponsors, membership in the Roja Kootam (a children's support group), life skills and leadership training, access to private practitioners, government hospitals, and district health centres for treatment free of charge, home care training for Anandan's grandmother, and linkages with local networks of people living with HIV/AIDS. In addition, Anandan's health is regularly monitored by NMCT, the private practitioner, and the Coimbatore Government Hospital, including testing for CD4 count.

As part of its efforts to provide nutritional supplements to eight children infected with HIV, NMCT provides Anandan with a monthly kit for children infected with HIV. It consists of health mix (1 kg), soya (½ kg), dates (500 g), green gram dal (1 kg), chick peas (1 kg), and thur dal (1 kg). Anandan's grandmother prepares a variety of appetizing and tasty dishes that are high on nutritive value for her grandson. An obvious effect of the excellent home care is the reduced incidence of opportunistic infections.

Anandan is a student of Class 7. He wants to acquire skills in computer literacy and play football. From stigma, discrimination and isolation, Anandan today lives like any other child of his age.



India HIV/ AIDS Alliance visit



*Lead partner review
and replanning*



Life skills training



*Meeting
with chief functionaries*



NACP III sharing meeting



PWDS-Alliance Seminar



Children Cultural Performance



Competition at Children's Club



Children support group meeting



*Meditation — a way
for spiritual support*



Life skills education training



*Benefitted
through IGP support*

Reverse Referrals

As a result of such efforts, an interesting development is that of reverse referrals where health care providers in turn refer infected people to NGOs who provide services for people with HIV/AIDS.

The care and support staff of several INGOs recall that in the early years, staff used to accompany people living with HIV/AIDS for treatment. In several instances, the infected persons would insist on it as they feared mistreatment or denial of treatment by healthcare providers. Currently, however, staff accompanies them only on the first visit.

Care and support staff attribute this shift to two reasons: First, the better rapport with health care providers has resulted in extensive linkages and referrals with healthcare providers. This has resulted in staff and people living with HIV/AIDS becoming aware of current treatments options. For example, at NMCT, a Coimbatore-based Implementing NGO, care and support staff meet the doctors at the department of STD and Venerology, Coimbatore Medical Hospital, every Monday where they are updated on current treatment options. Most people living with HIV/AIDS are referred to the government hospital for treatment options that are unavailable at the district government hospitals. In addition, the Implementing NGOs have established linkages and referrals with private practitioners for emergency services.

Strengthening Linkages with Healthcare Providers

Another instance of a best practice is building and strengthening linkages with health care system such as government services and private health care providers. Promoting the concept of integration among healthcare workers is an important move towards integrating HIV/AIDS with mainstream healthcare.

Several initiatives such as motivating primary health centres, taluk and district level hospitals to become involved in care and support activities, establishing formal working arrangements such as linkages with private hospitals and primary health centers, and inviting doctors to become members of Project Advisory Committee of the Implementing NGOs, has encouraged the integration of prevention and care and the establishment of links with local health care for sustained support.

NGO-IMA Partnership

Dr Krishnan is a busy general practitioner in Melur. His clinic overflows with patients at any time of the day. He is also the general secretary of the Indian Medical Association (IMA), Melur Branch. The 45 general practitioners in Melur, who are members of the IMA, meet every month for a Continuing Medical Education (CME) programme. For the past several years, the IMA members have been regularly attending CME programmes on HIV/AIDS, and STI, organised twice a year by PACHE Trust.

Dr Krishnan recalls that before 1996-97, most doctors and hospitals refused or were unwilling to treat people living with HIV/AIDS. He, however, attributes the high levels of acceptance and non-discriminatory medical treatment for people with HIV/AIDS provided by general practitioners in Melur to the efforts of the care and support staff of PACHE Trust in sensitising the medical community and the regular updates on treatment options for STI and HIV/AIDS at the CME programmes.

“The concept of partner treatment in STI bridged the communication gap and treatment gap between general practitioners and gynaecologists. PACHE Trust has succeeded in bringing people with HIV/AIDS to doctors,” admits Dr. Krishnan. He attributes the high levels of acceptance and knowledge about the latest treatment options in HIV/AIDS and STI to the efforts of the IMA in organising regular CME programmes.

