

Sharing for Caring



PwD Alliance



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A

Report on the

PWDS - Alliance HIV/AIDS Care and Support Seminar

October 14-15, 2003

Madurai

PWDS - Alliance

Crystal Street, Marthandam - 629 165
India

Palmyrah Workers Development Society

Registered Office :

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

Coordination Centre :

DATA,
11, Kennett Cross Road, New Ellis Nagar,
Madurai District - 625 010 Tamil Nadu, India.
Ph: 0452 - 2603652 Fax : 0452 - 2300369
E-mail : datapwds@eth.net

PWDS - Alliance Project Office :

Crystal Street,
Marthandam - 629 165,
Kanyakumari District, Tamil Nadu, India.
Ph: 04651- 273942 Fax : 04651 - 270138
E-mail : pwdscore@eth.net

website : www.pwds.org

Documentation :

Ms. Nandini Murali, DATA DOCS

Design & Printing :

DATA DOCS, Madurai - 625 010.
Ph: 0452 - 2603652, e-mail : datapwds@eth.net

LEO Prints, Madurai - 625 001. Ph: 0452 - 2560159.

Introduction

A number of efforts have been taken by both central and state governments and voluntary organizations to address issues related to HIV/AIDS. In Tamilnadu, the initiatives and various projects implemented by National AIDS Control Organization (NACO), Tamilnadu State AIDS Control Society (TNSACS), AIDS Prevention and Control Project (APAC), Positive Women's Network of South India (PWN+), Indian Network of Positive People (INP+), and YRG CARE are well known. These programs respond to the issues with varied approaches and emphasis.

Palmyrah Workers Development Society (PWDS)

Support services to sustain community initiatives

PWDS is a development support organisation established in 1977. It represents the collective efforts of a group of socially committed individuals to improve the living conditions of palmyrah workers and other marginalised communities. Its interventions aim at empowering the community by building people's organisations, equipping through awareness generation and skill training, and linking them with the mainstream for sustenance. The main approach MEALS, includes the following steps: Motivating, Equipping, Accompanying, Linking and Sustaining the community organisations.

In over two decades of development efforts, PWDS programs have transcended geographical barriers and traditional frontiers. PWDS works with palmyrah workers and other marginalized groups such as rural women, children, and rural artisans in 17 districts in the states of Tamilnadu and Kerala. PWDS believes in collective forms of functioning and coordinates network programs through the coordination centre - DATA-based at Madurai.

HIV/AIDS is not purely a health issue but has significant development implications as well. Development thinking has also undergone a shift from viewing HIV/AIDS as purely a health issue to accepting that it is a larger development issue that should be addressed with a development agenda.

Therefore HIV/AIDS cannot be effectively dealt in isolation, but needs to be addressed through an integrated cross sectional approach sensitive to economic conditions and community norms. Thus it has to be integrated in the development agenda and addressed with community-based initiatives.

The International HIV/AIDS Alliance

Supporting community action on AIDS

The International HIV/AIDS Alliance is a UK-based international non-governmental organization, 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

The India HIV/AIDS Alliance office based at New Delhi was established in February 1999. It coordinates and provides support to the programs in India.

The Alliance provides technical support along with financial support to in-country intermediary organizations termed “linking organizations” or “lead partners” that in turn provide financial and / or technical support to NGOs and CBOs in their respective countries.

The PWDS-Alliance project was started in the Southern districts of Tamilnadu with emphasis on community based care and support. The project is a pioneering community based HIV/AIDS care and support effort in Tamil Nadu.

PWDS-Alliance HIV/AIDS care and support program is one of the networks that emerged in 2000 when the UK-based International HIV/AIDS Alliance selected PWDS as the lead partner to coordinate the program in Tamilnadu. International HIV/AIDS Alliance, UK; and India Alliance, New Delhi; offer technical support for project implementation. The project is currently implemented in 13 districts in Tamilnadu with 20 NGO partners known as INGOs (Implementing NGOs).

The project mission is to work for enabling, supportive environment towards community- based care and support for people living with HIV/AIDS, children affected with HIV/AIDS and families affected with HIV/AIDS in TamilNadu.

The major objectives of the project are to:

- Initiate and strengthen community based care and support for people living with HIV/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;
- Mobilize the community towards care and support; and
- Initiate policy-related interventions towards promoting the integration of care and support and community based activities in Tamilnadu.

The project provides the following services to the people living with HIV/AIDS

- Psychosocial support services
- Health care services
- Voluntary Counseling and Testing (VCT)
- Food and nutritional support
- Economic support
- Emergency relief
- Direct services to children affected with AIDS
- Spiritual care
- Capacity building activities

An important development in PWDS-Alliance Care and Support Project has been the involvement of self-help groups in supporting families affected by HIV/AIDS.

This has been highlighted in one of the project publications *Integration Initiatives*. A *Home Care guide*, which could help the care and support work, is to be published shortly in English and Tamil.

There are also two other publications *Community Compassion Care*, the first annual report of the project, and *Collective Responses*, the second annual report highlighting the main features of the project and major issues in the care and support work. A half yearly News Letter in Tamil *Puthu Vazhvu (New life)* is also published and circulated.

Purpose of the Care and Support Seminar

During the implementation of the PWDS-Alliance care and support project it was felt that the problems caused by HIV/AIDS cannot be addressed by any single agency or project with isolated efforts. Therefore all government and non-governmental agencies need to come together to work in coordination to address the issues.

The PWDS-Alliance state level seminar on HIV/AIDS care and support is a small attempt in this direction to bring all major players in Tamil Nadu on a common platform, share experiences and identify possible areas for coordinated efforts.

INAUGURAL SESSION

The two-day state level seminar on HIV/AIDS care and support was held on October 14-15, 2003, at Madurai. One hundred and fifty six representatives from 65 organizations participated. Dr. Raviraj William moderated the sessions.

Prof. P. Joseph Yesudian, Secretary, PWDS welcomed the participants and provided an introduction of PWDS, PWDS-Alliance project, and the purpose of the seminar.

Dr. N S Murali, Secretary, Voluntary Health Services (VHS), Chennai, inaugurated the seminar. In his inaugural address, Dr. Murali remarked that the enormity of the HIV/AIDS problem makes it imminent that it cannot be addressed by any agency working in isolation. Rather there is a need for concerted efforts by various players such as the government, voluntary agencies and networks of positive people.

According to Dr. Murali, while HIV/AIDS awareness levels were high thanks to extensive HIV/AIDS prevention and control programs, there is also a pressing need to address HIV/AIDS issues in areas where there is a high incidence of people living with HIV/AIDS. Thus there is a need to replicate the awareness program success in care and support.

Mr. K. Deenabandu, IAS; Project Director, TNSACS, in his keynote address remarked that HIV/AIDS is the greatest challenge of modern times for there are 40 million people living with HIV/AIDS in India. Do we have the capacity to provide care and support in our health care systems? Care and support cannot be addressed by medical interventions alone but needs an integrated approach that addresses the psychological, legal and human rights aspects.

Reiterating Dr. Murali's observation, Mr. Deenabandu said that the complex nature of care and support and inadequate healthcare infrastructure in the country made it impossible for a single agency to implement it. Rather different sectors of the community such as the government, voluntary agencies, private sector, individuals, families and immediate relatives of people living with HIV/AIDS need to be involved in providing holistic care and support. A partnership between the public and private sectors would be a step in this direction. As a first measure, TNSACS has forged a partnership with ten private hospitals in Tamilnadu to provide care and support services.

Dr. Bimal Charles, Director, AIDS Prevention and Control (APAC), Chennai, said that following the success of the prevention and control program, there is a need to move towards leadership building in cost effective care and support that mobilizes the community and enlists political support to ensure its success. Besides, HIV is a major threat that needs interventions in matching scale. It is important that people infected and affected speak with one voice and also sensitize the general public to espouse HIV/AIDS causes. He also remarked that the PWDS-Alliance initiative is the first of its kind in HIV/AIDS intervention in both care & support and community based approach.





Thematic Presentations and Sharing of Experiences



Prevention Initiatives and Care and Support

*Dr. Devasish Dutta,
Program Officer, APAC, Chennai*

The APAC strategy for care and support grew out of its strengths and success with the HIV/AIDS prevention programs with high risk groups. The approach is based on a comprehensive continuum of care that includes prevention and control, VCTC, counseling, and care and support.

