

# Collective Responses



PWDS-Alliance HIV/AIDS Care & Support Programme

# **Collective Responses**

A  
report on  
PWDS - Alliance  
HIV/AIDS Community Based Care and Support programme



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## Palmyrah Workers Development Society

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### From the staff team

Yet another year has passed, a fruitful year with new insights and learning. We expanded our team with two more staff joining us. The experience we gained during the previous years enabled us to work in 13 districts with eight more implementing NGOs. New issues kept emerging in the current year along with the existing issues. The efforts to continue and, strengthen the existing activities and plan for the future was really challenging. The focus for the year was on enhancing capacities of stakeholders at different levels and establishing effective linkages with the existing service providers. The response was encouraging, thanks to the commitment of the implementing NGOs.

We take this opportunity to thank them for their continued participation in this cause. We are happy to see that two years of our involvement and contribution, though not able to address the issues completely, has generated a considerable impact on the affected people and community.

Aji Abraham, L. Edwin Sam, Rani, Sundar Singh, Samuel Kumar, and Selwin Rose,  
PWDS-Alliance Team

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*Collective responses* is the outcome of the collective efforts of a partnership; the experience of collective functioning.

We record our appreciation to all those who are a part of this process and express our gratitude for their support.

We feel that the response, though valuable, is in fact insignificant compared to the magnitude of the problem. We also feel the urgency to initiate interventions that will match such a magnitude-interventions that lead to collective, comprehensive, and community-based responses; and efforts sustained by mainstream linkages. Coming together for sharing strengths and learning from each other is important for such collective responses.

While we realise our response is limited, we believe it is an important beginning.

D.T. Reji Chandra  
Director, PWDS

# 1. Introduction

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## **PWDS**

*Offering support services to sustain community initiatives*

**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 skill training, and linkage with mainstream for sustenance. The main approach **MEALS**, includes the following steps: **Motivate, Equip, Accompany, Link, and Sustain**. In this approach, the community owns the activities, while PWDS extends the needed support services as a facilitator, a process that emphasises community ownership rather than community participation.

In over two decades of development efforts, reaching out to thousands of villages and creating impact on many communities with wider spheres of activities, PWDS programmes 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.

## **Reach and Impact**

Currently, PWDS coordinates five field projects, promoted ten support organisations with mainstream linkages, and works in 17 districts in Tamil Nadu through network programs with 40 (45 projects) NGOs as partners.

PWDS, through the various programmes, covers seventeen districts, and reaches out to 1280 villages in 26 taluks. Currently, 2380 self-help groups function in these villages, most of which are linked with mainstream financial institutions and resource organisations. The total group membership is around 40,950 families that amount to more than 204,750 people.

## **Paving Ways**

For more than a quarter century, PWDS has been serving as a development support organisation that offers support services to sustain community initiatives. It works with a wide range of professional teams in partnership with the government, national, and international resource organisations, and the corporate sector. With a thrust that professional services to the poor should be perceived by the mainstream as a viable operation, and not as a subsidiary activity with a charity approach, PWDS believes in promoting and strengthening community based support services to sustain community initiatives. This shift in development paradigm makes PWDS look for innovative concepts, approaches and leads for new avenues in development cooperation.

**PWDS: Paving Ways for Development Services.**

It is gratifying to note that communities are realising the importance of preventing the spread of this disease and taking a compassionate attitude towards those affected, particularly women and children. The NGOs participating in this project have greatly benefited by the training programmes and detailed discussions on community care and support of People living with HIV/AIDS held at different levels.

A carefully selected team of full time staff, ably guided and advised by a Project Advisory Committee work with dedication and commitment to fulfil the aims and objects of the project.

I am very happy to offer my heartfelt felicitations and good wishes to all those who are directly involved in this highly relevant, timely and vital project that they may meet with a high measure of success in their endeavours.

**Arthur J. Harris**  
Vice President, PWDS

### **HIV/AIDS Care and support Project - A Joint Effort**

I am happy that PWDS-Alliance HIV/AIDS Care and Support Project has successfully completed another year with more implementing NGOs covering a larger geographical area as well as providing care for more affected people. The project is recognised as a pioneering HIV/AIDS Care and Support effort in Tamil Nadu. An important development has been the involvement of the community through the Self Help Groups in supporting the affected.

The Programme Advisory Committee meeting at Madurai involved all the major players in Tamil Nadu. Since the problems related to HIV/AIDS cannot be addressed by a single agency or Project by isolated efforts, all the government and non-governmental agencies need to come together to put up a joint front to address HIV/AIDS issues. A series of workshops were organised on relevant topics for the implementing NGOs with the technical support of both International and India Alliance for effective implementation. The national thematic meeting on children affected by HIV/AIDS organised by India Alliance at New Delhi during December 2002, was a special event and the participants gained new insights to discharge their responsibilities effectively among affected children.

I congratulate the project team and the Director, PWDS, for devoting considerable time for this project and for their excellent work. Let us hope that the work will be continued with the same vigour and dedication.

**P. Joseph Yesudian,**  
Secretary, PWDS

## The International HIV/AIDS Alliance

### *Supporting community action on AIDS*

The International HIV/AIDS Alliance (The Alliance) is an international development non-governmental organisation established in 1993 by a consortium of international donors. The Alliance was established to respond to the need for a specialist, professional intermediary organisation that would work in effective partnership with non-governmental and community-based organisations in developing countries, and with national governments, private and public donors and the UN system.

**“The mission of the International HIV/AIDS Alliance is to support communities in developing countries to play a full and effective role in the global response to AIDS.”**

#### **The Alliance core goals are to:**

- **Catalyse increased attention to HIV/AIDS** by promoting the integration of HIV work into other health and development initiatives;
- **increase the quality of HIV prevention, AIDS care and AIDS mitigation** activities in the non-governmental and community sectors;
- **build the capacity of civil society institutions responding to AIDS** and promote partnerships between civil society institutions, governments, and the private sector;
- **develop new knowledge** through monitoring and evaluation and operations research; and
- **promote good practice** through development and dissemination of practical tools, technical reports and policy papers.

In the course of eight years, Alliance technical and financial support for HIV prevention, AIDS care and orphan projects has benefited millions of people. In 2001, Alliance funded services reached an estimated 4.4 million people from the poorest and most vulnerable populations and more than 941,800 people were trained or supported through programs for volunteers, and care givers.

In turn, Alliance learns from these community partnerships and uses these experiences to more broadly promote effective AIDS strategies encouraging both better programs and better public policy. The Alliance has helped people with AIDS and other affected community members to influence laws and policies in several countries, and to strengthen United Nations action declarations and program frameworks.

The Alliance works in countries heavily affected by AIDS to help people cope with the epidemic, and in less affected countries to stop HIV from becoming a serious problem. Currently, Alliance has provided technical assistance to NGOs and CBOs from more than 40 countries. Ongoing programmes are underway in 18 countries in addition to regional and international work (June 2002).

**India HIV/AIDS Alliance** The India HIV/AIDS Alliance (Alliance India) was set up in 1999 as the country office of the International HIV/AIDS Alliance to expand and intensify the Alliance's programme of supporting community action on HIV/AIDS in India.

**The Alliance's core goals in India are:**

- To make a significant contribution to HIV prevention, AIDS care, and support to children affected by the epidemic, by working together with communities in India.
- To promote the sustainability and scaling-up of effective community AIDS efforts, by building the capacity of CBOs, NGOs and NGO support programs.
- To influence and improve the HIV/AIDS policies and programs of national agencies, donors and the NGO sector, with a particular emphasis on the role of community action 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 HIV/AIDS. All activities supported under the Alliance programme in India operate within the framework of the National AIDS Control Programme (NACO).

### **Care and support for People living with HIV/AIDS and Children Affected by AIDS and their families**

Since 2000, the International Alliance has provided programmatic and organisational technical support and financial support to 37 Implementing NGOs (INGOs), through three intermediary Lead Partners (LPs). These INGOs include AIDS service organisations and organisations with strong community development and primary health experience. Currently, 34 INGOs implement:

twenty projects in 14 districts of Southern and Central Tamil Nadu;  
seven projects in seven coastal districts of Andhra Pradesh; and  
seven projects in urban Delhi.