At Dr Krishnan’s clinic, the paramedical staff are trained to observe universal precautions, and counselling people with HIV/AIDS. The ‘Good Doctor’ provides the following special services for people with HIV/AIDS: no consultation fee, medicines free of charge, injections free of charge or a nominal rate of Rs. 5/, waiver of room rent charges, and referrals to government hospitals, if necessary.

For instance, CAST, a Tirunelveli-based INGO, established a linkage with a local private 40-bed hospital. The care and support staff team requested the doctor heading the hospital to provide treatment free of charge for people with HIV/AIDS in the project area. The doctor treats at least ten people with HIV/AIDS free of charge and does not hesitate to do so even if the number of patients who need his services is higher than expected. He is also a member of the CAST project advisory committee and also trains people living with HIV/AIDS, children with HIV/AIDS, peer educators, and volunteers.

Formation of Networks of People living with HIV/AIDS

An interesting aspect of referrals and linkages is formation of networks of people living with HIV/AIDS. Often people living with HIV/AIDS are referred by the INGOs to these networks for membership. Many Implementing NGOs have been instrumental in forming district networks of people living with HIV/AIDS and have also strengthened existing networks. Several interactive workshops involving network members and NGO staff have contributed to increased understanding and better coordination of the network.

Poyamozhi (33) and Jeyakumar (36), both HIV positive, were referred to Imayam, a Coimbatore-based INGO. On attending the Imayam support group meetings, both of them realised it was possible for them “to live like anyone else” despite their HIV positive status. Both of them were referred for VCTC, ART, and membership in networks. Poyamozhi is a member of the Sneha Network for Positive People that offers free monthly medical check ups for people living with HIV/AIDS. Having studied up to Class 12 and a qualified lab technician, Poyamozhi now works as Outreach Worker, TB and HIV Co-infection Project. Jeyakumar is a member of the Coimbatore Network for Positive People (CNP+) and is a much sought after motivational speaker who inspires people living with HIV/AIDS to lead fulfilling lives.

Both of them reiterate that people living with HIV/AIDS who are referred to NGOs have a better quality of life due to counselling services, and linkages and referrals for treatment options and memberships in networks of positive people.

Local Resource Mobilisation

The Implementing NGOs in the PWDS-Alliance HIV/AIDS care and support project initiated local resource mobilisation in 2002. The reasons for such an initiative were two-fold: With the increase in the number of people living with HIV/AIDS reached out by the care and support project, and the constraints in the direct reach of the project, it became imperative for sustainable alternatives to bridge this gap. Local resource mobilisation emerged as a suitable strategy that would not only augment the services provided by the project but also ensure community participation and sustainability of services.

According to several INGOs, in the initial years of local resource mobilisation, people living with HIV/AIDS were diffident and unwilling to disclose their status. R. Parameshwari, Secretary, Imayam, recalls that in the early years, fear, and negative messages about HIV/AIDS were widespread in the community. Thus the increased community acceptance made it possible for the Implementing NGOs to evolve several innovative strategies in resource mobilisation with the involvement of the larger community.

Individual philanthropy, the involvement of service organisations such as Lions Clubs and Rotary Clubs, corporate social responsibility, placement of coin boxes at shopping complexes,

Interventions in Health Care Services: Linkages with Local Hospitals

Dohnavur Fellowship Hospital in Tirunelveli district is seven kms from the CAST Project (an Implementing NGO) Office in Tirunelveli district. The 40-bed hospital provides cost effective treatment for people from 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. Dr Karunya, 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 free of charge. Following the intervention of the CAST care and support team, the hospital provides treatment for opportunistic infections free of charge. More important, they provide treatment for people living with HIV/AIDS without isolating them from 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 advisory committee.

In another instance, the care and support staff of CSR (Centre for Social Reconstruction), an Implementing NGO, established a linkage with a local private hospital—Annammal Hospital, Kuzhithurai, Kanyakumari district. Dr. Jayalal, general surgeon and Dr Sheila Jayalal, gynaecologist, run this 40-bed hospital. Even as a student, Dr Jayalal was interested in medical service for the rural poor. Later as a practicing doctor, he treated people living with HIV/AIDS free of charge.

The care and support staff of CSR requested Dr. Jayalal to provide treatment free of charge for people living with HIV/AIDS in the CAST project area. Dr Jayalal enthusiastically responded to the request. While treating at least ten people with HIV/AIDS free of charge, Dr Jayalal does not hesitate to do so even if the number of patients is higher than expected. Dr Jayalal is a member of the CSR Project Advisory Committee, which provides overall guidance and support to the project at the community level, also trains people and children living with HIV/AIDS, peer educators, and volunteers.