The objectives include integrating care and support with the existing APAC prevention programs; providing psychosocial support to people living with HIV/AIDS and their families; and reducing stigma and discrimination towards people living with HIV/AIDS in families and communities.

The key features of the APAC strategy for care and support are increased access and availability of VCTC; reduced stigma and discrimination towards people living with HIV/AIDS in their families and communities; increased capacity of communities to provide care for people living with HIV/AIDS and their families; strengthened health care related services to provide a continuum of care to people living with HIV/AIDS and their families; increased involvement of people living with HIV/AIDS in care and support programs; accessing locally available primary health resources; components of home based care such as self-care and spiritual support; and community care.

One of the methods of integrating care and support with existing prevention programs is by including care and support messages in all existing communication programs. There is also a need for orientation and capacity building of existing staff, peer educators, volunteers, and other stakeholders (such as the media) involved in prevention.

A key feature is to build the capacity of trained health care workers on care and support components. This is done by the following methods: integrating care and support in existing health care modules; undertaking basic research on care and support issues; building the capacity of SHGs, CBOs, CSOs and mantrams who are involved in prevention and control programs; promoting VCTC as a bridge between prevention and care programs; and involving decision makers for care and support advocacy issues.

A key feature is the increased role of VCTC in care and support. In contrast to its earlier diagnostic role, the new approach envisages an increased role of VCTC as a link between prevention and care programs.

Stigma and discrimination towards people living with HIV/AIDS and their families is a pervasive social problem. One of the reasons for this trend is the all too powerful fear and negative messages of HIV/AIDS in the initial years. Thus there is a pressing need to counter the fear campaign with messages of positivism and hope. It is also important that people get the message that nobody is immune to HIV/AIDS and potentially every person runs the risk of contracting the disease. Such a message would go a long way in normalizing HIV/AIDS as just another disease.

Sensitizing the media through workshops and exclusive literature is an important step in this direction. Another would be by asking people living with HIV/AIDS to share their experiences that highlight the fact that they lead as normal a life as anyone else. Involvement of celebrities in media campaigns to deliver positive messages on the need for care and support for people living with HIV/AIDS is another means of fostering attitudinal change.

Ironically there exists widespread stigma and discrimination even among health care providers. Thus there is a need to sensitize and promote a positive attitude among health care providers too. Sensitizing policy makers, political and religious leaders for advocacy, and non-judgmental attitudes are important, as they are potential change agents.

People living with HIV/AIDS subject themselves to self-discrimination that is far worse and compounds the stigma and discrimination in the larger society. Building a strong self-esteem through counseling is an effective counter strategy.

People living with HIV/AIDS are valuable resources in a care and support program. They can be inducted into care and support with a more visible role for them such as involving the already existing networks of positive people in the programs, promoting networks of positive people in areas where they do not exist, utilizing their services in counseling, training, advocacy and care, and building the capacity of people living with HIV/AIDS through training in prevention and care and support. People living with HIV/AIDS and their carers need to be oriented to self-care and spiritual aspects of home based care for a better quality of life and greater enjoyment of the activities of their daily living.

Supporting Community action on AIDS in India

Tara Manchin Hangzo,

Program Officer, India HIV/AIDS Alliance, New Delhi

The Alliance was set up in 1993 by a consortium of international donors to support community action on AIDS in developing countries. It was established in response to the need for a specialist, professional intermediary organisation to work in effective partnership with developing country NGOs/CBOs as well as with national governments, private and public donors and the UN system.



The Alliance approach is based on evidence that HIV/AIDS work is particularly effective when carried out by local organisations, which are guided and supported by local people while being linked to a wider body of ideas and information. The Alliance supports direct community action and services, capacity building, and the identification and promotion of good practice and policy.



Since it was established, the Alliance has provided technical support to thousands of NGOs and CBOs leading prevention, care and impact mitigation responses in over 40 countries. In 2000, the Alliance worked with NGOs and CBOs in 25 countries in Africa, Asia, Eastern Europe, and Latin America. In 13 of the 25 countries, the Alliance managed ongoing programs of support to a range of groups; the Alliance is currently implementing such activities in Bangladesh, Brazil, Burkina Faso, Cambodia, Ecuador, India, Mexico, Mongolia, Morocco, the Philippines, Senegal, Ukraine and Zambia. In addition, new country programs are in development in: China, Ethiopia, Madagascar, Mozambique, Nigeria and Zimbabwe.

The India HIV/AIDS Alliance

The India HIV/AIDS Alliance was established in February 1999 as a **Country Office** of the International HIV/AIDS Alliance. As in other countries, the mission of the India HIV/AIDS Alliance is to build and link existing capacity and expertise in HIV/AIDS prevention and care within the NGO sector in India.

The India HIV/AIDS Alliance is led by a director and governed by a Board of Trustees. There are two main departments. Programs and Finance and Administration both led by a department director. In addition, the India HIV/AIDS Alliance has established a unit in Andhra Pradesh to support the scaling up and intensification of work in the state. The Andhra Pradesh unit is led by a director and also has two departments. Programs and Finance and Administration led by department co-ordinators. The four directors together constitute the management team of the India HIV/AIDS Alliance.

Program Implementation mechanisms

In March 2000, the India HIV/AIDS Alliance started a major new initiative to mobilize community care and support for people living with HIV/AIDS and their families in three priority states – Andhra Pradesh, Delhi and Tamilnadu – with support from the European Union. The program is based on an NGO support model and is managed by a selected Lead Partner (LP) Organization who plays an intermediary role in each state. In Delhi, MAMTA HEALTH INSTITUTE supports seven implementing NGO partners. VASAVYA MAHILA MANDALI (VMM), the Alliance's lead partner in Andhra Pradesh, supports seven implementing partner organizations. Lepra India has also been working as the LP in Andhra Pradesh, supporting community mobilization and NGO strengthening for community HIV/AIDS programs. PALMYRAH WORKERS DEVELOPMENT SOCIETY (PWDS), as the LP in Tamilnadu, supports 22 implementing NGO partners to implement a community based care and support program for people living with HIV/AIDS, and children and families affected by AIDS.

Program strategies

While VMM and PWDS have a strategic focus on establishing and strengthening services and referrals, MAMTA in Delhi has a focus on making the environment conducive for care and strengthening community services for PLHA, their families and

children affected by AIDS. Promotion of Voluntary Counseling and Testing Centres (VCTC) through strong community sensitization is also a major focus in Delhi. Lepra India plays a key role in providing technical support to NGOs and in community mobilization, especially with key populations, including men who have sex with men, sex workers, injecting drug users and people living with HIV/AIDS.

The India HIV/AIDS Alliance's programs in these three states concentrate on prevention, low-cost community-based HIV/AIDS care and support, and impact mitigation. This is complemented by state and national level advocacy efforts to build on and support community level action on HIV/AIDS.

The programs complement existing NGO/CBO support structures and initiatives being implemented by the National AIDS Control Program, State AIDS Control Societies and other NGOs, as well as ongoing efforts by health care providers and others to meet the current and anticipated increase in demand for services for people living with HIV/AIDS, children affected by AIDS and their families.

Program expansion and intensification in Andhra Pradesh

In 2003, the Alliance received commitment for financial support from Avahan (the India HIV/AIDS initiative of the Bill and Melinda Gates Foundation) and the Step Forward Initiative of the Abbot Laboratories Fund to support the scaling up of programs in Andhra Pradesh. The newly established Andhra Pradesh Unit of the India HIV/AIDS Alliance will play a central role in directing, managing and delivering an integrated and comprehensive HIV/AIDS program in Andhra Pradesh.

The program in Andhra Pradesh will continue to strengthen the care and support work at community level, with a focus on children affected by AIDS and orphans and vulnerable children. In addition, the program will seek to mobilize and empower key populations, including people living with HIV/AIDS, men who have sex with men, Sex Workers and injecting drug users to take action on HIV/AIDS. The program will work closely and collaborate with several state and national partners.

Community-based approaches in HIV/AIDS interventions

Experiences from PWDS-Alliance Care and Support Program, Tamil Nadu, India

D.T. Reji Chandra,

Director, PWDS

Palmyrah Workers Development Society (PWDS), a development organization founded in 1977, offers support services to sustain community initiatives.

