GOOD PRACTICES

In Facilitating Access to Care and Treatment

A Study of District Level Networks for People Living with HIV/AIDS

POPULATION FOUNDATION OF INDIA

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Table of Contents

Acknowledgments

Population Foundation of India is indeed grateful to the PLHA who had expressed their views without any hesitation. PFI gratefully acknowledges the immense support received from all the District and State Level Networks of people living with HIV/AIDS and Indian Network for people living with HIV/AIDS. It is needless to say that without useful comments and insights by INP+; this report would not have taken a good shape. PFI is thankful to SAATHII for undertaking this study and acknowledges its impressive efforts of meeting the stakeholders and beneficiaries determinedly.

Prelude

Population Foundation of India is implementing the project "Access to Care and Treatment" in six HIV high prevalence states in India funded by The Global Fund To Fight AIDS, Tuberculosis and Malaria under Round 4 grant. The year 1 programme evaluation had identified good practices carried out by the district level networks that are worth of documenting and make available for wider dissemination. Acting on this recommendation, PFI commissioned this study to *Solidarity and Action Against The HIV Infection in India* (SAATHII) for documenting the good practices by the district level networks of people living with HIV/AIDS.

Hope this document would be of significant use to networks of people living with HIV/AIDS across the country and to Managers implementing care and support programmes.

1 Background and Context

The Population Foundation of India (PFI) is one of the Principal Recipients of the Global Fund grant (R4) for the programme **Access to Care and Treatment** that offers care and support services to PLHA. The programme focuses on setting up and strengthening district level networks for People Living with HIV/AIDS (PLHA) called as District Level Networks (DLNs), Treatment Counselling Centres (TCCs), Positive Living Centres (PLCs) and Comprehensive Care & Support Centres (CCSCs), advocacy with corporate sector for setting up ART Centres at corporate health facilities, build the capacity of programme functionaries and conduct special studies.

INP+ is engaged in providing treatment education, counselling, ongoing care and support and follow up services for people living with HIV/AIDS – including those receiving anti-retroviral treatment from the ART Centres established in the six high HIV prevalence states through:

- District Level Networks for care and support services.
- Treatment Counselling Centres located at public sector ART Centres to provide treatment education, counselling and linking PLHA to DLNs for follow up, care and support services and promoting treatment adherence.
- Positive Living Centres for care and support services including opportunistic infections management.

DLNs serve the purpose of empowering people living with HIV (PLHA), identifying their needs, helping them access treatment and services, exercise their rights, evolve solutions and provide an enabling environment. The TCCs have been set up at the government anti-retroviral therapy (ART) Centres in the six high prevalence states, and provide supplementary services such as adherence counselling and link to other care and support services.

Many DLNs and TCCs established by the ACT project have provided appropriate and timely solutions to the problems experienced by PLHA. Many have evolved innovative good practices within the existing system. Such practices are essential for the long-term sustainability of the programme, for catalysing decentralised HIV/AIDS responses and to enhance the continuum of care and support beyond ART provision.

Based on field visits, PFI and INP+ identified 23 District Level Networks (seven in Andhra Pradesh, five in Maharashtra, six in Tamil Nadu, three in Karnataka and two in Manipur) and two Treatment Counselling Centres in Tamil Nadu

as having evolved good practices that could serve as models for replication and scaling-up. In July 2006, PFI appointed *Solidarity and Action Against The HIV Infection in India* (SAATHII) to document the good practices (including those previously identified and those identified during the field work) based on evidence generated from the organisations, their beneficiaries and external stakeholders, using qualitative research techniques.

2 Goals

The goals of this study were to document and analyse good practices of DLNs in five states of high HIV prevalence, share this information with other stakeholders, and promote cross-learning across district/states.

The following specific questions were addressed:

1. What are some of the correlates of good practices in district-level networks of PLHA and treatment counselling centres?

2. What recommendations can be made for future initiatives to initiate and/or strengthen the technical capacity of such institutions?

3 Definitions and Criteria

3.1 Access to Care and Treatment

Access to care and treatment is defined to include all those ways in which PLHA are enabled to receive quality care and treatment when they need. Care and treatment broadly encompasses diagnosis, treatment (ART, OI prophylaxis and management), referrals and follow-up, nursing, counselling and palliative care, as well as support to meet economic, social, legal, psychological and spiritual needs. (UNAIDS 2003, MAAS-CHRD 2006).