SHG support for infected/affected people at the community level through SHG linkages and SHG adoption of infected/affected children, and fund raising through appeals letters are some of the strategies employed by the Implementing NGOs in local resource mobilisation.

Like many of the other Implementing NGOs, at Imayam, a Coimbatore-based Implementing NGO, the mechanisms for local resource mobilisation are through individual philanthropy, building rapport with service organisations, and sensitising SHGs to provide various forms of

support for people living with HIV/AIDS. In fact in the Annai Theresa SHG in Coimbatore promoted by Imayam consists of women from the middle income group. The primary purpose in forming the group was the expressed desire of the members to help sections of the community who needed some form of support to improve the quality of their lives. Motivated by the care and support staff of Imayam who highlighted some of the needs and concerns of people with HIV, the group decided to support them in several ways.

The Coimbatore-based NMCT, another Implementing NGO, has placed coin boxes at several strategic places such as department stores, pharmacy, and stationery stores because of the high influx of people on a daily basis. AR Shoppee in Coimbatore city has the maximum number of walk-in customers on a daily basis. R. Senthil Kumar, the proprietor empathises with the needs and concerns of people living with HIV/AIDS. A coin box placed by NMCT in the shop has a collection of Rs. 1000 every three months—the maximum coin box collection in the city.

Another strategy is NMCT's **Join Hands Scheme** initiated in 2006. Under this scheme, an individual contributes Rs. 20 for a child every month. S. Krishnamurthy, a Coimbatore-based businessman contributes 1000 every month (Rs. 20 every month for 50 children.). S Krishnamurthy's involvement with People living with HIV/AIDS arose as a result of testing negative for HIV. "I felt so relieved that I decided to do something for people living with HIV/AIDS. I feel so happy and plan to influence my friends too to support this cause," says Krishnamurthy.

The most striking instances of NMCT's strategies in local resource mobilisation are evident in its partnership with the several industrial and manufacturing units in the city. Coimbatore being an industrial hub, local industries and manufacturing units have emerged as among the most responsive to NMCT's concerted efforts in local resource mobilisation.

Living Positively

“People living with HIV/AIDS who have been linked with NGOs do better as they are motivated and strengthened through linkages and referrals,” says V. Jeya Singh Mani, field worker and home care guide.

Testimony to his statement are people like AR Poiyamozhi (33), Meenakshi (30), and S. Jeyakumar (36).

Poiyamozhi, an HIV positive person, was referred to the TNSACS Care Centre for treatment for opportunistic infection. She met the care and support staff of Imayam who accompanied her to the ART centre. Poiyamozhi ten attended the support group meetings organised every month by Imayam. “At these meetings I came to know about networks of positive people,” recalls Poiyamozhi.

Poiyamozhi who has passed the Higher Secondary examination and has completed a Lab technician’s course, today works as an Outreach Worker, TB and HIV Co-infection Project.

Similarly Meenakshi, a TNSACS counsellor and peer educator at NMCT, and President, Society for Positive Mothers Network, Coimbatore, and Coimbatore Network of Positive People, attributes her role in spearheading the problems and issues of people living with HIV/AIDS to her interactions with networks of positive people and NGOs working in HIV/AIDS.

S. Jeyakumar, member Coimbatore Network of Positive People too says that meeting other network members infused a sense of self-confidence and the realization that there are many others like him who live like any one else. Today he is an inspirational positive speaker who believes that “People living with HIV/AIDS must draw into their own reserves of strength to lead productive satisfied lives. Only 50 percent of courage can be given by others. The rest must come from you.” He says this with a conviction born out of lived experience.

For Poiyamozhi, Meenakshi, S. Jeyakumar, and many others, linkages with NGOs and networks have helped them reinvent themselves as empowered people.

Service for Satisfaction

Mohanraj is simple and unassuming. At his office, he does not consider himself as the “boss” but as one of the co-workers. The successful Coimbatore-based businessman owns a waste paper recycling business and a travel agency, Iyyappa Travels. The religious-minded businessman, who claims he has an annual turn over of several crores, is a person with a giving heart. Whether it is eye camps, medical camps, health camps for women, voluntary blood donation (he has donated blood fifty times), Lion Mohanraj is generous to a cause.