PWDS promotes and works with community-based organizations and support service organizations aiming at '**self-management and sustainability.**' Its interventions aim at empowering the community by building people's organizations; equipping through awareness generation and skill training; and linking them with the mainstream for sustenance.

The approach, **MEALS**, includes the following steps: **M**otivating, **E**quipping, **A**ccompanying, **L**inking and **S**ustaining. In this approach, the community owns the activities, while PWDS extends the needed support services, a process, which emphasizes community ownership rather than community participation. The community initiatives are being sustained by offering the needed support services and facilitating linkages with mainstream.

In over two decades of development efforts, reaching out to thousands of villages and impacting on many communities with wider spheres of activities, PWDS programs have transcended geographical barriers and traditional frontiers. Over the years, PWDS has been instrumental and inspirational in initiating many innovative interventions as expressions of its social commitment.

Currently, PWDS directly implements five field projects, has promoted ten support organizations, a few of them with mainstream linkages, and works in 15 districts in Tamilnadu through three network programs with 40 NGOs as partners. The programs cover sectors like agriculture, enterprise and marketing, micro-finance, shelter technology, childcare and education, community health, and HIV/AIDS.

HIV/AIDS Interventions

PWDS initiated community health interventions in 1984. This community health involvement and community-based approach in development and health management led to an HIV/AIDS awareness and prevention program in 1984.

In 2000, PWDS was selected as a lead partner by International HIV/AIDS Alliance, UK, to coordinate a community-based care and support program in Tamilnadu. The project currently reaches out to people in low-income groups in 600 villages in 13 districts in Tamilnadu through 20 NGOs as implementing partners.

The project aims to mobilize community action for care and support of people affected by HIV/AIDS. 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, focusing on both direct services and referrals, collective functioning as a network, integrated approach and mainstreaming for sustaining the services.

Community mobilization process

The community was mobilized by the active participation of community-based organizations like Self Help Groups (SHGs), youth clubs, fan clubs, and community development NGOs. This process was effective because these organizations have certain advantages over other specialized agencies in accessing the affected people and responding to their needs in an integrated manner.

CBOs and NGOs have the potential to extend care and support activities as part of their existing community development initiatives. SHG members, sensitized on HIV/AIDS issues, create awareness among other sections of the community. The larger community was mobilized through volunteers, religious leaders and other opinion makers.

Community Responses

While widespread stigma and discrimination and negative attitudes towards people living with HIV/AIDS exist, there are also several instances of positive responses as a result of the mobilization and sensitization of the community through a community-based intervention. For example, the relative of an infected SHG member said, "I have two children. If she dies, I will take care of her two children and bring them up as my own."

In one village, SHG members began to collect rice for the affected families – a practice that spread to the nearby villages and is currently replicated by all the implementing NGOs as "a fistful of rice for people in need".

Such responses, with a little facilitation, have the potential of replication in the community with a tremendous effect for sensitizing the whole village. Thus instead of merely

focusing on negatives, a potential option would be to identify positive responses of the people, recognize them, strengthen them, and replicate such experiences in a natural process.

There have been several instances of community responses in the form of home-based care, support for food, education, shelter, scholarship support for affected children, adoption / sponsorship of children affected by HIV, integration of infected / affected persons in SHGs, and access to medicines and health care. A large number of private and government health care institutions and professionals are involved in this program.

Ingredients of Community Based (CB) approach

The community based approach essentially believes in building on already existing capacities and infrastructure. The need-based interventions emerge from the community, usually through rapid appraisals using participatory tools and methods. Collective functioning and integrated approaches with process planning are essential ingredients of a community-based approach.

Making existing services work for people by facilitating linkages and strengthening such institutional capacities improve access and add to the quality of services. Instead of developing independent service facilities, mainstreaming such services will be advantageous in many ways and this also helps to sustain the services beyond the project frame, time, and limited resources.

Advantages of community based approach

Community based models work with a process approach that can be replicated once established as an effective intervention. As in the case of “fistful of rice”, the community itself 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, in most cases, 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 after the project time. Community based approach works on community ownership and participation that is essential for sustainability. A program could be sustained by generating income from viable operation, and establishing mainstream linkages. Community ownership rather than community participation is the key.

Constraints and challenges of community based approach

Rural poverty, illiteracy, cultural issues, fatalistic attitude, lack of resources, capacity, and services, the limited capacity of NGO and their confined reach in a geographical area are some of the constraints in a community based approach.

Since HIV is an emerging issue and there are already many other poverty- related issues in poor countries, there is an absence of friendly policies. The project frameworks prepared with a need for monitoring also limits the space to work when new problems not envisaged earlier emerge in the field. The stigma attached to HIV, orphans, and people in poverty adds to complexity of the issue.

While the role of community remains central, it is also important not to overemphasize the community role by diluting the role and responsibility of the state. Overemphasizing 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. "If we want to send our children to school, we don't start a school but send them to an existing school; If we need health care, we do not start our own hospital but go to a hospital; if we want credit we do not opt to start a bank rather approach an existing bank. Then is it right to ask poor people to start and manage their own services when they seek services?"

In a community-based approach the community is expected to own the program. This also has the danger of placing all the responsibilities on the community which lacks resources and skills to manage the program. So while we talk about community based approaches the role and responsibility of governments, society and other civil society organizations should be recognized. The community should be always treated as a client for services and not as a service provider for themselves.

There is also a tendency to create new initiatives with project funds. While this is necessary in emergencies, in the long run, however, attempts to strengthen the existing services will help. Project-dependent initiatives have the risk of closure when the funds come to an end, if the project is not able to generate income for its operation.

As mainstream healthcare providers are generally not responsive to the healthcare needs of people living with HIV/AIDS, there is a tendency to create isolated specialized services.

Attempts to initiate institutional services as part of projects or by affected people and their associations as alternatives are however, only temporary responses.

What is needed is integration of healthcare needs of affected people as an integral part of mainstream health care system to improve quality, and make timely and sustained services available.

Exclusive networks, while having a specific role to play and fulfils certain needs of the community also has the danger of isolating the affected people. Integrating affected families with community based organizations help meaningful participation and provide opportunities for positive living.

Lessons and way forward

HIV is a development issue with larger implications. Sector specialization and isolated interventions also fail to yield the expected results. An integrated approach between ASOs, CBOs, NGOs and the network of affected people will help. Prioritizing HIV children/families in the context of marginalized children/poverty is also an important issue at the field.

One needs to keep in mind the importance of poverty related issues in planning community-based HIV/AIDS interventions. Poverty, girl child, rural context, and HIV/AIDS is a complex combination that demands interventions with a broader development perspective. Instead of focusing on negative experiences building on the positive responses of the community is the way forward.

'Participatory process' is the key in community-based approach. Reliable and competent partnership is essential for effective community-based interventions. Confidence in partners' reliability, implementing ability, and process managing capacity are more important than monitoring of strict adherence to the planned project frame and activities

A proactive comprehensive approach that promotes care and support is equally important as focusing on people with high-risk behaviour. Initiating integrated interventions, promoting collective functioning, mobilizing community participation and enabling mainstream linkages will strengthen community responses and sustain impacts.



Institution Based Care and Support: The Government Experience

*Dr. R. Ganesh, Prof. & HOD,
Department of Sexually Transmitted Diseases, Medical College, Tirunelveli*

The first instance of HIV/AIDS was detected in the country in Tamilnadu in 1986. By 1988-89, it was apparent that HIV/AIDS was not mere statistics but a serious health problem with development implications. The increasing numbers of people living with HIV/AIDS made it necessary to address their special needs and concerns.

The STD department of Government Rajaji Hospital, Madurai, treated its first patient with HIV/AIDS in 1989. Treatment for HIV/AIDS thus became integrated with treatment for sexually transmitted diseases and began to draw increasing numbers of people living with HIV/AIDS for diagnosis and treatment. It was possible to treat OIs immediately with existing facilities. There were two categories of people who tested positive for HIV: asymptomatic and symptomatic. For the asymptomatic group of patients the following clinical strategies were employed: counseling (both individual and group), baseline investigations (such as weight check, TC, DC, ESR, and X-Ray chest), screening for Sexually Transmitted Diseases (STD), spouse screening, and regular reviews.