The Alliance programme co-ordinates activities by the INGOs to ensure a holistic response in homes and communities within a continuum of care for people living with HIV/AIDS and with special focus on children affected by AIDS which includes prevention activities that are linked to care.

An essential and core component to the Alliance's work in India is the strengthening and capacity building of NGOs and CBOs to carry out care and support programmes for people living with HIV/AIDS, children affected by AIDS and their families. The capacity building activities include workshops and other technical support activities related to strategic planning, participatory community assessments, projects development and delivery of HIV related care and support services to people living with HIV/AIDS, children affected by AIDS and their families with an integrated approach.

## PWDS - Alliance HIV/AIDS Care and Support Project

*Work for an enabling, sustainable, supportive environment towards Community based care and support for people living with HIV/AIDS, children affected with AIDS and families affected with AIDS in Tamil Nadu*

**Background** The Alliance made its presence felt in the subcontinent with its effort to promote community based care and support in collaboration with NGOs and CBOs. In this connection, 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 the lead partner or primary partner to facilitate a broad range of response to the epidemic by coordinating, initiating, and implementing the program 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 selected implementing NGOs.

**Project overview** The project works with people living with HIV/AIDS and those affected by HIV/AIDS, especially women and children. It has been conceptualised on a vision of capacity building of NGOs in providing low cost community-based care and support for people living with HIV/AIDS. It also facilitates NGO partnership and strengthens community relationships.

### Objectives

- 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;
- Mobilise the community towards care and support; and
- Initiate policy-related interventions towards promoting the integration of care and support and community-based activities in Tamil Nadu.

**Structure** The project structure comprises the Lead Partner (LP) (PWDS) to coordinate the project, Implementing NGOs (INGOs) to work with the communities, and a Project Committee (PC) to discuss and decide on project related issues and monitor on behalf of PWDS, the lead partner, and the INGOs. The International HIV/AIDS, UK; and the India HIV/AIDS Alliance, New Delhi; provide technical support, mobilise financial resources, and monitor the program.



## 2. Timeline

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(January-December 2002)

**Staff Recruitment:** The PWDS-Alliance care and support project advertised in local and English language newspapers for the posts of coordinator (accounts and administration) and program officer. The selection committee short listed 20 candidates from the 33 applications for the post of coordinator and 61 for that of program officer. Mr. C. Samuel Kumar was selected as program officer and Mr. Aji Abraham Daniel as Coordinator (Accounts and Administration). The selected candidates were appointed from February 1, 2002.

**TNSACS Visit:** Dr. Asha Rao, Country Director, India HIV/AIDS Alliance, New Delhi; and Mr. Edwin Sam, Senior Program Officer, PWDS-Alliance; met Dr. 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.

The following areas were identified for future collaboration:

- Counselling support by NGOs in VCT centres managed by the government;
- Strengthening certain PHCs with the required medicines and doctors based on specific medical needs of people living with HIV/AIDS in that area;
- Joint publication of communication material such as a home care manual in Tamil;
- Improving NGO utilisation of available medical/technical facilities with the government/TNSACS; and
- Follow up meetings with NGO field staff for further discussion of their field experiences and learning in PCA and home care.

**TNSACS Follow up meeting:** A follow up meeting was held in TNSACS office, Chennai, on March 7, 2002. A team consisting of Ms. Anandi Yuvaraj, Program Officer, Alliance India; Mr. D.T. Reji Chandra, Director, PWDS; Mr. Edwin Sam, Senior Program Officer, PWDS-Alliance; Mr. Sylvester, Coordinator, SEDCO; Mr. Muthuselvan, Coordinator, CAST; Mr. Senthil Kumar, Coordinator, Seva Nilayam; and Mr. Joseph Vincent, Secretary, ARD; met Mr. Christudoss Gandhi, Project Director, TNSACS; and Mr. Muruganath, Deputy Director, TNSACS.

Two presentations were made on the activities of India HIV/AIDS Alliance, New Delhi, and on PWDS-Alliance community based care and support project. The coordinators shared their experiences, problems, and achievements in community based HIV/AIDS care and support. Participants also discussed various issues and intervention strategies.

**YRG CARE Visit:** Dr. Asha Rao and Mr. Edwin Sam met Dr. Suniti Solomon, Director, YRG-CARE, Chennai; on January 16, 2002, to mutually share their activities and experiences. They also discussed possible ways of collaboration of the technically sound YRG Care 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.

**CCSACS Visit:** Dr. Asha Rao and Mr. Edwin Sam visited the newly formed Chennai Corporation State AIDS Control Society (CCSACS) and held discussions with Mr. Dharmendra Prathap Yadhav, IAS, Deputy Commissioner.

### SUCCESSFUL RESPONSES TO THE EPIDEMIC

HIV/AIDS is an unprecedented global development challenge that has already caused too much hardship, illness and death. The pandemic affects individuals, but also devastates households and communities, and threatens entire nations. The behaviour that spreads HIV is fuelled by social, cultural, economic and legal factors which make it more difficult for people to protect themselves and which worsen the consequences of the epidemic. HIV epidemics start and spread in different ways in different places, but the epidemic is consistently accompanied by fear, blame and prejudice. In almost all cases, the poor and marginalised people are disproportionately vulnerable to HIV/AIDS and its consequences. This is particularly true for girls and women, because of biological, cultural, legal and social factors.

The most successful responses to HIV/AIDS and other development challenges are built upon local leadership, commitment and responsibility, and are supported by

resources from elsewhere. Local NGOs and CBOs are particularly well placed to facilitate community responses, as well as to effectively bridge the needs and capacities of poor people and poor communities with broader health and development efforts.

No one organisation can respond to HIV/AIDS in isolation. The pandemic demands mobilisation and collaboration at community, national and international levels. Government, civil society and private enterprise all have vital roles to play. Governments have a particular responsibility for leadership, but not at the expense - or to the exclusion - of leadership from other sectors. All stakeholders responding to AIDS must strive to complement each other's strategies and to actively collaborate together, while respecting each other's independence and acknowledging differences. Transparency, critical thinking, learning and sharing are essential elements of such successful partnerships, and of successful responses to AIDS.

- Source: [www.aidsalliance.org](http://www.aidsalliance.org)

**Participatory Community Assessment workshop (PCA)** This workshop enabled participants to arrive at a shared understanding of participatory community appraisal, the different tools of PCA, and familiarise themselves with the process of PCA through fieldwork. Participants also arrived at a consensus regarding the values, scope and components of community based care and support project, and the roles of International alliance, India HIV/AIDS Alliance, and PWDS in the project.  
Feb. 26, 2002 to March 3, 2002  
Kanyakumari  
**Facilitators:** Krupa Shinde, Anandi Yuvaraj, Sunder Singh, and K.B.Sudheer.  
**Participants:** Three staff from each second cycle INGO and NGO heads on the final day (32 participants).

**Workshop on Children Affected with AIDS** What does the umbrella term children affected with AIDS indicate? How does one arrive at a working definition of children affected with AIDS? What are the different groups of children and the problems faced by them. What are some of the guidelines to be followed while working with children affected with AIDS? How does one evolve a child-centered continuum of care for children?  
March 12-14, 2002  
Madurai  
**Facilitators:** Hannington Nkayivu, Meenak shukla, Anandi Yuvaraj, and Surabi Kukke.  
**Participants:** Coordinators and INGO staff.

**Resource mobilisation workshop** What is resource mobilisation? How does one understand the reasons people give? Why is it important to understand the current resource situation and its implications for NGO sustainability? What are some of the effective strategies to mobilise resources? How does one create a resource mobilisation action plan?  
March 18-21, 2002  
Madurai  
**Facilitators :** Mona Mishra, D.T. Reji Chandra, and Anandi Yuvaraj.  
**Participants:** INGO heads, LP representatives, and other potential NGO staff.

**Integration Study** Realising the need for a development response with an integrated approach, PWDS, supported by International HIV/AIDS Alliance, initiated a study in March 2002 on integration of HIV/AIDS interventions with community development initiatives. The study focused on the integration process and its impact on HIV/AIDS care and support interventions based on the experiences of the implementing NGOs and community responses, covered five NGOs from three districts. It aimed to identify, understand, and document the integration process and their impact on community based HIV/AIDS care and support interventions.