Mohanraj lost his parents when he was seven years, and since then has worked to support himself. “I’ve often been without food, and know what it is to feel hungry,” he says. A turning point in his life was being a witness to an elderly father being willfully abandoned on the Kanyakumari beach by his son and daughter in law.

“They gave the old man Rs 10 and asked him to have food. Later they whizzed away in their new car muttering to themselves that they had disposed the old man. The father was bewildered on finding himself all alone. The elderly gentleman was a retired Tahsildhar who had brought up his only child single-handed after his wife’s death. I helped him find a job in one of the nearby tea stalls. That incident made me determined to set up a senior citizens home that is to be inaugurated shortly. He will be my first resident,” recalls Mohanraj. He also decided to set apart 10 percent of his income for charitable causes.

Lion Mohanraj was impressed by Imayam’s efforts to rehabilitate children infected and affected with HIV/AIDS. At a meeting with Imayam staff, he was moved by the difficult lives of such children. He volunteered to help them even before he saw them. Mohanraj has been a regular source of support in meeting the educational needs of children infected and affected with HIV/AIDS. He has donated books, pencils, pens, geometry boxes, and lunch kits worth Rs.25,000 to 22 children infected with HIV/AIDS. Mohanraj currently plans to sponsor part of the expenses of a tour for the children by offering his bus free of charge. His philanthropic trait is evident in his son too who donated his pocket money of Rs.5000 to buy Diwali dresses for these children.

“My involvement with charitable causes gives me a sense of atma tripti (mental satisfaction. If you make others happy, you will be happy,” reflects Mohanraj.

At AIRD-Valliyoor, another Implementing NGO, a number of church-based groups have shown considerable involvement in reaching out to people living with HIV/AIDS. The Valliyoor Vattara Nachidi group supports 150 people from the low income group annually. According to Sathu, Director, AIRD-V, the increasing involvement of church-based groups in

social issues such as HIV/AIDS indicates that religious organisations are prepared to be more outward looking and widening their ambit from purely religious concerns to issues affecting the wider community.

Such initiatives in local resource mobilisation reflect greater community awareness and acceptance of people living with HIV/AIDS. The efforts also indicate the building of a relationship between the community the INGOs, and people living with HIV/AIDS.

Community Responses to HIV/AIDS

Suriya Priya (10) and Dasarathan (5) are children living with HIV. Their mother died of AIDS-related illness. After her death, their father abandoned them and migrated. The two children moved in with their grandparents. Their grandfather supports the family by supplying water in a tricycle. The meagre income was insufficient to meet the family's daily needs. Hence the children had to discontinue school. Besides they were under nourished.

The care and support staff of NMCT, an INGO, enrolled the two children in the non formal education school of the child rights project. The children received education, nutritious food, noon meal, medical facilities, and also ART. The care and support staff also provided counselling and follow up support to the family. The children's family was linked with the IGP of the child rights project and they were also provided economic loan for rearing goats.

Following a sharing of experiences in the inter project coordinator's meeting, the teachers in the child rights project have started a Children's Club for children in the non formal school. Suriya Priya and Dasarathan experience a sense of belonging through interaction with children affected and infected with HIV. Next year, the care and support team plan to enroll Suriya Priya and Dasarathan in a mainstream education institution and support their education.

Over the years, NMCT has developed a network of local supporters who respond to the specific needs of children and people living with HIV/AIDS. These include individual philanthropists, service organisations such as Lions and Rotary Clubs, faith-based organisations, corporate houses, and industries. Thanks to its ability to identify and build a network of people motivated to support people living with HIV/AIDS, NMCT is confident of supporting the education of the two children even beyond the three-year project frame of the child rights project.

Such inter project integration and the ability to build linkages that foster community responses generate possible solutions towards an integrated approach to HIV/AIDS beyond project frames.

Nutritional Supplements for people living with HIV/AIDS

Nutrition plays an important role in any disease condition, particularly so in people living with HIV/AIDS. Viral infection, opportunistic infections, and side effects of medication cause considerable nutritional deficiencies in people living with HIV/AIDS. About 70-90 percent of people infected with HIV experience weight loss.