The symptomatic patients were classified into early and late symptomatic. The following clinical strategies were used with the early symptomatic patients: reassurance and counseling, ruling out TB or initiating anti TB therapy, patient education on early signs/symptoms of OI, timely treatment of OIs, financial counseling, and ART therapy depending on affordability. In the late symptomatic patients, the treatment modality consists of reassurance/counseling, reassessment of ongoing ART therapy by including polymerase inhibitors, anti TB therapy if needed, skin care, and checks for pneumococcal pneumonia, gastrointestinal disorders, and brain diseases.

Terminal care of people living with HIV/AIDS includes an empathetic attitude, counseling patient and family, maintenance of basic nutrition, intensive treatment of opportunistic infections, special emphasis on detection of eye disorders, and home based care if the patient desires. There have been attitudinal changes towards people living with HIV/AIDS. It is important to dispose dead bodies of people with HIV/AIDS in a double-covered plastic bag as an infection control measure. Also, relatives need to be educated on how to handle the body.

It is also important to avoid mentioning the cause of death as HIV/AIDS in death certificates to avoid stigma and discrimination for the family members that denies them access to employment and insurance benefits. Confidentiality regarding the diagnosis of HIV/AIDS must be maintained. Even other health care workers need to be informed about the diagnosis only if absolutely necessary. It is possible to treat HIV/AIDS effectively in government healthcare settings, by utilizing the available infrastructure and resources. What is important is the ability to maximize existing resources and evolve strategies appropriate to the available resources.

Community based care and support

L. Edwin Sam, Senior Program Officer, PWDS-Alliance Care and Support

The PWDS-Alliance care and support program works for an enabling, supportive environment towards care and support for people, families, and children living with HIV/AIDS. Through activities such as improved care and support services, increased capacity of NGO staff to assist affected families and the local community to provide high quality care it seeks to reduce stigma and discrimination and thereby improve the quality of life of people living with HIV/AIDS at the individual, family, and community levels.

A comprehensive care and support program involves various sectors of the larger community with active involvement of local healthcare providers, community leaders, augmenting care and support efforts at the family and community levels with effective collaboration from the government, private sectors and NGOs.

Features of a community based care and support program include a non institutional approach, need-based responses, community priorities, affordability, maximum use of existing resources, participatory community sensitisation, strengthening linkages, sustainability, recognition of rights of individuals, creative ways of community ownership, and sharing of experiences.

The project provided opportunity for the staff in building our capacities and the capacities of staff of the implementing organizations as well. The project implementation, reporting and documentation system helped us to learn and enrich us in areas of planning, monitoring and implementation. The project also helped us to establish linkages with various agencies at different levels and initiate a process for future advocacy.

In general, the PWDS-Alliance HIV/AIDS Care and Support project has made visible changes in the life of PLHA and their families. It has motivated individuals and institutions in the general community for their effective involvement in HIV/AIDS issues. The changes have been so effective to move from dependency to independency and moving towards interdependency.



Institution Based Care and Support: YRG CARE Experience

Dr. A. Kala Malini,

Medical Officer,

YRG CARE (Center for AIDS Research and Education), Chennai

The YRG Center for AIDS Research & Education (YRG CARE) was formed in 1993 by Dr. Suniti Solomon, the founding Director of the center, a retired Professor of Microbiology from the Madras Medical College. In 1986, her laboratory documented the first evidence of HIV in India.

The organization works with a vision to prevent new HIV infection and to assist infected people live a life of dignity. It is driven by a mission to respond to the needs of those who do not receive care and support or education / information about HIV awareness and prevention.

YRG CARE has multiple activities in the areas of prevention, research, care and support. The YRG care model continuum includes VCT continuum of care, support services, networking, advocacy, research and publications, family counseling center, infectious diseases laboratory, drug center, tele counseling services, and the first exclusive intensive care unit for people living with HIV/AIDS.

The care program at YRG was initiated in 1993 with the introduction of VCT services. In 1994, VCT services were offered three days a week. It was extended to six days a week in 1996 and increased to all days in 1997 and 1998 with increased availability of beds. The family counseling center was started in 1999 and a scale up project with four partner sites in south India initiated. The YRG CARE infectious diseases laboratory was started in 2000, the VHS-YRG CARE drug center in 2001, tele-counseling services and learning resources unit in 2002, and the first exclusive intensive care unit for people living with HIV/AIDS in 2003. YRG CARE rural and MTCT Clinic and delivered around 220 deliveries. Out of 100 babies tested so a 89 are negative.

A pediatric clinic forms part of the services. Pediatrician experienced in treating pediatric HIV/AIDS visits the clinic once in two months

A YRG CARE survey on HIV infected women in South India revealed that the average

age of infected women was 29 years. A significant number were married (95%) and housewives (81%). Heterosexual infection was the most common source of infection and 88 percent of women were in a monogamous relationship.

HIV/AIDS is an immuno-compromised disease. The opportunistic infection clinical spectrum in HIV/AIDS includes oropharyngeal manifestation, dermatological manifestations (infections, autoimmune responses, drug-induced and cutaneous malignancy); central nervous system manifestations (acute HIV infection such as viral meningitis, encephalitis), opportunistic infections such as TB, PCP, CNS manifestation like Toxoplasmosis, cryptococcal meningitis, HIV encephalopathy, AIDS dementia complex, cryptosporidial diarrhoea, genital infections neoplastic diseases such as Kaposi's sarcoma.

Anti retro viral therapy is indicated in acute infections, in symptomatic manifestations, and if the patient is asymptomatic (CD4 < 200 cells). It is, however, important to observe an asymptomatic patient whose CD4 is greater than 350-200 cells. The goals of ARV therapy include maximum and durable suppression of viral load, restoration and/or preservation of immunologic function, improvement of quality of life; and reduction of HIV-related morbidity and mortality.

Possible ARV toxicities include initial problems tolerating therapy, hypersensitivity reactions, immune-reconstitution related changes, chronic toxicities, and drug-drug interactions.

Chronic toxicities include bone marrow suppression, hepatitis, peripheral neuropathy, body shape changes, (increased abdominal girth, breast enlargement, prominent leg veins, and enlargement of dorsocervical fat pad), depression, metabolic changes, and HIV-treatment associated hepatitis.

The most important aspect to be considered before initiating ARV therapy is to discuss treatment affordability with the patient. The physician must inform the patient about all aspects of ARV therapy such as providing information about the drugs, the cost of drugs and therapy, possible drug toxicity reactions, the affordability factor, and importance of clinical follow up and monitoring (CD4/viral load). The physician must stress the fact these drugs are to be taken life long and must be continued until more efficacious drugs are available.

At YRG the continuum of care includes a multi disciplinary team, enhanced universal precaution and decreased cost of care with trained and experienced doctors.

Care and Support from the perspective of Positive Women Network (PWN+)

*P. Kouslaya,
President, PWN+, Chennai*

Positive Women Network (PWN+), established in 1998, is a national organization of women living with HIV/AIDS. Based in Chennai, it is the outcome of a felt need for a support group of women living with HIV/AIDS to enable them deal with the many complex issues, special needs and concerns in their lives.

PWN+ activities reflect its goal of providing an enabling environment for women living with HIV/AIDS. These include counseling services, monthly support group meetings, training programs and workshops, initiating SHGs at the state and national levels, and networking with the government, NGOs, national and international agencies working with HIV/AIDS-related issues.

There is a distinctive difference between an NGO and a network of people living with HIV/AIDS. The former is a professional association that works for the benefit of people living with HIV/AIDS. The latter, however, is an association of, for, and by people living with HIV/AIDS, formed on the basis of their experiences of living with HIV/AIDS. So there is a need for integrated efforts for a better program implementation.

Women living with HIV/AIDS are often subject to stigma and discrimination in the family, work place and society, insensitivity of healthcare providers that denies them access to care and treatment, denial of employment opportunities, lack of access to legal literacy and inadequate support for accessing legal rights, and misinformed and insensitive media campaigns that indirectly contribute to the prevailing stigma and discrimination.

The following are some of the strategies to address these issues: Empowering women with skills and to emerge as role models, creating job opportunities, enabling them access appropriate information to make suitable life choices, and Greater Involvement of People living with HIV/AIDS (GIPA) at all levels.