**Thematic and Sharing Meeting** This meeting enabled participants to provide counselling services to people living with HIV/AIDS, children affected with AIDS and families affected with AIDS; health and nutritional care; manage opportunistic infections, and an overview of the epidemiology of HIV/AIDS and the different types of tests available.  
March 25-27, 2002  
Kanyakumari  
**Facilitators:** Dr. Mohammed Usman, Kilpauk Medical College, Chennai.  
**Participants:** Project staff from INGOs.

**Selection of INGOs (Second Cycle)** In the 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 NGOs 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 NGOs were selected in April-May 2002: Anbalayam, Trichy; Imayam, Coimbatore; HEALDS, Namakkal; SSH, Dindigul; CARE, Erode; Gramium, Karur; NMCT, Coimbatore; and WORD, Namakkal.

**Sex and Sexuality workshop** Why is it important to understand the role of sex and sexuality in the context of HIV/AIDS? What are the prevalent sexual practices in the community? What are some of the common myths and misconceptions regarding sex and sexuality and how does one deal effectively with it? How does one enhance the ability to communicate effectively on sex-related issues and foster safer sexual practices in the community?  
April 29-May 1, 2002  
Madurai

**Facilitators:** Gunjan Sharma, Shakeen, and Sampath.

**Participants:** INGO staff.

**Counselling workshop** This workshop enabled participants to explore the concept and nature of the counselling process, the goals of counselling, the different methods of counselling, and the qualities of a successful counsellor. It also helped participants understand the importance of HIV/AIDS counseling and related issues such as confidentiality, pre and post test counselling, and informed consent.  
May 18-21, 2002  
Kanyakumari

**Facilitators:** Gladstone Xavier, Florina Mary, Anandi Yuvaraj, and Sunder Singh.

**Participants:** INGO staff

**Participatory Community Review** How does one involve the community in project-related discussions? What is the relevance of terms and concepts such as road maps, triangulation of stakeholders and the role of the review process in participatory community review?  
May 29-31, 2002  
Kanyakumari

**Facilitators:** Kevin Orr, Chulani de Zoysa, Anandi Yuvaraj, Edwin Sam, Sunder Singh, Sudheer, and Samuel Kumar.

**Participants:** INGO staff (two from each INGO).

**Preparation of Home Care Handbook** PWDS-Alliance, supported by International HIV/AIDS Alliance, and India Alliance, decided to publish a home care handbook in Tamil for people living with HIV/AIDS, families affected with AIDS, home care providers, and field staff based on local needs and the realities of home based care in rural South India. The home care handbook team consisted of Dr. Chandrasekar, Nandini Murali, Anandi Yuvaraj, KB Sudheer, and Sunder Singh. The handbook was completed in October 2002.

**Consultation meeting of caregivers** PWDS-Alliance conducted a consultation meeting of caregivers. June 20, 2002  
Madurai

The purpose was to generate information for a home care handbook in Tamil to enable caregivers provide better care for people living with HIV/AIDS, children affected with AIDS, and families affected with AIDS.

**Facilitators:** Anandi Yuvaraj, KB Sudheer, Sunder Singh, and Samuel Kumar

**Participants:** Volunteers and peer educators.

**PCR Review and Project Design workshop** This workshop enabled participants to recapitulate the concept of PCR and redesign the proposals of individual INGOs (2002-2003) based on the needs of people living with HIV/AIDS, children affected with AIDS, and families affected with AIDS. July 2-4, 2002  
Madurai

**Facilitators:** Chulani de Zoysa, Anandi Yuvaraj, and Edwin Sam.

**Participants:** INGO heads and coordinators.

**XIV International HIV/AIDS Conference** The theme of the conference was “Knowledge and commitment for action.” Some of the special features of the conference were the India Evening (attended by experts from the Government of India and the private sector, NGO functionaries, the health minister of India, Mr. Shatrugun Sinha, Meenakshi Ghosh, Director, NACO; and Mr. Christudoss Gandhi, Director, TNSACS), skill building workshops, and poster exhibits. Dr. Peter Piot, Executive Director, UNAIDS, presided over the opening ceremony. Mr. Nelson Mandela, former president of South Africa; and Bill Clinton, former American president, were the special guests during the closing ceremony. July 7-12, 2002  
Barcelona, Spain

Mr. A. J. Sunder Singh attended the conference and presented a poster on “Problems faced by children affected with AIDS in South Tamil Nadu.”

**Thematic and Sharing Meeting: Gender and HIV** What do the terms sex and gender mean? What is the difference? What is the role of gender as a cross cutting issue in community based care and support? What are some of the strategies to address gender issues? July 8-9, 2002  
Madurai

**Facilitators:** Daniel Daisy, Nandini Murali, and Edwin Sam.

**Participants:** Two staff representatives from each INGO and 18 volunteers from 13 INGOs.

**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. September 4-6, 2002  
Marthandam

**Participants:** Dr. Asha Rao, Country Director, Alliance India; Anandi Yuvaraj, Program Officer, Alliance India; Mona Mishra, Consultant, Alliance India; Joseph Yesudian, Secretary, PWDS; Mr. D.T. Reji Chandra, Director, PWDS; Aji Abraham Daniel, Coordinator, (Accounts and Administration) PWDS-Alliance; Edwin Sam, Senior Program Officer, PWDS-Alliance; Sunder Singh, Program Officer, PWDS-Alliance; K.B.Sudheer, Program Officer, PWDS-alliance; and Samuel Kumar, Program Officer, PWDS-Alliance.

**Care and Support workshop** What are the components of care and support? What are the psychosocial problems faced by people living with HIV/AIDS? What are the special features of treatment of opportunistic infection? What are the components of self-care? The workshop also looked at the needs of children affected with AIDS, documentation requirements in the context of HIV/AIDS and the experiences of the first cycle INGOs.

Sep 9-11, 2002  
Madurai

**Facilitators:** Dr. Chandrasekar, Sunder Singh, KB Sudheer, Samuel Kumar, Sylvester (from SEDCO, a first cycle INGO) and Senthil Kumar (from Seva Nilayam, a first cycle INGO).

**Participants:** Two staff from each second cycle INGO.

**Documentation and Communication workshop** This workshop explored the concept of documentation and communication and the special features of HIV/AIDS documentation and communication. Other aspects included target audience-specific communication, preparing a documentation and communication plan, skill building with reference to case study, reports, minutes and abstracts. The workshop concluded with a practical session on skill building.

Sep. 23-24, 2002  
Madurai

**Facilitators:** D.T. Reji Chandra, Nandini Murali, K.B.Sudheer, and Samuel Kumar.

**VCT workshop** What are the key elements of Voluntary Counseling and Testing (VCT)? What is its role in a community based care and support program? How do participants arrive at a shared model of VCT implementation in the context of CBCS? What are some of the legal and ethical issues with reference to people living with HIV/AIDS and children infected and affected with HIV/AIDS?

October 1-4, 2002  
Kanyakumari

**Facilitators:** Rebecca Mukasa and Sunder Singh

**Participants:** Coordinators and field staff /counsellor from care and support.

**Project Advisory Committee (PAC) Meeting** The first PAC meeting of the PWDS-Alliance Care and Support project was held at Hotel Germanus Days Inn, Madurai. Participants included Dr. Tokhuga Yepthomi, Medical Officer, YRG-CARE, Chennai; Sebastian Jayaraj, NGO Advisor, TNSACS; Anandi Yuvaraj, Program Officer, Alliance India; Dr. Saraswati Sarojini, Professor and Head, STD/HIV/AIDS, Government Rajaji Hospital, Madurai; Prof. P. Joseph Yesudian, Secretary, PWDS; Mr. D.T. Reji Chandra, Director, PWDS; Nandini Murali, Consultant, PWDS; Edwin Sam, Sunder Singh, KB Sudheer, Aji Abraham, and Samuel Kumar, PWDS-Alliance.

October 12, 2002  
Madurai

All participants expressed the need for a forum or coordination efforts beyond project frames and grant requirements. The PAC members identified the following key issues:

- How do we initiate a coordination/sharing forum among the different actors in the field such as implementing agencies, positive networks, and donor representatives?
- What are the strategies that could be applied to mobilise the community to demand for quality service including access to treatment as a right?
- How do we integrate different dimensions involved in the process of prevention, care and support?
- How do we identify and utilise the different strengths available with various actors instead of multiplication of efforts?