Most people living with HIV/AIDS in the care and support project area belong to the low income group. Hence they are unable to afford the cost of commercially available nutritional supplements. Several people living with HIV/AIDS reported increased frequency of opportunistic infections, and expressed a need for nutritious food. Hence the INGOs decided to supply them with nutritious health mix as part of the direct services of the project. Subsequently in order to ensure a regular supply they imparted self-preparation know how to infected people and their families and also initiated local resource mobilisation through supply of raw materials from potential donors and involvement of SHGs in preparing the health mix.

Although all infected people are entitled to receive nutritional supplements, priority is given to people on ART, infected children, and ante natal and post natal mothers.

All people infected with HIV/AIDS reported decreased incidence of opportunistic infections, increase in weight, improved digestion, and reduced incidence of constipation after regular consumption of the health mix. Most infected people taking the health mix also reported feeling more energetic and healthier. In addition most of them reported that their weight has shown fewer fluctuations and weight maintenance is a tangible benefit of the health mix. The people infected who were interviewed reported a reduced incidence of opportunistic infections such as common cold, fever, and indigestion.

Building Community Support Structures

The formation of a cadre of volunteers, home care guides, and community counselors, increased involvement of faith based organisations, formation of district level networks of people living with HIV/AIDS and their linkages with state and national networks, and greater involvement of the local community (through SHGs, community based organisations, faith based organisations, industries, clubs, and individual philanthropists), establishment of children's clubs and support groups illustrate the importance of building the capacity of the community and responses based on a sustainable long term perspective rather than mere service delivery.

The PWDS-Alliance care and support programme with a perspective of empowering communities and sustaining HIV/AIDS initiatives, initiated community support structures by involving the primary stakeholders: people living with HIV/AIDS, children living with HIV/AIDS, affected children, their family, and community members.

Thus support groups for people living with HIV/AIDS, children's support groups, children's clubs, and village development committees were formed. Capacity building has been provided to the members on basics of HIV/AIDS, self care, home care, orientation on available services, referral and linkages.

A Collective Response

A group of women living with HIV/AIDS in Kulasekaram formed themselves into a support group. In 2001, the group promoted the Roja SHG with 20 members. The SHG started another bank account to save the excess money generated through savings and credit. The group utilised the money to support their children's education. They then decided to support other children and currently support 52 children.

Crena, a support group member and treasurer, and Project Advisory Committee (PAC) member, shared this response in a PAC meeting. The members were appreciative of the group initiative to reach out to children in need. A few members of the Helping Hearts Club, a village club, wanted to support the initiative. They requested the project team to share their experiences and were inspired to extend their support.

The project team and the club members organised a musical evening by the Komakam troupe of visually challenged singers who became famous with the film Autograph. They printed and sold tickets for Rs. 1, 20,000. Over 900 people attended the performance. The organisers mobilised Rs. 1, 00,000 and handed it to the SHG.

"All of us plan for our children's future and now we have done so for these children too," said one of the organisers.

The community resource mobilisation effort mobilised funds for educational support of deserving children, and sensitised the community to participate and contribute to the programme by purchasing tickets.

In addition a cadre of volunteers, home care guides, and community counselors were developed to provide ongoing support to HIV/AIDS initiatives. The structures during the years have become self-reliant and responsibilities were transferred gradually from the staff to the members. As a result they are now able to access the mainstream services by themselves; the support structures are equipped to handle the problems and needs of the persons infected and affected inter-dependently thus moving towards sustainability. The process of community owning the support structures is also evident at the community level. Currently there are 152 children's clubs, 58 village development committees, 113 support groups of people living with HIV/AIDS, and 112 children's support groups.

Such initiatives illustrate the importance of building the capacity of the community and responses based on a sustainable long term perspective rather than mere service delivery.

Child Centric Programming

Children are most affected by HIV/AIDS. HIV threatens the already fragile conditions of children who face deprivations in a poverty context. The needs and issues of children infected and affected by HIV/AIDS can be broadly grouped into stigma/discrimination-related or economics/poverty related.

Participation of the wider community through sensitisation leads to acceptance. Several interesting community responses include formation of children's clubs, community based counselling, life skills training, resource mobilisation, adoption of children by SHGs, and linkages with healthcare providers, cost effective nutritional support, promoting savings, food support, supplementary income, and tuition/coaching centres.

Some of the current initiatives include promotion of children's support groups, publication of a newsletter "Children's Voices," leadership training for children, formation of children's support groups, formation of children's cultural groups, child to child education, policy initiatives on banking for children, and promotion of working groups for children—strategies and activities that aim for greater development impact for children that need to be sustained beyond HIV/AIDS.