Besides imparting a human face and voice to the epidemic, GIPA enables them to participate in planning, developing and implementing strategies in addressing the

issue. People living with HIV/AIDS must be empowered to participate in prevention and care and support activities as strategy makers, educators, community mobilizers and active participants. Involving them in prevention campaigns brings about behavior change and reduces fear and stigma by correcting the misconceptions about HIV/AIDS. The involvement of people living with HIV/AIDS at various levels in a project or organization creates greater visibility for the needs and concerns of affected people and increases credibility within the community. In short, GIPA means a partnership in all programs related to care, support and prevention.

There is a need for people living with HIV/AIDS to share their experiences without reserve and portray stories of hope and courage in the media. This would enable attitudinal changes among the larger community that could demythicize the disease and people living with HIV/AIDS. Revealing a person's HIV status in a safe non-threatening environment has been found to have therapeutic effects. Care and support involves both being with and for people living with HIV/AIDS.

Community Based Approach in action:

P.Manoharan, Director, PACHE, Madurai

Since the past three years, the experiences in the PWDS Alliance Care & Support project has made it obvious that care and support is the need of the hour. As one of the INGOs involved in implementing the project, I see a number of distinctive features that I believe are the project's strengths and which to some extent have been responsible for the impacts at the field level.

The PWDS Alliance project was implemented in stages. It was preceded by intense participatory planning, strategic planning, participatory community appraisal, team approach, and maximal INGO involvement.

What strikes me most is the community based approach and the capacity building process inherent in the project, and the timely and need-based responses. The indirect benefits of the project consist of a feeling approach in contrast to a project approach and community sensitisation.



Care and Support from the perspective of PLHA network

S. Jeypaul,

Program Coordinator, Indian Network of Positive People (INP+)

A network of people living with HIV AIDS is an association of people living with HIV/AIDS that provides peer support and raises with the government and community the issues of people living with HIV/AIDS

The Indian Network of Positive People (INP+), Chennai, is a national organization established in 1992 to improve the quality of life of people living with HIV/AIDS in India. Beginning with just 12 members, it now has more than 2000 members from all over the country.

One of our community member in Namakkal expressed, “ I thought i was alone. But now I have the support of other people living with HIV/AIDS.” Our positive speakers are proud to say “ I didn’t know I could make a change.”

Its activities include providing opportunities for the voices of people living with HIV/AIDS to be heard, promoting a positive image and visibility to groups of people living with HIV/AIDS, networking with HIV positive groups, providing opportunities for skill building, advocacy, promotion, and lobbying for treatment and drugs, and government legislation for human rights.

One of its members said, “ I didn’t know I could make a change.”

Another said, “ I thought I was alone. But now I have the support of other people living with HIV/AIDS.”

What does providing care and support mean? It means to be concerned or interested and to provide necessary assistance. For some it involves providing basic needs, while for others it could be emotional, education or some other specific need.

A network of people living with HIV/AIDS has a strong element of concern and interest in the welfare of its members. It equips people living with HIV/AIDS to care for themselves, their families, and peers.

It is important to support every aspect of a HIV positive person's life. Network's care and support program offers the following kinds of support to people living with HIV/AIDS: psychosocial, human rights and legal assistance, spiritual, nutrition and shelter, health and medicine, education, income and employment.

The lived experiences of people with HIV/AIDS ranging from the type of care required, the need for psychological support, knowledge and experience of opportunistic infections, and treatment options, and peer support make membership in such networks a therapeutic experience. Networks of people living with HIV/AIDS are effective in treatment advocacy.

Several examples highlight the fact that involvement of people living with HIV AIDS in a care and support program increases its effectiveness.

The advent of the Greater Involvement of People living with HIV/AIDS (GIPA) addresses the issue of stigma and discrimination towards people living with HIV/AIDS. INP+ 'Positive Living Project in Namakkal is exhibiting the effectiveness of involvement of people living with HIV/AIDS in its comprehensive prevention and care and support program. Experiences of people living with HIV/AIDS who have revealed their status have drawn attention to its therapeutic benefits of doing so. When does a person living with HIV/AIDS choose to reveal his/her status? Doing so in a safe, accepting, and non-threatening environment is most beneficial.

To Serve with Love

Mani, a volunteer with PACHE Trust, talks about what made him volunteer for a cause.

My uncle's son died of AIDS. Our family faced stigma and discrimination in the village because of this. Around this time I witnessed a street theatre play on the causes of HIV and its prevention. I also saw many women, children, and men in our village who were HIV positive.

I wanted to do something to help them. I joined PACHE Trust as a volunteer. I meet and counsel people living with HIV/AIDS, make home visits, provide home care, and accompany them to hospitals. Because of my association with people living with HIV/AIDS, I'm popularly known as "AIDS Mani".



Care and Support issues related to children

Dr. P. Manorama,

Director, CHES (Community Health Educational Society), Chennai

The first instance of HIV/AIDS in children was diagnosed in 1982. Globally 2000 children are infected every day. (UNAIDS / WHO 2002). Children account for 14 percent of the 4.58 million people living with HIV/AIDS in India.

Children acquire HIV infection through parent to child transmission, contaminated blood transfusions or sexual abuse. Estimates reveal that one-third of babies born to HIV infected mothers will be infected. A positive correlation exists between impact of HIV/AIDS on women and infection in children. Children infected with HIV often have the same illnesses as children without HIV, but these may be more serious, frequent or difficult to treat. HIV/AIDS has a significant impact on infant and child mortality.

Community Health and Educational Society (CHES) was established in 1994 as a response to two children infected with AIDS whose parents had died of HIV/AIDS (AIDS orphans). CHES is a registered NGO headed by pediatric gastroenterologist Dr. P. Manorama, and does doing pioneering work in AIDS prevention and care. The organization's activities encompass the whole spectrum of communities whose lives are threatened by HIV/AIDS.

The key stakeholders in care and support for children both infected and affected are care givers such as doctors, nurses, parents/foster parents, NGOs, volunteers, peers, and community leaders. A study conducted by CHES revealed that most infected and affected children belonged to low income groups and both parents were infected more than half the number. 58.8 percent of children infected were girls, and 78.8 percent are less than ten years old. Most of the children (98 %) on follow-up were infected perinatally.

A child-centric care and support program needs to incorporate children's participation and take care of children's special needs and concerns such as school education, routine pediatric care, medical management of minor ailments and opportunistic infections, family support and counseling, disclosure of the child's HIV status if the child is emotionally mature, nutrition care, and child-friendly doctors and clinics.

The needs of children affected with AIDS also depend on the following factors: HIV status of parents, whether the parents are dead or alive, parental health, family support and prevailing stigma and discriminatory attitudes towards the disease.

Care and support at the family level includes educating and sensitizing family members about HIV/AIDS and related issues, training care givers on everyday management of HIV/AIDS, and addressing myths and misconceptions about the disease. A rapport must be established with the family and referral services such as VCTC, medical centers, and support services made accessible.

At the community level, care and support could be initiated by mobilizing and involving the community by creating awareness about children affected with AIDS through street plays and cultural shows and conducting educational and sensitization programs. Others include developing linkages with networks of people living with HIV/AIDS and with schools, noon meal centers, creches, medical centers and balwadis.



Care and Support in human rights perspective

Indumathy,

SIAAP (South India AIDS Action Program), Chennai

SIAAP is a non-government organization, that has espoused HIV/AIDS issues since the beginning of the epidemic in India (1986). Its first intervention challenged the illegal detention of women testing positive for HIV in the country.

SIAAP won the case, and over 600 women were released and a precedent set against future detentions. Since then, SIAAP has pioneered interventions that integrate human rights advocacy, gender and sexuality issues among people vulnerable to HIV.

SIAAP is currently a training resource organization for counseling, community interventions and advocacy programs in India. Over the years, SIAAP has pioneered grassroots prevention and care interventions among the trucking industry, women and men in sex work, people with HIV/AIDS, gay, lesbians and bisexuals, adolescent girls and rural women.

SIAAP offers different trainings and the following courses: Certificate course in HIV and AIDS, diploma in HIV and AIDS counselling, certificate course in supervision skills and theory, certificate course in peer development and support, and certificate course in community based interventions.