3.2 Good Practices

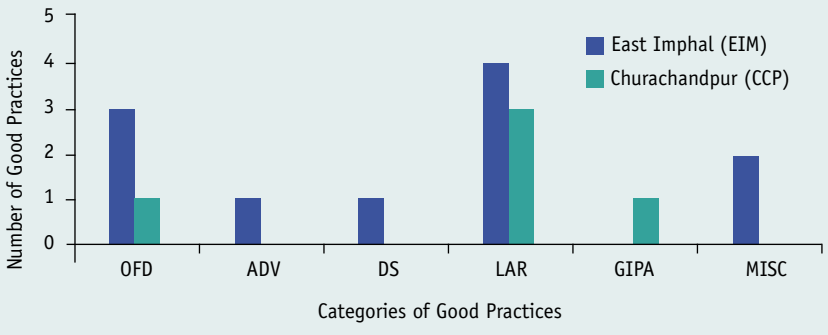
The concepts of good practices, promising practices, and best practices have been borrowed from the business sector and have now permeated in the fields of science, technology, development and industry. These terms have lately also been adopted in the arena of public health:

Best practice: "[It] is a practice that upon rigorous evaluation, demonstrates success, has had an impact, and can be replicated."

Good practices and promising practices: "These … are … practices or approaches that have not been evaluated as rigorously as 'best practices', but that still offer ideas about what works best in a given situation." (INFO)

In the HIV/AIDS arena, the Joint United Nations Program on HIV/AIDS, uses the term 'best practice' to refer to the accumulation and application of knowledge about what is working and not working in HIV prevention, education, treatment and care, in different situations and contexts. *(UNAIDS)*

Figure 1: Manipur District Level Networks – Categorisation of Good Practices



In a more conservative approach, UNESCO adopts the term "good practice" to refer to an "approach, frequently innovative, tested and appraised, which points to its success in other contexts. A good practice is the innovation that makes it possible to improve the present and therefore intends – or can intend – to be a model or a standard in a given system." (UNESCO)

For the purpose of this study, the following working definition of good practice was used:
A good practice is a programme, strategy or activity undertaken by the DLN or TCC that has demonstrated a direct role in improving access to care, support and treatment, in improving organisational function and sustainability and/or in decentralisation of services to PLHA.

3.3 Criteria for Selection

For this project, good practices were selected in two ways: (i) Previous identification by PFI and INP+ during their field visits, and (ii) A subset of those that were identified by SAATHII, in consultation with PFI.

Once the list of good practices emerged, several were selected for follow-up and analysis. These included good practices based on the following criteria:

a. They went beyond merely carrying out funders' mandates.

b. They suggested potential for replication and scaling up in other districts.

c. They could be substantiated by triangulation of evidence.

4 Methods and Activities

The study was qualitative in nature, and involved the following key activities and methods.

4.1 Desk Research

In July and August 2006, SAATHII's team consisting of the team-lead and programme managers reviewed the preliminary list of good practices identified by PFI/INP+, and examined previous collections of good practices (e.g. UNAIDS 2000) and documentation methodologies (e.g. CCF 2006).

4.2 Data Collection and Validation

Data on good practices were validated in three ways:

- Focus group discussions (audio-recorded with informed consent)
- Individual and joint in-depth interviews (audio recorded with informed consent)
- Collection of additional evidence (documents, press-clippings, etc.)