The Nutrimix Way to Health

The first thing that P. Velankkani (35) of Kuruchi does when she gets up in the morning is to gulp a glass of health mix porridge. She also mixes the health mix with rice and ghee and has it as a mid morning snack and gives it to her two children as well.

Velankanni is an agricultural laborer. She was diagnosed HIV positive three years back and her husband died of AIDS-related illness. Since she came into contact with Imayam in 2003, Velankanni has been taking the health mix.

Velankanni recalls that before she took the health mix she often felt tired, dizzy, nauseated, and had headaches. Today, however, she says that the frequency of opportunistic illness like fever and cough has decreased. Although her CD4 count is low and she is on ART, she feels energetic—a fact she attributes to the nutrimix she takes every day. In addition, she says that there has been no weight loss.

According to Velankanni she was unaware of nutritional supplements before she came to Imayam. For infected people in the low income group, the interface with INGOs is a blessing in many ways. For one, Velankkani is now aware of several ways to live meaningfully after being diagnosed with HIV. Counselling and ART referral enabled her to have timely, affordable, and accessible treatment services for HIV/AIDS. Her children receive educational support and festival gifts from Imayam.

In addition, the provision of nutritional supplements makes it possible for her to live a reasonably healthy life. More important, she is aware of the importance of adequate nutrition in an immuno compromised condition like HIV/AIDS. For instance, as advised by her doctor, Velankkani also supplements her diet with beef and fish. Her health awareness has resulted in several self-made modifications such as mixing the health mix with hot water instead of milk when she has diarrhoea. Velankanni believes that a steady supply of the nutrimix would enable her to lead a healthy life and enjoy a normal life span.

Lessons and Challenges

Every challenge provides an opportunity to strengthen our capacity to respond appropriately. HIV/AIDS is no exception. What has emerged clearly is that effective and sustainable responses to HIV/AIDS has to shift from mere service delivery towards capacitating the community and create linkages with the mainstream to enable people with HIV/AIDS live a life of dignity and respect.

Community based models work with a process approach that can be replicated once established as an effective intervention. As in the “fistful of rice” scheme, the community takes it across the border once the effectiveness is established and the skills are mastered. It travels across villages and communities with limited external support and with some motivation and external facilitation.

A space within the project frame for sustainability built in from the beginning helps to continue the activity even beyond project frame and time. In a community based approach, community ownership and participation is essential for sustainability.

Community based approach is an empowering process. It involves mobilising and organising communities, strengthening their capacities, and linking with mainstream for sustained services and availing rights. It is not participating in projects, self-help, or people serving themselves as an alternative to mainstream services.

Rural poverty, low literacy, cultural issues, fatalism, lack of resources, capacity, and services, limited capacity of NGOs and their confined reach in a geographical area are some of the constraints in a community based approach.

While the role of the community remains central, it is also important not to overemphasise the community role by diluting the responsibility of the state. Overemphasising community responsibility and self-help without state responsibility has the danger of discarding the human rights aspect of the issue. Community based approach is not a substitute for state responsibility and people’s rights for services.

In a community based approach the community is expected to own the programme. This also has the danger of placing all the responsibilities on the community which lacks the skills and resources to manage the programme. Hence while talking about community based approaches, the role and responsibility of governments, society, and other civil society actors should be recognised. The community is in reality a client for services and not service providers for themselves.

Beyond Project Frames

“Even without the care and support project, we’re confident of taking it forward,” says V. Nagarathinam (57), federation leader, and President, Thulasi SHG in Kaundampalayam, near Coimbatore.

Nagarathinam’s confidence stems from her experience as a home care guide and volunteer. During her home visits, Nagarathinam met Baby (32), an HIV positive person with two children, the younger of whom is HIV positive as well. Although her family was supportive, Baby was depressed after her husband’s death and knowledge of her HIV status. Nagarathinam counselled her and also spoke to the SHG members to invite Baby to become a member of the SHG. “We need to do something to help her,” Nagarathinam reasoned with them.

As an SHG member, Baby avails interest-free loans and receives educational support for her school-going daughter and gifts on festive occasions such as Diwali. The SHG members have also linked Baby with a local paediatrician. The local Canara Bank sponsors her child’s tuition and educational fees. In addition, the SHG oversees the functioning of a Children’s Club in the village. The club has an impressive collection of books. Currently the SHG members plan to set up a library that could be used by all children in the village.