SIAAP has served on international and national advisory boards to develop policy and standards of practice. It has trained 200 NGOs and CBOs in intervention design, counseling, community outreach, peer education, community development, and advocacy.

SIAAP has trained and placed counselors at 125 VCTCs in South India and worked to prevent parent to child transmission of HIV (PPCT). As a complement to NGO efforts, SIAAP has supported and developed 25 community organizations of women in sex work, people with HIV, gay and bisexual men and visually challenged people in South India.

SIAAP has addressed stigma and discrimination in more than 100 rural communities with the help of local village councils and helped form thrift and credit co-operatives among vulnerable communities. A lawyer represents each sangam or village level community organization. The sangams also hold periodic solidarity and peer meetings.

SIAAP has worked with UNDP, UNAIDS, WHO, Australia-India Council, USAID, DFID, the National AIDS Control Organization (NACO) and its regional counterparts, the Women's Commission and the Human Rights Commissions in India.

In 1996 SIAAP protested against police violence against sex workers and led an agitation. The Home Ministry then issued orders informing all police stations in the country to desist from violence against sex workers.

Living Positively

Meenakshi (27), a TNSACS counsellor who works with NMCT as a peer educator, talks about her experiences of living with HIV/AIDS. Neatly dressed and articulate, Meenakshi says that HIV/AIDS does not mean the end of life; but rather an opportunity to reinvent herself into an empowered woman.

When I knew that my husband was HIV positive, both of us wanted to commit suicide. At that time neither of us had even heard of HIV/AIDS. But we had a baby girl to take care of and so I decided to be brave and face life at least for the child's sake.

We lived with my in laws. They believed that my husband's frequent illness such as fever and diarrhoea was due to black magic. Later when he died of AIDS, they held me responsible and threw me out of the house. I had little education (discontinued schooling after Class 9) and no means of taking care of my daughter and myself. Fortunately my parents were supportive and I went back to them.

Meanwhile I too began to fall sick and often developed fever and lost weight. I tested positive for HIV. I could not believe it and was shocked, angry, and hurt. What had I done to deserve it? Why should it happen to me? A chance meeting with a counsellor helped me to learn all about HIV/AIDS.

Soon I decided to do something with my life. For the first time I realized that lack of education was a handicap in finding suitable job. I worked in a series of low paid exploitative jobs that made me realize how vulnerable women are.

A turning point in my life was participating in *Aratai Arangam* (a popular TV talk show on current issues). I disclosed my HIV status and talked about stigma and discrimination faced by people living with HIV/AIDS.

I also came to know about many people with HIV who were living just like anyone else. The true-life stories of many members of Positive Women Network (PWN+), Chennai, inspired me. I underwent training in counselling at SIAAP, Chennai.

I'm a counselor at TNSACS and a peer educator at NMCT, Coimbatore. I'm doing my Master's degree through correspondence and want to enrol in a spoken English course as well. Today I'm a self-confident person and I live as normal a life as anyone else and am thankful for the many opportunities to discover my strengths as a person.

TNVHA experience in HIV/AIDS interventions

J.P. Saulina Arnold,

Executive Director, TNVHA, Chennai

Tamil Nadu Voluntary Health Association (TNVHA), established in 1971, is a network of 550 member institutions such as NGOs, hospitals, dispensaries, and community based organizations. TNVHA operates in Tamil Nadu and Pondicherry. Premised on the belief of health through people, TNVHA works with appropriate agencies to promote holistic health development with the people. Its decentralized district wise activities include networking, capacity building, IEC promotion, research and documentation, advocacy and lobbying.

In 1985 the first surveillance center for HIV/AIDS detection was established at CMC, Vellore. In 1986, blood samples of six sex workers from Mumbai sent by Madras Medical College to CMC, tested positive for HIV. The first message that the government issued was characterized by fear-based campaigns such as “AIDS kills” and “Do not go to sex workers.”

TNVHA's HIV/AIDS initiatives consisted of the following activities: It was the first to disseminate information to NGOs in 1988, and also organized the first state level workshop in Chennai in 1990. TNVHA produced the first IEC materials such as posters, booklets, and handbills in Tamilnadu in 1990. Then in the next four years (1990-1994), TNVHA printed posters and relevant handbills every year. From 1991 to 1994, TNVHA also organized training programs for NGOs such as orientation trainings, training of trainers, counseling, and training for sex workers. Later TNVHA, VHAI, and CMC conducted two courses in counseling for participants from all over India.

A KAPB study conducted by TNVHA with the support of VHAI was one of the first studies in India covering youth and adults, persons with high-risk behaviours, sex workers and truck drivers. From 1995 onwards, under the TNVHA training of healthcare providers program, 2200 TNSACS nurses, 1774 allopathic medical practitioners (APAC), 1585 health care providers of other systems, and 1452 health workers have been trained.

TNVHA's advocacy programs include state level planning, media workshop, school curriculum development, support to HIV positive networks, support to marginalized groups, and advocacy for sex workers.

Following awareness generation through workshops and training, TNVHA has also evolved new interventions. As an institution promoting health, TNVHA believes that HIV/AIDS must be viewed and addressed as an integrated part of health care services. This implies that it should be introduced as part of primary health care and not as a vertical program. If PHCs are strengthened, and people entrusted with responsibility for their health, it would enable HIV/AIDS issues to be addressed in a more comprehensive manner. Hence from 1990 onwards, all TNVHA activities have been geared towards initiating NGOs and capacity building.

Targeted intervention reaches out only to a specific group of people and not the entire community. Many NGOs who initiated targeted interventions had either no experience in community health or were not involved in community work. This resulted in a time bound, project-oriented approach that was not sustainable. Besides targeted intervention led to increased stigma and isolation because of increased visibility and did lack of community involvement.

This rationale provided the basis for two TNVHA initiated community based pilot projects in 2003: Enhancement of the capacity of member organizations to extend community based care and support to persons living with HIV/AIDS and families affected with HIV/AIDS (Project 1) and enhancing the capacity of NGOs to integrate care and support for people living with HIV/AIDS in their ongoing RCH activities (Project 2).

Project 1 operates in ten districts in Tamil Nadu. The following are the major strategies adopted: Capacity Building of TNVHA staff, district facilitation centers, and GOs; networking at block, district, and state levels; linkages with government and other resource agencies; promotion of IEC materials on care and support and prevention; campaigning for care and support, prevention, and rights of people living with HIV/AIDS; and lobbying and policy advocacy with government departments and community.

Project 2 operates in Madurai, Namakkal, and Tirunelveli districts. The strategies include multilevel capacity building of NGOs, participatory community assessment of SHGs and panchayat leaders, participatory planning, monitoring and linkage with government services.

TNVHA expects that the interventions would have the following outcomes: Motivate heads of voluntary organizations to integrate care and support activities with ongoing RCH activities; equip them with knowledge and technical skills required to implement care and support activities; Create a cadre of committed community based volunteers; improved utilization of IEC materials in care and support; and tangible changes in the lives of people living with HIV/AIDS and their families in the intervention area.

The Spirit of Volunteerism

Justice S. Joseph, former judge, Madras High Court, talks about his passionate activism for bettering the life of people living with HIV/AIDS.

When the diminutive Justice S. Joseph walked up to the stage, little did the audience realize that he had many surprises for them. His opening remark that inspired by Swami Sivananda, he believed that the whole world is one large community, struck a chord immediately with everyone. The audience sat upright when the former assistant sessions judge, Madras High court confessed, “ Do you know, I've reached a stage that if I don't visit everyday a family affected by HIV/AIDS, I can't sleep?”

How did this person who was otherwise removed from the world of HIV/AIDS become such a passionate HIV/AIDS activist? True, his altruistic tendencies were evident early in life. “I've always believed in helping the poor, sick, and the helpless. Even while in service, I was associated with the Society of Vincent de Paul that was involved in helping the poor,” recalls Joseph.

After retirement, he devoted his time to social service, visiting the sick on a daily basis, consoling them, rehabilitating the poor, elderly people, destitute, and the sick, and helping them in securing food, shelter, education, and medical assistance.

Justice Joseph's involvement with HIV/AIDS came about accidentally. “I first came to know about people living with HIV/AIDS through AIRD, Valiyoor. The problems and suffering of these people moved me and I wanted to do my bit for them. The staff of AIRD educated me about HIV/AIDS and cleared myths and misconceptions about the disease,” he explains.