**Thematic and Sharing Meeting: Legal and ethical issues** What are the legal rights and ethical values in the context of HIV/AIDS? What are the legal and ethical practices in the Indian context? How does one undertake capacity building to face challenges related to HIV/AIDS legal rights and ethics?

October 21-22, 2002  
Madurai

**Participants:** Coordinators and field staff from each INGO.

**Facilitator:** R.W. Angeline Prebula, Legal Consultant, SIAAP, Chennai.

**Review and Replanning 2002** PWDS-Alliance and India Alliance conducted an R&R (Review of activities in 2002 and replanning for 2003). Dr. Asha Rao, Anandi Yuvaraj, and Mona Mishra represented Alliance India. 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 listed out the capacity building training required for INGOs.

October 23 26, 2002  
Madurai

The review of PWDS activities in 2002 was held on October 24. The director and secretary of PWDS and the project staff team held detailed discussions with the Alliance India team. The re-planning for 2003, based on the discussions on the preceding days. Mr. Bhaskara Menon, Administrator, Alliance India, was also present. Participants prepared the draft work plan and budget in a participatory manner. A consensus was reached to discuss these in the R&R meeting for Alliance India in November 2003.

**Resource mobilisation follow up meeting** Following the resource mobilisation workshop, the PWDS-Alliance care and support project team formed a committee consisting of Samuel Kumar, PWDS-Alliance; Sathu, Director, AIRD-V; and Dr. Tagore de rose, Director, Chevalier Trust; to initiate possible ways to mobilise resources. All 14 INGO heads agreed to join a forum for resource mobilisation and form a trust for this purpose. A sub committee consisting of Aji Abraham Daniel, PWDS-Alliance; Sunder Singh, PWDS-Alliance; Sushila Pandyan, CAST; Vijayaraman, Seva Nilayam; and A.Francis, Auditor, was formed to formulate trust rules, regulations and guidelines. The first meeting was held on March 27, 2002, followed by another on May 16, 2002.

**HIV/AIDS Resource Centre** PWDS-Alliance established an HIV/AIDS resource centre at DATA, Madurai. It stocks books, journals, and newsletters from different agencies working in HIV/AIDS such as UNAIDS, USAID-APAC, NACO, and YRG CARE.

**Capacity Building Training Accountants** This workshop enabled participants acquire an orientation on book keeping and accountancy, maintain records related to accounts, discuss financial reporting formulae, and orient them on laws relating to FCRA and IT.  
Nov. 15-16, 2002  
Madurai  
**Facilitators:** A. Francis, P. Arockiasamy, Aji Abraham, and Edwin Sam.  
**Participants:** Part time accountants from all 20 INGOs.

**India Alliance team visit** Mr. Bhaskara Menon, Administrator, India Alliance, visited PWDS office in Marthandam from October 3-5, 2002. The purpose was to provide technical support relating to finance and administration. Mr. Menon held detailed discussions with the project team on finance and administrative matters.

**International Alliance team visit** Dr. Sujith Gosh and Divya Bajpai from International Alliance visited some of the INGOs from November 6-7, 2002. The discussions centred on the following areas: Activities of the INGOs; role of staff; role of volunteers/peer educators; strategies adopted to address stigma and discrimination; experiences in working with children affected with AIDS; facilities available and strategies adopted for VCT; strategies for sustainability, and maintenance of records.

On November 8, the visitors had a meeting with the director, and secretary, PWDS; and the PWDS-Alliance care and support team.

**Sex and sexuality workshop** Why is it important to understand the role of sex and sexuality in the context of HIV/AIDS? What are the prevalent sexual practices in the community? What are some of the common myths and misconceptions regarding sex and sexuality and how does one deal effectively with it? How does one enhance the ability to communicate effectively on sex-related issues and foster safer sexual practices in the community?  
Nov. 20-22, 2002  
Coimbatore

**Facilitators** : R. Mathivanan, Dr. Chandrasekar, and Edwin Sam.

**Participants** : Coordinators and one field staff from each second cycle INGO.

**Counselling workshop** What is the role of counselling for people living with HIV/AIDS, families affected with AIDS and children affected with AIDS in a care and support program? What are the factors in effective counselling? How does one build the capacity for effective counselling and develop awareness of the specific counselling needs of children and evolve specific child-centred counselling strategies?

December 3-7, 2002  
Madurai

**Facilitators:** Dr. M. Kannan, and Mr. Guru Bharathy, Faculty, Madurai Institute of Social Sciences, and Mr. Sunder Singh.

**Participants:** Coordinators and one field staff from each second cycle INGO.

**National Thematic Meeting** India HIV/AIDS Alliance conducted a national thematic meeting and workshop on “Children Affected with AIDS .” 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.

December 16-19, 2002  
New Delhi

One representative from 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 program. The INGOs also presented posters and case studies on issues relating children affected with AIDS.

**External Relations Meeting** Twenty-seven participants attended the external relations meeting. Its objectives were to involve service organisations such as the Rotary and Lions Club in community based HIV/AIDS care and support; create a link between the government, NGOs, and institutional care organisations, an integration between the various development projects of the same NGO; integration with general health stream and the development sector; and networking of NGOs involved in HIV/AIDS.

December 28, 2002  
Madurai

A planning committee was formed consisting of Mr. Arulmoni, Resource and Development Manager, Meenakshi Mission Hospital and Research Centre (MMHRC), Mr. Vijayaraman (Seva Nilayam INGO representative); Ms. Sushila Pandyan (CAST INGO representative); Mr. Sunder Singh (PWDS-Alliance representative); Mr. Sebastian, NGO Advisor from TNSACS; Representative from APAC; Mr. Anburaj, MADITSIA; Mr. Raju, NSS Coordinator, Madurai; Dr. VN Rajasekaran, Physician, MMHRC; Dr. N. Krishnamurthy, Urologist (MMHRC) and Rotarian; and Mr. Thomas Varghese, DATA, Madurai.

## 3. Services

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The second phase of the PWDS-Alliance HIV/AIDS Care and Support project provided services to people living with HIV/AIDS and children affected with AIDS. This year the project reached 4,889 adults and children infected and affected by HIV/AIDS and offered direct care and support services and through referrals. The project provided direct services to 1213 people, 476 children, and 1852 families, Referral services were provided for 521 people, 132 children, and 594 families.

### Services provided to people living with HIV/AIDS

The PWDS-Alliance Care and Support project provided services to 3393 people living with HIV/AIDS in 13 districts of South Tamil Nadu. Of these 1363 adults were HIV infected and 2030 adults HIV affected. In the infected group, the number of men (682) and women (681) infected was almost equal. In the HIV affected group, the number of women affected (1070) was more than that of men (960).

Among the districts, Tirunelveli accounted for the highest reach of people living with HIV/AIDS and children affected with AIDS (777), followed by Madurai (667), Dindigul (642), Theni (579), Tuticorin (553), Kanyakumari (466), Virudhunagar (219), Coimbatore (210), Erode (206), Namakkal (182), Ramnad (139), Trichy (137), and Karur (112).

### DOCTORS WHO CARE

Radha (27) is an HIV widow. Her husband died of AIDS-related causes two years back. Her son is also HIV positive. Volunteers of the PWDS-Alliance care and support project supplied her with a medical kit. They also helped her to undergo referral treatment at CBH hospital.

Radha recalls, “I once visited the GH at Kuzhuthalai for medical treatment. The doctor concerned advised me to get admitted. When he came to know that I was HIV positive, he abused me and asked me to get out of the hospital. He even asked

me to get a certificate that I was HIV positive.” Naturally she was depressed when she met the CSR care and support team. They then spoke to the doctor who then realised the folly of not providing medical care based on prejudices about HIV when required. From then on he has always given me good medical help when required.

Radha cannot afford treatment at a private hospital. She is grateful to the care and support staff team for their support. She also says that thanks to HIV/AIDS awareness and sensitisation programs doctors are “humane and understanding and offer treatment and guidance whenever needed.”

**The project provided the following services to people living with HIV/AIDS :**

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

**Psychosocial Support**

The project provided psychosocial support such as counselling, home visits, spiritual support, facilitating formation of support groups of people living with HIV/AIDS, recreational facilities, meetings of family members, and barefoot counselling. The project provided direct counselling services to 1213 people living with HIV/AIDS, 1852 families affected with AIDS, and 476 children affected with AIDS. Referral services were provided for 521 people living with HIV/AIDS, 594 families affected with AIDS, and 132 children affected with AIDS.