“Being a member of the SHG has given me a lot of confidence. I want to live,” says Baby who is currently being trained as a tailor and hopes to set up a tailoring unit.

Projects are not solutions, especially in the context of HIV/AIDS that are complex and have larger implications. In such issues, projects, apart from emergency services, initiate sustainable community processes, strengthen existing services, introduce innovations and alternatives, and establish mainstream linkages for influencing policies and sustaining impacts.

The involvement of development organisations in HIV/AIDS responses is both a challenge and a lesson learned; an opportunity to view HIV interventions in a larger social perspective and not merely as technical or service delivery projects.

Building on Positive Responses

HIV/AIDS is a new development challenge. Therefore sustained intervention with the joint effort of all players is necessary. There is a need to involve the larger community through effective strategies that call for greater community involvement and collective functioning. There are experiences in the form of community responses, linkages, and skills. These therefore need to be replicated to wider geographical areas and through the involvement of more NGOs. There are a number of ways in which such experiences can be replicated in improved and more effective ways. These include enabling people with HIV/AIDS to form networks, and networks of NGOs who work in HIV and community development.

Stigma and discrimination is a serious issue that prevents control, care and support. While societal responses leave a lot to be desired, the responses of individuals have been exemplary. The common person from different walks of life—the family, friends, members of voluntary and government organisations, and religious leaders—have shown courage, sensitivity and compassion in responding to the challenge of HIV/AIDS. A supportive community facilitates the ability of people with HIV/AIDS to cope with the challenges of living. What seems important is building on positive responses of the people, recognise them, strengthen and replicate such experiences in scale rather than being swamped by the negativity that surrounds HIV/AIDS.

Integration, not isolation

Interventions with a focus on specialisation such as special schools and care institutions for people with special needs have retrospectively realised the myopia of an exclusivist approach. While such specialised organisations are undoubtedly necessary, they have an inherent danger of isolating the affected persons from mainstream society. Hence many specialised interventions have realised the wisdom of adopting an integrated and community based approach in a move towards an inclusive society. The integration of HIV infected and affected persons with community based organisations like SHGs and other associations is one such promising initiative. Although the potential of SHG integration of infected/affected people appears to be a charity or welfare approach, in reality it is an effective intervention for integrating people with HIV/AIDS into the community for acceptance and productive living.

This exemplifies GIPA (Greater Involvement of People with HIV/AIDS) in a life context and extends the principle beyond the project frame. Such an approach implies greater participation of people with HIV/AIDS and families affected by AIDS that transcend project limitations. Other instances of integration initiatives include improving mainstream services, establishing linkages, promoting networks of NGOs and people with HIV/AIDS for collective functioning that are based on enabling the community through appropriate responses.

The integration of HIV/AIDS concerns with community development programmes as one of the components cuts across all sectors of interventions, addresses all dimensions of HIV/AIDS,

and creates wider impact in the community. Involving development NGOs and technically proficient specialised organisations, integrating affected people with CBOs, integrating health care needs of affected people with mainstream healthcare providers, and integrating HIV/AIDS interventions with community development initiatives, such initiatives reduce stigma, facilitate acceptance, promote care and support, and thereby effect prevention and control. In addition, this strategy helps to mainstream and sustain programme initiatives beyond the project frame and time.

Addressing Stigma and Discrimination

While HIV/AIDS poses a threat to all strata of society, it is the poor and marginalised, especially women and children, who are most vulnerable. In the early years of the epidemic, the skewed emphasis on prevention and control with its fear-based messages led to widespread stigma, discrimination, denial of rights, isolation, and absence of care and support for the infected and affected people. Knee jerk social responses such as blame, discriminatory attitudes and stigmatisation of HIV positive people further exclude the already marginalised.

The growing realisation, however, that it is important to fight the epidemic and not the affected people; and the resulting emphasis on acceptance, care and support are some of the positive impacts generated by alternative initiatives. Hence there is a need to create an enabling environment in the community to ensure AIDS-competent societies and empower families and communities to adequately cope and respond to the epidemic.

In the initial years of the PWDS-Alliance care and support programme, it was difficult to counter deeply entrenched gender inequalities and the prevalent stigma and discrimination that impeded people's willingness to access treatment. The programme focus on an open, compassionate and participatory approach to care and support played a decisive role in fostering attitudinal change towards the disease in the community, particularly regarding fear of infection and stigma and discrimination.