His meeting with people living with HIV/AIDS was an eye opener, he says. For the first time he experienced first hand the problems and suffering such people faced.

Did he have any fears and misconceptions? “No, because by then, thanks to the AIRD staff, I was such a well informed person that I even talked to my family members about people living with HIV/AIDS, who then shared my commitment to the cause,” says Joseph.

Justice Joseph contributes money on a monthly basis to 20 families throughout Tamil Nadu and has also adopted three families affected by HIV/AIDS. In addition, the Vincent de Paul Society has also adopted five families affected by AIDS. He visits them regularly, counsels them, and helps them get their ration cards, old age pension, and other basic needs. “My work with people living with HIV/AIDS gives me a lot of satisfaction,” says Joseph.

More people like Justice Joseph, with a shared passion and commitment can make a BIG difference to the lives of people living with HIV/AIDS.

HIV/AIDS care and support initiatives of the government and future options

*Dr. K. Krishnamurthy, Director,
Public Health Services, Government of Tamil Nadu*

Government policies are formulated based on people's belief systems and also depend on prevailing social norms. Ever since the first instance of HIV/AIDS in the country was detected in 1986, the government has been continuously modifying its HIV/AIDS policies.

In the early stages, the emphasis was on prevention. There were even attempts to isolate people who tested HIV positive. For example, Commercial Sex Workers (CSWs) who tested positive for HIV were even imprisoned. Later the policy focus shifted to Information Education Communication (IEC). Behavior Change Communication (BCC) became the keyword. Mass communication and educational material to educate the community about the mode of spread and methods of prevention were implemented. However, the limited benefits of general awareness soon became obvious.

The strategy of targeted intervention then gained momentum. Specific high risk sub groups like CSWs and truckers were approached to prevent the spread. In that phase, however, the needs and sufferings of people living with HIV/AIDS were not recognized. One reason was that no specific cure could be provided. By this time networks of people living with HIV/AIDS were formed who demanded their right to services. The government is considering their views and care and support now forms an important policy. Reduced cost of ARV and improved quality of services to the affected people is picking up. Another encouraging development is reduction in discrimination due to stigma. Thus the current situation is favorable for people living with HIV/AIDS to access better facilities and live longer with improved quality of life.

The government support is two-fold: strengthened institutional care for treating OIs and efficient management of terminally ill patients. Support services in the form of establishment of VCTC centers was an encouraging development. In addition to extending the facilities to many government hospitals, private medical institutions were encouraged to provide non-stigmatized services.

The government was conscious of its limited resources and therefore supported NGOs to start community-based services. Networks of positive people and other NGOs received assistance to start community based services. This approach provided

psychosocial support and institutional medical care through referrals by linking to healthcare institutions. The true spirit of public-private partnership was followed in all these endeavors.

The Government Hospital of Thoracic Medicine at Tambaram has been augmented with additional resources to provide institutional care. So far 9082 people living with HIV/AIDS have availed the institution's services. Although one-third of the patients came from Andhra Pradesh, the rest were from all the districts of Tamil Nadu. Similar specialized facilities were provided at Namakkal and Perundurai. All government medical institutions provide medical, psychological and social services to people living with HIV/AIDS.

Recently the government has constituted a committee to review possibilities of introducing ARV drugs in government medical institutions. Recognizing the needs of people living with HIV/AIDS, the committee is considering recommending ARV drugs in government medical institutions on a cost-sharing basis.

A notable intervention is prevention of parent to child transmission. Fifty institutions in Tamilnadu are involved in the research. Pregnant women attending these institutions are counseled to undergo HIV testing. Pregnant women who test positive for HIV and who express willingness are administered nevirapine and followed up. Out of 39,553 mothers screened so far, 273 tested positive for HIV and are being followed up.

Many research studies were undertaken in Tamilnadu to strengthen care and support activities. Siddha medicines are being tried in some of these studies with varying degrees of success. Vaccine trials are also underway. The Indian Council for Medical Research (ICMR) plans a multicentric study on human trials of HIV vaccine.

Other activities that impact on HIV transmission include various governmental efforts to prevent HIV transmission by establishing STD clinics adding it with family health awareness.

A matter of concern is the growing menace of quacks who assure magic cures for AIDS at exorbitant costs. Lured by tall claims, many people living with HIV/AIDS have become their victims and lost precious resources. While the government is trying to curb their exploitative practices, NGOs too must contribute by educating people about such dubious claims. Another step would be to identify such quacks and mobilize social pressure to dislodge them.

The government is concerned about the welfare of people living with HIV/AIDS and takes every step to strengthen the quantity and quality of services to ensure a healthy and longer life for them.

My experience in care and support: “A work of God”

Silvester, Programme coordinator, SEDCO

The villages we work in are economically backward, and don't have transport and health care facilities.

The people we work with are mostly infected widows, children, infected/ affected persons who have lost money, home, burdened with debt, stigmatized, with nobody to take care of them, denied treatment; orphaned children, and husbands who have lost their wives and staying with children.

We are proud that we are there for them to provide some kind of care and support either directly or indirectly to the people living with HIV/AIDS.

Every day is learning for us in our work with the infected/ affected persons. We are happy that we are able to share whatever we have learned through trainings and workshops with others. We share with SHG members, community leaders, students, youth, religious leaders, VHNs, doctors, other NGO leaders through trainings, discussions, and meeting and when we see the changes that brought through them, there is hope that care and support will continue.

The care and support initiative has resulted in the following changes:

The persons who were against the infected/ looking at them with stigma have now started accepting them as one among them. Now they provide economical, psychological, health, educational support to the infected and affected.

When the infected/ affected share their experiences among themselves, it helps to build their confidence to live and face the world.

The project focuses on integration, linking, and mainstreaming and has an integrated approach.

The staff in the project are committed to the cause. We are proud and feel elated when we understand that we are providing care and support to the infected and affected which others denied to them.

We faced difficulties in the beginning of the project but planning and implementation and the positive results made us confident.

Earlier we had external resource persons, now PWDS-Alliance staff team has started conducting training programs. We consider this as an achievement from our front.

Out of my 30 years of experience in the development field, I consider this to be different and satisfactory. I consider this work as a work to God.

Group discussions and recommendations_____

The presentations, and the ensuing interactive sessions, and sharing of experiences, served as a spring board for the following four key issues to be discussed in groups:

- Possible collaborations between NGOs, networks of positive people, and technical players, and the strengths and limitations of such an endeavour.
- Methods of integration of components such as stigma reduction, prevention and control, and care and support at the organizational level.
- Collaboration at the grassroots level of projects implementing AIDS programs.
- GIPA value statements.

Participants were divided into eight groups. Each group discussed two of the above issues and presented their recommendations in the plenary session.

The role of NGOs, positive networks, and healthcare professionals was emphasized. The need to address the technical, socio-economic, and the human right dimensions of HIV makes a combined effort essential. Since HIV/AIDS is a complex issue with larger implications, there is a need for collaboration among the three players. Thus there is a need to complement each other to address socio-economic issues, health care issues, and policy initiatives.

A partnership between NGOs, positive networks, and health care sector is perceived as an effective measure to address the problem and is to be preferred to the differences among the three players that sometimes tends to surface. It is important that all these sectors work together with an integrated and comprehensive approach that would help develop a future perspective that is need-based, relevant, and sustainable.

Participants, while appreciating the present change in the prevention messages, voiced the need for a shift towards more positive prevention strategies. The emphasis was on stigma reduction through integrating prevention and control and care and support components. However, greater emphasis was placed on stigma reduction and to approach prevention and control from a care and support perspective.

There was a general consensus on a broader agreement on the need for collaboration within a geographical area like a taluk or district. The possibilities of associating with other projects in the same area and nearby NGOs to avoid duplication and to synergize the impacts were also need to be explored. Participants also expressed the need for some initiatives at the donor level to achieve this because of limitations of the need to adhere to the project frame.

Among the GIPA principles, formation of support groups/networks of people living with HIV/AIDS, advocacy and lobbying for the rights and dignity of people living with HIV/AIDS were expressed as important.

The major discussion points and the outcome of the group discussions were consolidated by Dr. Raviraj William the moderator at the end of the seminar.