**A CRUSADE FOR CHILDREN'S RIGHT TO EDUCATION**

Kala (30) is an HIV widow with a ten-year-old daughter and a nine-year-old son. Her husband died of AIDS-related causes six months back. After his death, Kala had to support her mother in law and her children. She works as a construction labourer and Rs. 30 she earns daily is insufficient to meet the needs of her family. She told the SRDPE staff that the only way she could lessen the economic burden would be to withdraw her children from school.

The SRDPE care and support staff met the principal of the school in which Kala's children were studying and explained her predicament. The principal, however, remarked that as there were many children from low income groups in the school, he could not show special concession to Kala's children. Despite the principal's initial unwillingness, and resistance in altering management policy, the SRDPE staff explained Kala's peculiar situation and her trying circumstances. The principal decided to give the children concession in books, school fees, and uniform in the current and subsequent academic years. Following the decision, both children were able to continue with their schooling.

**Advocacy by INGO staff for the rights of children affected with AIDS can make a BIG difference in the lives of such children by fostering attitudinal changes in the community.**

## Health Care Services

This includes prevention activities and their links to care provision such as training for people living with HIV/AIDS in self and nursing care; training for families affected with AIDS in nursing care; training for children affected with AIDS; supply of medical kits; supply of medicines; managing opportunistic infections; medical care; providing travel expenses for treatment; and home care services for people living with HIV/AIDS, children affected with AIDS, and their families. Direct services were provided for 1709 people living with HIV/AIDS and 566 children affected with AIDS. Referral services were provided for 1272 people living with HIV/AIDS and 558 children affected with AIDS.

## Voluntary Counselling and Testing (VCT)

The central features of VCT are that it is voluntary and confidential, and accompanied by pre and post test counseling. It helps people to come to terms with their HIV status and cope with complex emotions such as guilt, fear, self-blame, and to cope with a chronic condition such as HIV/AIDS.

## Food and nutritional support

This is important to prevent wasting and nutritional deficiencies one of the most adverse features of HIV infection. Food and nutritional support consists of nutrition demo, nutrition supplements, and promoting kitchen gardens. Direct services were provided to 1399 people living with HIV/AIDS, 1381

### HOME IS WHERE THE CARE IS

“I’m so happy now,” exclaims Kannan.

Kannan (12) is an HIV orphan and is HIV positive as well. Doctors initially advised his aunt and uncle who were looking after him to abandon him, but they were reluctant to do so. Today, Kannan, an intelligent boy of class seven, can even explain the treatment he undergoes for HIV.

The SEDCO care and support team interacted with Kannan and his uncle and aunt. They talked frankly with the adults and cleared many of their misgivings about the disease. They also spoke about the need for Kannan to live in a home where there was a lot of love and care. The team also provided information on caring for a child infected with HIV/AIDS, with emphasis on the importance of nutritious food, personal hygiene and medical treatment when necessary. Today Kannan enjoys the unconditional love and support of his uncle and aunt.

**Children affected with AIDS need an atmosphere of unconditional love and support provided in a family. Institutional care is not a substitute for home care.**

## Economic Support

Economic welfare and material support is a key component in a continuum of care and support. Economic support in the form of IGP activities linked with community development programs of INGOs are a promising solution to the need of people living with HIV/AIDS for a sustained source of income to meet the cost of treatment. The project provided direct services to 221 people living with HIV/AIDS, 319 children affected with AIDS, and 102 families affected with AIDS. Referral services were provided to 255 people living with HIV/AIDS and 194 families affected with AIDS.

## Emergency Relief

This includes funeral service support, and providing medical treatment and food. Direct services were provided to 219 people living with HIV/AIDS, 36 children affected with AIDS, and eight families affected with AIDS.

## Services provided to children affected with AIDS

The PWDS - Alliance Care and Support project provided services to 163 (91 males, 72 females) HIV infected children and 1133 HIV affected children in the 12 districts in south Tamil Nadu. While males (91) outnumbered females (72) in the infected group, females (691) outnumbered males (642) in the HIV affected group.

### NO MORE FEAR

“Prasad is now free of fear,” says Guruvammal, HIV/AIDS care and support staff, AIRD.

Prasad (12) studies in class seven in a government school. His mother is an HIV widow and his father died of AIDS-related causes six months back. The intelligent and perceptive boy began to learn about HIV/AIDS through wall posters, TV messages, and school text books all of which proclaimed in black and white, “AIDS is incurable. AIDS kills.” Naturally he began to relate it to his father's death and his mother's HIV positive status. Prasad was anxious and depressed and wondered if he would also lose his mother. The possibility of losing his mother made the child insecure.

When Guruvammal visited Prasad's mother at home, he asked her, “The wall posters say that people always die of AIDS. Will my mother also die like my father?” Guruvammal and the program coordinator provided him with psychological support to counter his feelings of fear and anxiety and enable him cope with being affected with AIDS with courage and hope. Today, a bright and cheerful Prasad continues going to school like any other child.

**Timely and appropriate psychological support to children affected with AIDS can make a world of difference in their lives.**

### **The range of services provided to children affected with AIDS include:**

- Psychosocial support
- Health care services
- Food and nutritional support
- Economic support
- Educational support
- Capacity building activities

A combination of institution based services, community based organisations, and the government services in care and support activities, improve the quality of services and covers a wider area. Community participation, self-care and referral service were encouraged. Affected people were enabled to access existing government and institutional services. Collaborative efforts were also initiated wherever possible to strengthen existing services.

The involvement of self-help groups in care giving and the initiative to integrate HIV care interventions with community development initiatives provided sustained services in economic, health care, nutritional and psychological aspects.

#### **AN ACT OF LOVE**

Twelve-year-old Shakila is an HIV orphan who lives with her disabled grandmother. Her parents, brother, and sister died of AIDS-related causes. Shakila's relatives are fearful of adopting her, as they believe she could infect the other members of the household. The lonely and depressed child longed for the comfort and security of her parents. She was also disinterested in school.

The SEDCO staff began to initiate the care and support project in Shakila's village. The team imparted training in community care and support to SHGs in the village. In an inspirational show of care and support, two SHG members volunteered to adopt Shakila. Today, Shakila is another child to them, no different from their birth children. She loves being with her new 'family', enjoying the love of her 'parents', and her 'brothers' and 'sisters'. Today a happy Shakila is rediscovering the pleasures of childhood such as going to school and playing with her peers. However, the precocious and sensitive girl is also particular about her right to inherit the house that belonged to her birth parents. "It should come to me. It should not go to anyone else," she declares. As for Shakila's adoptive parents, they remark, "Shakila is not an orphan. She is another daughter to us."

**Such positive community responses can make a BIG difference in the lives of children affected by AIDS.**

**PWDS - Alliance HIV/AIDS Care and Support Project  
Reach Through The Integration Process**

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

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





**Reach as on December 2002**

Districts	HIV infected			HIV affected			Grand Total						
	Adults		Children	Adults		Children							
	Male	Female	Total	Male	Female	Total							
Kanyakumari	40	70	110	17	23	40	77	116	193	52	71	123	466
Tirunelveli	114	109	223	13	7	20	99	148	247	143	144	287	777
Tuticorin	83	86	169	11	11	22	124	116	240	52	70	122	553
Ramnad	20	23	43	1	1	2	17	27	44	19	31	50	139
Madurai	77	80	157	10	7	17	186	159	345	85	63	148	667
Virudhunagar	41	26	67	1	2	3	36	42	78	34	37	71	219
Theni	129	92	221	13	9	22	61	105	166	80	90	170	579
Dindigul	72	45	117	7	3	10	216	188	404	53	58	111	642
erode	29	35	64	0	0	0	41	47	88	25	29	54	206
Coimbatore	28	31	59	6	2	8	33	43	76	31	36	67	210
Namakkal	15	35	50	8	6	14	33	36	69	26	23	49	182
Karur	7	19	26	0	0	0	16	26	42	23	21	44	112
Trichy	27	30	57	4	1	5	21	17	38	19	18	37	137
<b>Total</b>	<b>682</b>	<b>681</b>	<b>1363</b>	<b>91</b>	<b>72</b>	<b>163</b>	<b>960</b>	<b>1070</b>	<b>2030</b>	<b>642</b>	<b>691</b>	<b>1333</b>	<b>4889</b>