Towards Mainstreaming HIV/AIDS Issues

Although HIV/AIDS cannot be addressed in isolation, it is apparent that there is a lack of coordination and collaboration between the different actors. HIV/AIDS responses often focus only on project framework and direct results. Such a strong project orientation leads to isolated results and often fails to address larger issues. Several initiatives in the care and support project such as SHG integration, linking with mainstream health care providers illustrate a perspective shift from a rigid project orientation to an approach beyond project frames creates a larger space within project frameworks conducive to a wider outlook, working partnerships, and sustained impacts.

Several issues that people with HIV/AIDS face do not need to start from the very beginning. Rather they could be linked with existing development initiatives and rights movements like human rights, consumer movements, and legal support services. Instead of initiating new, exclusive or parallel interventions, a more effective strategy would be to mainstream HIV agenda into existing mainstream movements. Experience has shown that it is difficult to achieve sustained impacts through isolated results without taking into consideration factors in the larger social context.

Therefore the intensity, importance, and complexity of the problem demand responses that are more comprehensive and collective in approach. The growing threat of HIV/AIDS could well serve as an opportunity to improve systems and attitudes. It is also an opportunity for various players involved to step outside project frames and jointly address the issue to demonstrate that integrated interventions and collective functioning are more effective.

It is important to understand an issue like HIV/AIDS from a larger development perspective. It is also more important to plan interventions keeping the larger development impact in perspective. Only in an improved context, where care is more humanised and accessible, and people more sensitive, can we expect major changes.

Beyond HIV/AIDS

Although a development threat, HIV/AIDS has created a few development options to work for long term impacts. The changing trend to openly discuss sex and sexuality issues, awareness on HIV/AIDS and gender issues, social dimensions of healthcare with special reference to integrating counselling services with healthcare, strengthening primary and public health systems, focus on orphans and vulnerable children are some of the development issues related to HIV/AIDS responses that need to be addressed with a long term development agenda.

The development approach believes in mainstreaming. This process starts from the community, considers local needs, builds on what is already there, essentially addresses the causes of the problem, and also aims to sustain the impact beyond HIV/AIDS through HIV/AIDS. Though HIV is a sex (health) related infection, it is evidently vulnerability, and specifically, a poverty-related issue. The current reality is that for the development sector it is not enough to understand HIV from a development perspective; but it is essential to understand development from an HIV perspective.

Partners

Kanyakumari District

SACHDP, Nagercoil, Ph: 04652 275517, Email: benny@sachdp.com
CSR, Nagercoil, Ph: 04652 265155, Email: csrnagar_ngc@sancharnet.in

Tirunelveli District

AIRD, Valiyoor, Ph: 04637 221509, Email: aird@bsnl.in
CAST, Cheranmahadevi, Ph: 04634 263355, Email: cast123@rediffmail.com
RED, Tisaiyanvilai, Ph: 04637 271462, Email: red_tisaiyanvilai@yahoo.co.in

Thoothukudi District

Chevaliar Roche Society, Thoothukudi, Ph: 0461 2346220, Email: chevaliar_society@yahoo.co.in
SEDCO, Sattankulam, Ph: 04639 266450, Email: sedcogeorge@yahoo.co.in

Virudhunagar District

BLOSSOM, Virudhunagar, Ph: 04562 269238, Email: blossomtrust@gmail.com

Ramnad District

AIRD, Ramnad, Ph: 04567 230536, Email: airdrmd@yahoo.co.in

Madurai District

PACHE TRUST, Madurai, Ph: 0452 2381987, Email: pachemano@gmail.com

Theni District

Seva Nilayam Society, Aundipatti, Ph: 04546 249222
SRDPE, Theni, Ph: 04546 254973

Dindigul District

Arulagam Hospice, Reddiarchatram, Ph: 0451 2554202, Email: arulhos@yahoo.co.in
SSH, Sempatti, Ph: 0451 2556405, Email: brittocell@gmail.com

Erode District

CARE, Erode, Ph: 0424 2274667, Email: carecharles@dataone.in

Coimbatore District

ISWA, Coimbatore, Ph: 0422 2537637, Email: imayamcovai@gmail.com
NMCT, Coimbatore, Ph: 0422 2647512, Email: nmctcbe@rediffmail.com

PWDS HIV/ AIDS Care and Support Programme