People living with HIV/AIDS are the best resource available in a care and support program.

Community care is a vital care component and all-round capacity building of volunteers and peer educators, staff, healthcare providers, family members, and the community is the need of the hour.

Institutional care and community care are challenging activities and must complement each other as also integration of prevention and control with care and support and other development activities. Preventive medicine and management of opportunistic infections are as important as ARV therapy.

Care of children is an important issue in a care and support program.

HIV/AIDS is a larger social issue that should be addressed from a development perspective. There is a need to take community responses into consideration and look for possibilities of scaling. Small is beautiful; but large is productive.

Healthcare providers need to be sensitised about the need to integrate treatment and care with mainstream healthcare. What one often sees is that STD departments of hospitals are adequately sensitised; but unfortunately this does not transfer to other departments even in the same hospital. HIV related infections need the attention of all departments in a hospital.

A partnership between NGOs, positive networks, and health care sector with the support of the government is perceived as an effective measure to address the problem and is to be preferred to the conflict between the three players that sometimes tends to surface. It is important that all these sectors that have specific roles in the problem work together with an integrated and comprehensive approach that would help develop a future perspective that is need-based, relevant and sustainable.

Venue : Pandian Hotel, Madurai

Date : October 14 & 15, 2003

DAY - 1 (October 14, 2003)

- Registration : 9.30 a.m.

Inaugural Session : 10.30 a.m.

- Prayer Song : Ms. M. Sarala
Director, WORD, Namakkal
- Welcome : Prof P. Joseph Yesudian
Secretary, PWDS, Marthandam
- Inaugural Address and Lighting of Kuthuvilakku : Dr. N.S. Murali
Secretary, VHS, Chennai
- Presidential Address : Dr. B. Chandra Mohan, I.A.S.
District Collector, Madurai
- Key note Address : Shri. K. Deenabandu, I.A.S.
Project Director, TSACS, Chennai
- Vote of Thanks : Mr. C. Samuel Kumar
Convenor, Seminar Organising Committee

Tea Break

Session 1 : 11.45 a.m.

- Prevention Initiatives and Care & Support : Dr. Devasish Dutta
Program Officer, APAC, Chennai
- Supporting Community Action On AIDS in India : Ms. Tara Manchin Hangzo
Program Officer, India HIV/AIDS Alliance, New Delhi.
- Community Based Care & Support : Mr. D.T. Reji Chandra
PWDS experience Director, PWDS
- Sharing of Experience : Ms. R. Meenakshi, Coimbatore
- Sharing by a Volunteer : Mr. C. Mani, Madurai
- Concluding remarks by : Dr. Ravi Raj William
Moderator Director, CCOORR, Chennai

Lunch Break

Session - 2 : 2.30 p.m.

- Institution based Care & Support-Government experience : Dr. R. Ganesh, Prof. & HOD of STD Dept.,
Medical College, Tirunelveli
- Institution Based Care & Support - YRG CARE experience : Dr. A. Kalamalini
Medical Officer, YRG CARE, Chennai
- Care & Support from the Perspective of Positive Women Network : Ms. P. Kousalya
President, PWN, Chennai
- Care & Support from the Perspective of PLHA network : Mr. Jeyapaul
Program Co-ordinator, INP+, Chennai
- Concluding remarks by Moderator

DAY - 2 (October 15, 2003)**Session - 3 : 9.30 a.m.**

- Care & Support issues related to Children : Dr. P. Manorama
Director, CHES, Chennai
- Care & Support in Human Rights Perspective : Ms. Indumathy
SIAAP, Chennai
- TNVHA experience in HIV/AIDS AIDS Interventions : Ms. J.P. Saulina Arnold
Executive Director, TNVHA, Chennai
- HIV/AIDS Care & Support Initiatives by Government and Future Options : Dr. K. Krishnamurthy
Director of Public Health Services, Govt. of Tamil Nadu
- Concluding Remarks by Moderator

Tea Break**Session - 4 : 11.30 a.m.**

Community based Care & Support Experience Sharing by representing

- Children : Ms. C. Prasheela, Kanyakumari
- INGO Staff : Mr. S. Silvester, Co-ordinator, SEDCO
- INGO Chief Functionary : Mr. P. Manoharan, Director, PACHE Trust
- Community Well wisher : Mr. S. Joseph (Retd. Judge), Valliyoor
- Lead Partner Staff : Mr. L. Edwin Sam, Senior Prog. Officer
- Cultural Events : INGO staff

Lunch Break

2.00 p.m. - 3.30 p.m.

Group Discussions

3.30 p.m.

Concluding Session

Chennai

- AIDS Prevention and Control Project (APAC), Chennai
- Christian Council for Rural Development and Research (CCOORR), Chennai
- Child Health and Education Society (CHES), Chennai
- Department of Public Health Services, Government of Tamilnadu, Chennai
- Indian Network of Positive People (INP+), Chennai
- Positive Women Network of South India (PWN+), Chennai
- South India AIDS Action Program (SIAAP), Chennai
- Tamil Nadu State AIDS Control Society (TNSACS), Chennai
- Tamil Nadu Voluntary Health Association (TNVHA), Chennai
- Voluntary Health Services (VHS), Chennai
- YRG Care, Chennai

Coimbatore District

- Imayam, Coimbatore
- Swami Vivekananda Gurukulam, Coimbatore
- VEST, Coimbatore

Delhi

- India Alliance, New Delhi

Dharmapuri District

- Rural Integrated Development Organisation (RIDO), Dharmapuri

Dindigul District

- Arulagam Hospice
- Axiom Social Service Society, Dindigul
- Society for Serving Humanity (SSH), Sempatti

Erode District

- CARE, Erode
- Human Integrated Life and Learnings (HILLS), Sathyamangalam

Karur District

- Gramium, Kulithalai
- Mother Saradhadevi Social Service Society (MSSSS), Karur

Kanyakumari District

- Catherine Booth Hospital (CBH), Nagercoil
- Centre for Social Development (CSD), Nagercoil
- Centre for social Reconstruction (CSR), Nagercoil
- Good Vision, Kanyakumari
- Palmyrah Workers' Development Society (PWDS), Marthandam

Kancheepuram District

- Voluntary Educational & Economical Development Organisation (VEEDO) , Kancheepuram

Madurai District

- DATA, Madurai
- Institute for Social Awareness and Rural Development (INSARD), Madurai
- Meenakshi Mission Hospital and Research Centre (MMHRC), Madurai

- Pache Trust, Madurai
- Peoples Association for Rural Development (PARD), Madurai
- SPEECH, Madurai
- Sustainable Agriculture and Environmental Voluntary Action (SEVA), Madurai
- Society for Weavers Education & Appropriate Tech (SWEAT), Madurai
- SWEED, Madurai
- Teddy Trust, Madurai
- YSSWA - PMK Nehru Yuvakendra, Madurai

Namakkal District

- HUNS, Namakkal
- Women's Organization for Rural Development (WORD), Pallipalayam

Nirgiris District

- SARAS (A Trust for Social Service), Nirgiris

Pudukkottai District

- Gramodaya, Pudukkottai

Ramnad District

- Association for Integrated Rural Development (AIRD), Ramnad
- Nehru Yuva Kendra, Ramnad

Salem District

- St. Mary's Hospital, Salem

Theni District

- Seva Nilayam, Aundipatti
- Society for Rural Development and Protection of Environment (SRDPE), Theni
- Theni District Network for Positive People (TDNP+), Theni

Thiruvarur District

- Bharathi Women Development Centre, Thiruvarur

Trichy District

- Anbalayam, Trichy
- OASIS, Trichy

Tirunelveli District

- Community Action for Social Transformation (CAST), Cheranmahadevi
- Rural Education for Development (RED), Idayankudi
- RICE, Tirunelveli
- Rural Women's Educational Development Society, (RWEDS), Cheranmahadevi
- Suviseesapuram Neighbourhood Development Society (SANDS), Tirunelveli
- Tirunelveli Medical College & Hospital

Tuticorin District

- AWED, Tuticorin
- Chevaliar, Tuticorin
- EMPOWER, Tuticorin
- Scientific Educational Development for community Organisation (SEDCO), Sathankulam

Virudhunagar District

- Blossom, Virudhunagar
- DEEPAM Trust, Sattur, Virudhunagar