**PWDS-ALLIANCE HIV/AIDS Community Based Care & Support Project, Tamil Nadu**

**Beneficiaries Reached Through Direct Services**

Name of INGO	People		Families		Adults		Children		Grand Total
	Male	Female	Male	Female	Male	Female	Male	Female	
CBH	20	41	27	54	47	95	32	41	215
CSR	20	29	50	62	70	91	37	53	251
CAST	39	41	45	60	84	101	63	55	303
AIRD-V	43	35	39	72	82	107	50	59	298
RED	32	33	15	16	47	49	43	37	176
SEDCO	19	24	26	42	45	66	16	28	155
CHEVALIAR	64	62	98	74	162	136	47	53	398
BLOSSON	41	26	36	42	77	68	35	39	219
AIRD-R	20	23	17	27	37	50	20	32	139
PACHE	35	37	150	114	185	151	49	43	428
SEVA	69	35	38	66	107	101	61	55	324
SRDPE	60	57	23	39	83	96	32	44	255
SSH	22	10	57	68	79	78	27	30	214
ANBALAYAM	27	30	21	17	48	47	23	19	137
GRAMIUM	7	19	16	26	23	45	23	21	112
HEALDS	11	27	24	15	35	42	12	9	98
WORD	4	8	9	21	13	29	22	20	84
CARE	29	35	41	47	70	82	25	29	206
IMAYAM	16	16	12	18	28	34	18	18	98
NMCT	12	15	21	25	33	40	19	20	112
ARULAGAM (2002)	50	35	159	120	209	155	33	31	428
ARD (2002)	44	41	36	45	80	86	46	27	239
<b>TOTAL</b>	<b>684</b>	<b>679</b>	<b>960</b>	<b>1070</b>	<b>1644</b>	<b>1749</b>	<b>733</b>	<b>763</b>	<b>4889</b>

## 4. Issues and Interventions

The PWDS-Alliance HIV/AIDS community based care and support project reaches out to affected people, families, women and children in low income groups in around 1053 villages in 60 blocks and 300 panchayats spread over 13 districts of Middle and South Tamil Nadu. While each of these groups has special needs and concerns, they nevertheless share a certain commonality in that they all suffer the direct and indirect impact of HIV/AIDS on their lives. Poverty, low literacy rate, gender inequalities, inadequate health care facilities, poor health-seeking behaviour among the rural people, especially women and girls, and ignorance about the nature of the disease is a dangerous combination that fuels the spread of the disease and its impact on the affected families in the project area.

**The human dimensions of HIV/AIDS** People are the epicentre of the HIV/AIDS epidemic. The poor, especially poor women and children, are most vulnerable. The impact of HIV/AIDS whether on individuals, families or society, is ultimately a human impact. In recent years, there has been a growing realisation that HIV/AIDS is not purely a health issue but has significant development implications that needs to be addressed with a development agenda. Majority of people with HIV/AIDS live in low income countries. Women and young girls are physiologically vulnerable to heterosexual transmission of infection.

Interaction with INGO staff, and people living with HIV/AIDS in the project area revealed that most men and women who were infected/affected were between 20-35 years. Thus with its targeted assault on the working population who play important economic and social roles in family and society, HIV/AIDS saps human resources and intensifies poverty and hardship.

### BACK TO SCHOOL

Pradeesh (15) would often play cricket with his friends in school. Some time back he quit school. An anguished Pradeesh told the CSR staff, “My father died due to AIDS. The school authorities feel that if I continue to study, the other children too would be infected. They didn't want me to come to school.” The CSR care and support team met the headmaster of Pradeesh's school. He frankly told them that the other children were fearful of Pradeesh as he might transmit HIV to them. Besides as Pradeesh was a risk to school's reputation and prestige, he had no other option but to dismiss the boy.

The CSR staff team educated the headmaster about HIV/AIDS and how it affects the lives of people. They also pointed out that although Pradeesh's father had died of AIDS, the boy was not infected. The headmaster was finally convinced. The headmaster agreed to readmit the boy, but his mother was unwilling to send him to school because of economic difficulties. Pradeesh, however, was keen on going back to school. The staff team talked to his mother about the importance of schooling for the boy. After a lot of resistance, both his mother and the headmaster agreed to let him go to school. The headmaster, admitted him in school without paying the school development fund.

Today a happy Pradeesh can once more be seen playing cricket with his friends in school.

**Sensitise school authorities to the rights of children affected with AIDS, especially to that of normal schooling.**

**Stigma and discrimination** People living with HIV/AIDS, whether adult men, women, or children, are subject to widespread stigma and discrimination in the family, society, and in health care settings. Interaction with people living with HIV/AIDS, and INGO staff revealed that the common forms of discrimination towards people living with HIV/AIDS in families are antagonism, hostility, and refusal to interact with the infected family member(s). Besides families often forced them to live away from the other members (as in an outhouse) and subjected them to degrading practices such as forcing them to eat from utensils especially earmarked for them. Other common discriminatory practices were depriving the wives of inheritance rights (property grabbing), coercing the wives to undergo testing for HIV, and starving the wives and children. In some instances, the husband's family, fearful of the wife's refusal to play the role of a caregiver, withheld a HIV positive result from her. The most common form of discrimination was families blaming the wife of an infected husband for being the source of infection and forcing her to leave. Families also forbid the other children in the family from playing with children of people living with HIV/AIDS.

The discrimination in society ranged from adverse publicity about HIV status such as word-of-mouth publicity, and boycott of business run by such people, and a high incidence of school dropouts in children either infected or affected.

### **“AUNTY, PLEASE BRING MY UNCLE HOME!”**

Seven-year-old Akhil is an HIV orphan. Both his parents died of AIDS-related causes recently. Akhil, however, tested negative for HIV. As Akhil had no other relatives, his maternal aunt Rajam (his mother's sister) decided to bring him up along with her two children.

Rajam's husband Raju, however, resented Akhil's presence, as he believed that he would infect the other members of the family. Therefore he asked his wife to send Akhil out. Despite his insistence Rajam refused to do so. This led to tensions and conflict in the family with quarrels and arguments between the couple a daily feature. The sensitive child realised that he was the source of the domestic discord. Feeling helpless and lonely, Akhil would stand before his parents' photo and cry. In a fit of anger, Raju deserted the family.

The CSR care and support staff visited Akhil's home. Rajam talked to them in a frank and forthright manner about her love for Nikhil and the resulting conflict with her husband. A desperate Nikhil hugged one of the staff members and cried, “Aunty, please bring my uncle home.” She reassured him that she would do so. The CSR team counselled Rajam about the need to contact her husband. After much hesitation and unwillingness, Raju agreed to meet the staff team. The staff talked to him about HIV/AIDS the nature of the disease, modes of transmission and how it affects the lives of people. In the process, they tried to clear many of his misgivings and fears about the disease. The staff also told him that although Akhil's parents were infected, the child was not.

Raju realised the vulnerability of the child in such a situation. He began to reach out to Akhil without any of the earlier reserve. He now says, “I have three children, and Akhil is one of them.” As for Akhil he is happy to have found a loving family.

**Sensitise all members of the family on HIV/AIDS issues before adopting an HIV orphan.**

In health care settings, stigma and discriminatory practices targeted at people living with HIV/AIDS is a double-edged sword, as it leads to denial of treatment and isolation of people living with HIV/AIDS. This in turn also leads to unwillingness of people living with HIV/AIDS to reveal their status that contributes to rising infection rates and delay in accessing treatment. People living with HIV/AIDS also face problems when they try to access treatment from private doctors. Many of these doctors are unwilling to treat them for fear of being branded as “AIDS Doctors” which could drive away other patients.

**Migration and the risk of HIV/AIDS** In an ESRM Meeting, INGO staff remarked that poverty and unemployment in the project area led to rampant population migration in search of livelihood opportunities. The men were migrant laborers who worked in Mumbai, truckers, or itinerant merchants. Most often, they returned to marry and either took their wives back or as is common in the project area, the wives stayed behind. Shortly before marriage or thereafter, the men acquired the infection and transmitted it to their wives. Thus migration is a leading cause for the high rate of infection in the project area.