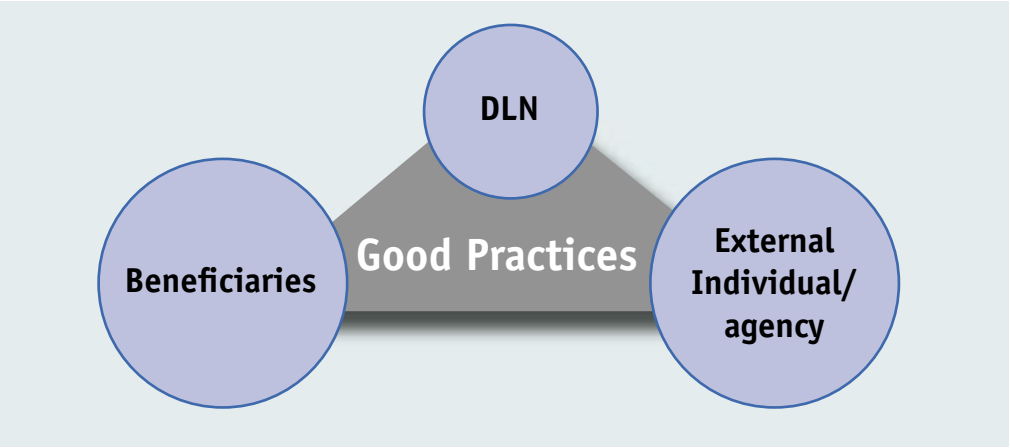
Interactions with stakeholders included focus group discussion (FGD), in-person, or telephonic interviews.

Confidentiality considerations: In the case of beneficiaries who were community members (PLHA) other than District Network staff, no names were used in reporting. In the case of facilitators and supporters, oral consent was obtained for some who have been named, and the others have been treated as anonymous.

During the process of data collection, additional good practices were identified and shared immediately with PFI, and a subset of these were selected for validation using the above steps. Three lines of evidence were deemed necessary for validation:

1. Evidence from DLN staff
2. Evidence from beneficiaries, typically adult PLHA, but also occasionally beneficiaries of advocacy events conducted by DLN staff
3. Evidence from other stakeholders, either individuals or organisations, who had helped in the development of the activity or event identified as a good practice. These are illustrated in Diagram 1.

Diagram 1: Lines of Evidence for Validating Good Practices



The data were collected during 250 person-days of field work.

4.3 Data Analysis and Report Preparation

Data collected and validated were summarised through collation of researcher field notes and audio recordings. They were then coded according to category of good practice (e.g. advocacy, networking, direct services: see Results section). For each state, the good practices were enumerated according to category (see Results section). Finally case studies were developed for all validated good practices.

5 Results and Learnings

5.1 Good Practice Areas and Summary

District Level Networks

The field work yielded 131 validated good practices in the 23 District Level Networks.

These good practices are listed by state and district, with complete information on field-visit dates, stakeholders contacted, types of interactions, information gathered and supporting materials, where available.

Each good practice was classified under one or more of the categories listed in the Table 1 below:

Table 1: Good Practice Categories, Codes and Examples

GOOD PRACTICE CATEGORY	CODE	EXAMPLES
Organisational functioning and development	OFD	• Existence of vision and mission statement • Existence of concrete objectives and activities • Development of second-line leadership • Fundraising strategies and sustainability plans • Regular monthly meeting • Involvement of HIV negative persons in Network • Involving local professionals/influencers in advocacy/ advisory capacity • Mechanisms to ensure cooperation and resolve conflict among individual members • Sound documentation procedures
Advocacy	ADV	• Advocacy with • Family of Infected • Communities (infected Groups) • Communities, (At-risk Groups) • Communities (General Populations) • Healthcare providers • Law enforcement • District administration • Educational institutions • Insurance agencies • Pharmaceutical companies • Youth clubs/Fan clubs • Elected people's representatives • Media
Direct services	DS	• Accompaniment to service provider (e.g. to ART clinic) • Facilitating support groups • Peer counselling • Home visits • Supply of food and/or nutrient supplements • Delivery of medication • IGP and micro-credit • Training of caregivers • Demand-generation for counselling and testing centres • Positive prevention • Services for infected and affected children

GOOD PRACTICE CATEGORY	CODE	EXAMPLES
Linkages and referrals	LAR	• Resource mapping and directory development • Medical services (STI, TB, ART, OI) • Psychosocial care and support services (Counselling centres, psychiatrists, suicide-hotlines, etc.) • Educational institutions • Employment generation schemes • Sources of nutritional support, food schemes • Resources for orphans and vulnerable children (OVC) • Short stay homes for adults • Financial institutions (e.g. banks) for availing credit/ loans • Humanitarian organisations • Academic/research based individuals and institutions • Youth clubs/Fan clubs
Greater involvement and/or employment of PLHA	GIPA	• In Regional/National Positive Networks • In District AIDS Advisory Committee • In Counselling and Testing Centres (PPTCT/ICTC/VCTC) • In NGOs (HIV/AIDS Prevention and care & support projects) • In other developmental work such as Tsunami relief, etc.
Miscellaneous	MISC	• Arranging marriages among positive people • Institutionalisation of advocacy through positive speakers bureau