Families in the project area, fearing stigma and discrimination, are forced to migrate when faced with a HIV positive status. Thus we have a situation where migration leads to rising infection rates, and concomitantly, spiralling infection forces families to migrate.

## THE RIGHT TO A QUALITY OF LIFE

Three-year-old Monisha and her parents lived in Mumbai. They were a happy family until her first birthday. Monisha often became ill with fever and diarrhea. Her father also began to develop symptoms such as unexplained weight loss and fever. He tested positive for HIV and so did his wife and child. The family, dejected and feeling hopeless, decided to return to Ramnad, their hometown.

The AIRD care and support staff team, on hearing their story, visited them at home. They were disturbed to find that although Monisha was suffering from severe diarrhea, her parents did not know how to care for her. The staff team then counselled the parents about the importance of medical treatment for the child. The AIRD support made a lot of difference to the family...

Meanwhile Monisha's father died of AIDS-related causes. Monisha's health began to deteriorate. To make matters worse, social customs and traditions following the husband's death, prevented the mother from seeking medical treatment for the child. The AIRD team talked to the family about the importance of timely medical treatment that could save Monisha.

Thanks to the initiative of the grandmother, Monisha was admitted for treatment in Tirunelveli Medical College. Today Monisha's health is a lot better. Her mother too has come to terms in coping with the challenges of being a person living with HIV/AIDS.

**It is important for family members to be aware of the need to provide appropriate timely medical help for people living with HIV/AIDS. This can improve their quality of life.**

**Poverty, illiteracy and gender** Most people living with HIV/AIDS are trapped in a vicious cycle of poverty, illiteracy and ignorance about the disease. While both men and women living with HIV/AIDS face stigma and discrimination in society, women face “double discrimination” because of their gender and the nature of the disease. Gender inequalities and an environment of exclusion where women and young girls are marginalised and denied choices and opportunities fuel the spread of the disease. INGO staff remarked that people in the project area, especially women and children, generally exhibit poor health-seeking behavior. When infected, the resulting opportunistic diseases, together with such negative health seeking behaviour, adds to the hardship and suffering. The problem is worsened by poor nutrition that renders them vulnerable to infection, lack of health care amenities such as local testing centres, and easy accessibility to treatment and care, and non-acceptance by health care providers for various reasons.

**HIV/AIDS and the health care system** The disease also has far reaching impacts on the health care system. As the disease mounts, there is an increased demand for treatment and care that cause additional stress on an already overburdened health care system. The shortage of beds implies that most people living with HIV/AIDS are forced to wait for their turn to get admitted. Thus late admission and the non availability or irregular supply of essential drugs endangers their already fragile chances of early recovery. The situation is compounded by the presence of opportunistic infections such as TB that requires additional resources to tackle. Lack of nutritional support and poor environmental condition worsens an already grim scenario.

**HIV/AIDS and the family** HIV/AIDS makes inroads into families and households widely regarded as the “first safety net of society.” The grounding of family bread winners whether due to sickness or death results in many families being reduced to poverty. In most poor rural households in Middle and South. Tamil Nadu, the disease results in chronic indebtedness. Interaction with INGO staff, people living with HIV/AIDS, and affected families revealed that families often sell available resources such as land and livestock, borrow from moneylenders at exorbitant rates of interest or pawn the wife's jewelry to meet expenses related to care, funerals, and to ensure a minimal standard of living. In such cases, the descent from relative well being to abject poverty is rapid.

**Women as caregivers** Women are faced with the disproportionate burden of coping with the disease. In the wake of the loss of the male breadwinner, women bear the brunt of economic responsibility and female-headed households are common among affected families. In the

project area, it is common to find a disproportionate number of HIV widows between 20-30 years. These semi-literate women are either jobless or employed in low paying jobs such as seasonal agricultural labour. They are forced to take on multiple roles such as income earning labour, household maintenance, childcare, and nursing. Women are particularly disadvantaged in these roles because most often they are denied access to productive resources such as land, credit, knowledge, skills, and technology. Most women revealed that their families were hostile and antagonistic to them when the husband's HIV positive status was confirmed for they held that the women were the source of infection. Break up in the family structure due to divorce/separation, loss of jobs, and remarriage of either spouse were other common reactions women had to cope with.

**Paediatric face of HIV/AIDS** While women and men face numerous problems relating to everyday life, the paediatric face of HIV/AIDS poses special challenges. According to a UNAIDS estimate (2002) there are nearly there are 11.8 million children and young people living with HIV/AIDS.

There are four distinct groups of children affected with AIDS:

- **Orphans** HIV negative children whose parents have died of AIDS.
- **Semi Orphans** HIV negative children whose mother/father have died of AIDS.
- **Infected Children** Children of HIV positive parents who are also HIV positive.
- **Affected Children** HIV negative children whose parents or either parent is HIV positive.

### **Children at risk**

Children affected with HIV/AIDS face rampant stigma and discrimination in the family, among relatives, in the community, in school, and in healthcare settings. In an Experience Sharing Review Meeting (ESRM), INGO staff observed that children affected with HIV/AIDS are psychologically and emotionally vulnerable and face considerable psychological stress. The pain and suffering of the infected parents (s) and their subsequent death is often a traumatic experience for the children. The distress is worsened by the fact that often these children are confused by happenings at home and have no source of support to turn to. The trauma is compounded by feelings of isolation, hopelessness, anger, confusion, depression and anxiety about their future. Interaction with several children affected with HIV/AIDS revealed confusion, low self-esteem, guilt, and a fatalistic attitude towards life.

## **Migration**

Children affected with HIV/AIDS are frequently subject to the stress and strains of dislocation as their families are forced to migrate when faced with a HIV positive status. The process of relocation is seldom pleasant or even successful due to their already fragile psychological health.

## **Malnutrition**

The impact of HIV/AIDS on children and families is compounded by the circumstances of people's lives. Most families in the project area live in communities disadvantaged by poverty, inadequate infrastructure, and limited access to resources and services. For children affected with HIV/AIDS, a compromised nutritional status is a harsh reality. Children from families where adult(s) are infected, face the risk of starvation and malnutrition due to lack of steady family income. In some instances, even children in families not infected with HIV bear the brunt when cousins from infected families come to live with them following parental death. This puts an additional strain on the family's finances.

## **Child headed households**

Children feel the impact of the disease even before they are orphaned. In many instances, once the parent begins to fall ill, children have to shoulder domestic responsibilities. They have to undertake a greater share of domestic chores, care for sick parents, look after the younger siblings and become involved in income generating activities. Thus it is common to find child-headed households. Some adolescent children affected with HIV/AIDS, unable to cope, often run away from home. They fall prey to antisocial gangs, or lured into child prostitution.

## **School dropouts**

According to INGO staff, children affected with HIV/AIDS often drop out of school for various reasons. These include stigma and discriminatory attitudes of school authorities and other children, and the increased domestic workload and economic responsibilities thrust on these children. In many instances, adults at home decide that children should discontinue schooling to take on the role of caregivers at home. This is particularly so with girls.

## **Property grabbing**

Children affected with HIV/AIDS are often subject to loss of inheritance and “property grabbing” by relatives who refuse to acknowledge their claim to legal rights.

## 5. Way forward

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

*- INGO staff*

HIV/AIDS is a new challenge. Therefore sustained active interventions with the joint effort of all players are 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. Therefore these experiences 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 living with HIV/AIDS to form collectives or networks, and networks of NGOs who work in HIV and community development.

The integration of HIV/AIDS concerns with community development programmes as one of the components cuts across all sectors of intervention, 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 community based organisations, integrating health care needs of affected people with mainstream health care providers, and integrating HIV/AIDS interventions with community development initiatives reduce stigma, facilitate acceptance, promote care and support, and thereby effect prevention and control. In addition, this strategy helps to mainstream and sustain program initiatives beyond the project frame and time.

It is essential to work with reliable and competent partners, with space for experimentation and innovation within the project frame. Confidence in partners' reliability and implementing ability seem to be more important than the monitoring of strict adherence to the planned and agreed upon project frame and activities. People interact in specific contexts. They are aware of what is available, they know what works. So learning from community responses, working with them, and starting from what is there seems to be the best approach.

Stigma and discrimination is a serious issue that prevents control, care, and support. While it is a cause for concern, there are also several positive responses from the community towards people living with HIV/AIDS. A supportive community facilitates the ability of people living with HIV/AIDS to cope with the challenges of living. Instead of merely focusing on negatives, a potential option would be to identify positive responses of the people, recognise them, strengthen and replicate such experiences in scale.

Although the potential of SHG integration of affected /infected people appears to be a charity/welfare approach, is in reality an effective intervention for integrating people living with HIV/AIDS into the community for acceptance and productive living. This exemplifies GIPA (Greater Involvement of people living with HIV/AIDS) in a life context and extends the principle beyond the project frame. Such an approach implies greater participation of people living with HIV/AIDS and family affected with AIDS that transcend project limitations and move towards greater involvement for meaningful living and productivity.

Improving mainstream services, establishing linkages, promoting NGO and people living with HIV/AIDS networks for collective functioning, and enabling the community for appropriate responses through integration initiatives seems to be the agenda for the future.

## 6. INGO Profiles

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### 1. AIRD - R

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**Association for Integrated Rural Development, Ramanathapuram** : Operates in Ramnad and Tuticorin districts. The organisation is involved in a range of comprehensive development activities such as promotion of SHGs, training, linkages, enterprise promotion, community preschools, school enrollment and elimination of drop outs, children's clubs, herbal gardens, awareness programmes, and HIV/AIDS care and support.

### 2. AIRD - V

**Mr. V. Sathu, Secretary**

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**Association for Integrated Rural Development, Valiyoor** : Operates in Tirunelveli district. Its activities include reproductive and child health program, total sanitation, and HIV/AIDS care and support.

### 3. BLOSSOM

**Mrs. Mercy Annapoorni, Managing Trustee**

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Virudhunagar - 626 001

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**Blossom** : Operates in Virudhunagar district. It works towards the development of the rural and urban poor, especially women and children. Its programmes include RCH, family counseling, rural creches, microcredit, IGP, awareness programs, vocational training, and HIV/AIDS care and support.

### 4. CARE

**Mr. Charles Prabhu, Director**

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**Centre for Action and Rural Education** : CARE operates in Erode district. Its activities include day care centres for rural children, maternal and child health, supplementary nutrition, mobile medicare for the aged, family counseling, IGP, *mahalir thittam*, HIV/AIDS awareness, prevention and control, HIV/AIDS care and support.

### 5. ANBALAYAM

**Mr. P. Senthil Kumar, Chief Functionary**

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**Anbalayam** : Operates in Trichy district. Its activities include STD/HIV/AIDS prevention and control and care and support.

## **6. CAST**

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## **9. Gramiyum**

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**Community Action for Social Transformation :** Operates in 167 villages in Tirunelveli district. It works towards the empowerment of women and children with an integrated development approach. The major programs include integrated education program on water and sanitation, STD/HIV/AIDS intervention for Women in Prostitution (WIP), HIV/AIDS care and support, RCH education for adolescent girls and rural women, DANIDA comprehensive watershed development project, wasteland development project (DRDA), networking and advocacy, gender issues, and promoting herbal medicinal practices among rural communities.

Operates in Tuticorin district. Its major activities include child labour eradication, health and environmental awareness, STD/HIV/AIDS prevention and control, HIV/AIDS intervention, prevention and control, HIV/AIDS care and support, and paramedical training.

**Centre for Social Reconstruction :** Operates in Tuticorin and Kanyakumari districts. Its activities include community organisation, women and child development, skill promotion among rural artisans, promotion of SHGs and micro credit management, eradication of child labour, capacity building of NGOs, STD/HIVAIDS prevention and control, and care and support services.

**Gramiyum :** Operates in Karur district. Its activities include savings and micro credit, IGP, maternal and child health, vocational training, nonformal and supplementary education, legal aid camps, HIV/AIDS awareness, and care and support.

## **10. HEALDS**

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## **12. NMCT**

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## **13. PACHE Trust**

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## **14. RED**

**Mr. T. Muthunayagam, Director**  
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## **Health and Education Alternative Development**

**Services** : Operates in Namakkal district. Its activities include Reproductive and Child Health (RCH) Program, SHG formation, good governance of panchayat raj, empowering elected women panchayat leaders, attracting more women to participate in the panchayat raj process, and entrepreneurship development training. It also implements HIV/AIDS prevention and control and care and support programs.

## **Imayam Social Welfare Organisation**

**Imayam Social Welfare Organisation** : Operates in Coimbatore district. Its activities include women's development programs, SHG formation, HIV/AIDS prevention and control, care and support.

## **Native Medicare Charitable Trust (NMCT)**

**Native Medicare Charitable Trust (NMCT)**: Operates in Coimbatore district. Implements a community based HIV/AIDS care and support project.

## **People's Association for Community Health Education**

**Trust**: Operates in Madurai district. Its major activities include community based activities, non formal education, health camps, awareness campaigns, distribution of condoms, educational programs for women on STD/HIV/AIDS and care and support.

## **Rural Education for Development (RED)**

**Rural Education for Development (RED)**: Operates in 93 villages in Tirunelveli district. Its programs include community preschool education, community health, SHG formation, micro credit, community based enterprises, self-employment training, community based care and support, and eradication of child labour. RED works with children, women, rural artisans, dalits, people living with HIV/AIDS, children affected with AIDS and families affected with AIDS.

### 15. CBH

#### **Major P. Sudhanantha Das, Administrator**

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### 16. SEDCO

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### 17. Seva Nilayam Society

#### **Mr. A. Vijayaraman, Director**

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### 18. SRDPE

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### 19. SSH

#### **Mr. A. Britto Selvaraj, Secretary**

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### 20. WORD

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### **The Salvation Army Catherine Booth Hospital (CBH):**

Operates in Kanyakumari district. CBH provides community health services and conducts training programs for nursing and allied health professionals. Its range of programs include health education, community development, school health programs, IG programs, RCH, rural women's empowerment, VCT cum STD intervention, HIV/AIDS awareness and HIV/AIDS care and support.

### **Scientific Educational Development for Community**

**Organisation :** Operates in Theni district. It works with women, youth, rural artisans, children, and dalits. Its programs include women's empowerment, entrepreneurship development, HIV/AIDS prevention and control, and HIV/AIDS care and support.

### **Seva Nilayam Society in association with Ryder Cheshire**

**Foundation :** Operates in Theni district. Its main activities include community based primary health care, integrated medical services, RCH, IEC activities and STI care program, community based integrated mother and child health, family welfare and STD/HIV/AIDS program, water and sanitation project, networking, and women development programs.

### **Society for Rural Development and Protection of**

**Environment :** Operates in Theni district. Its main activities focus on areas such as health, gender, social and economic upliftment. Its activities include socioeconomic development activities, community health, self-reliance programs for women, and community organisation.

### **Society for Serving Humanity :**

Operates in Dindigul District. The main activities include rural development services, food security program, non-formal education, medical care for dropout and street children, and integrated sustainable agriculture. AIDS awareness among Tannery workers funded by APAC and Targeted intervention program among industrial workers TNSACS

### **Women's Organisation in Rural Development :**

Operates in Namakkal district. Its major activities include vocational and skill training for working children, environmental awareness, RCH, reproductive health and rights, women's empowerment, entrepreneurial development program for women, disability rehabilitation, HIV/AIDS awareness, intervention, counselling, care and support services.

The epidemic is becoming generalized in many parts of the region, and focused public action that goes beyond a purely medical or communicable disease approach is needed to tackle it. HIV/AIDS has a major impact on human development attainments, especially of the poor and marginalised communities / groups, including women. At the micro level, it has a significant impact on individuals, households and firms. Till now, the macro-economic impact of the epidemic in South Asia has been relatively low compared to the situation in sub Saharan Africa. However, sine the structural determinants of HIV prevalence such as high levels of poverty, migration, illiteracy, ill-health, gender inequality and urbanisation are widely present in South Asia, the region can ill-afford to wait for a full-blown crisis. The mutually reinforcing relationship between HIV and human deprivation in South Asia needs to be brought at the centre of all efforts to combat the epidemic.

Source : HIV/AIDS and Development in South Asia 2003 - UNDP