State-wise

The figures below summarise the good practices in various categories by state. Note that the total numbers will be greater than the number of good practices, because each good practice may fit one or more of the above categories: e.g. a good practice may fall under Advocacy, Direct Services, and Linkages and Referrals. At the analysis stage, some cross-agency good practices were identified, i.e. those that involved collaboration among two or more networks.

Figure 2: Categorisation of Good Practices in Andhra Pradesh DLNs

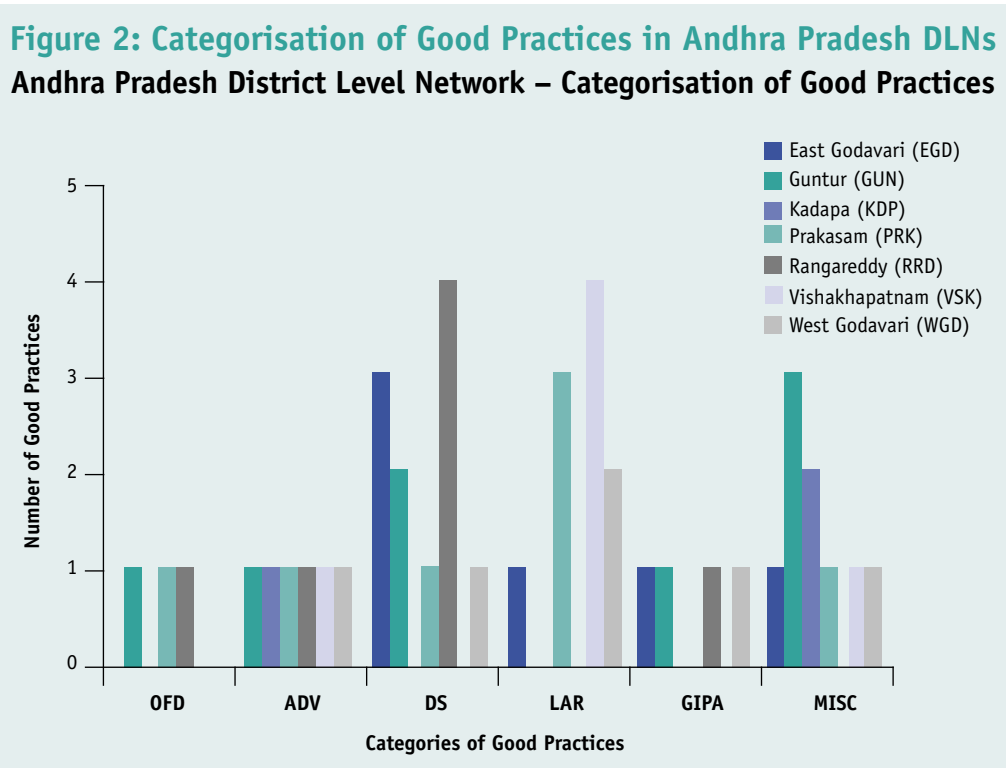


Figure 3: Categorisation of Good Practices in Karnataka DLNs

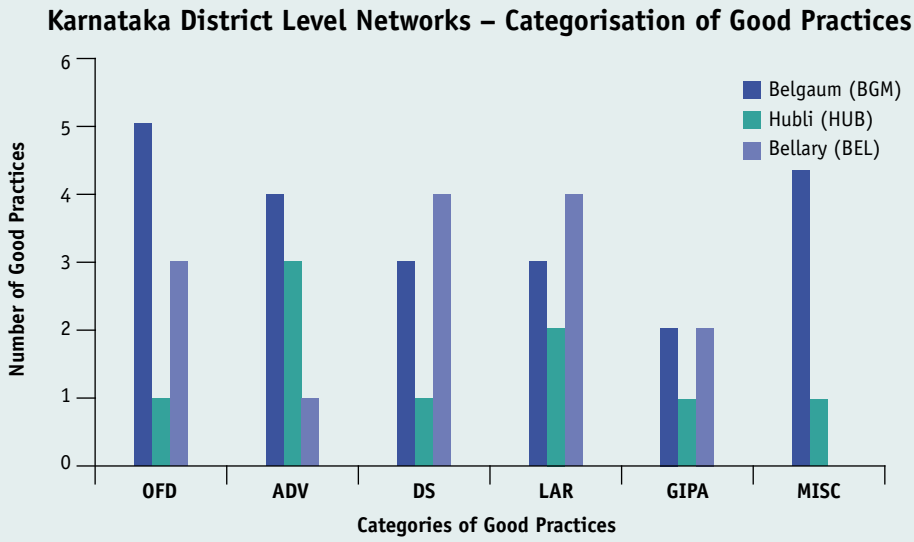


Figure 4: Categorisation of Good Practices in Maharashtra DLNs

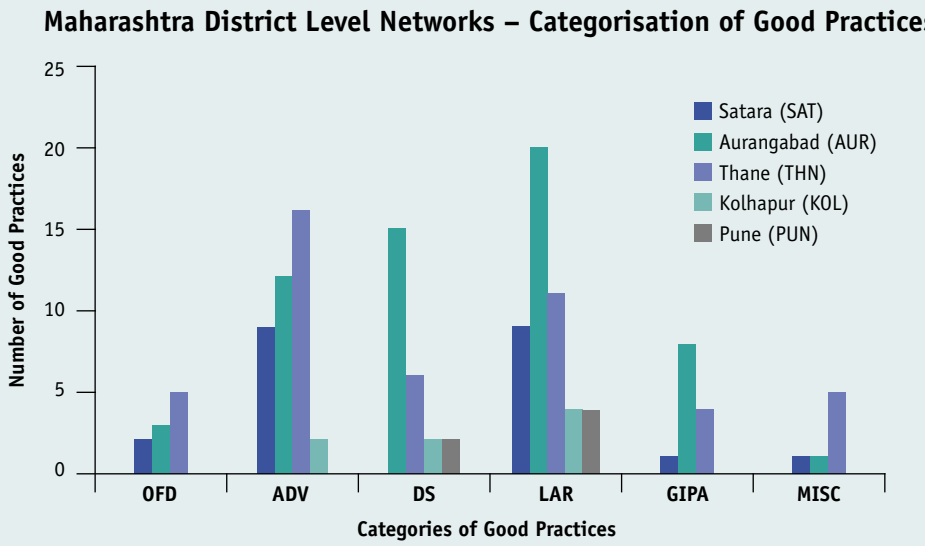


Figure 5: Categorisation of Good Practices in Manipur DLNs

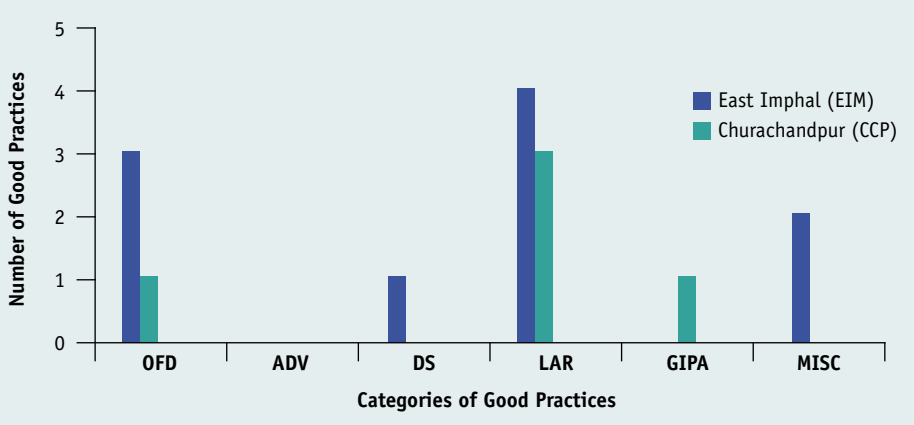


Figure 6: Categorisation of Good Practices in Tamil Nadu DLNs

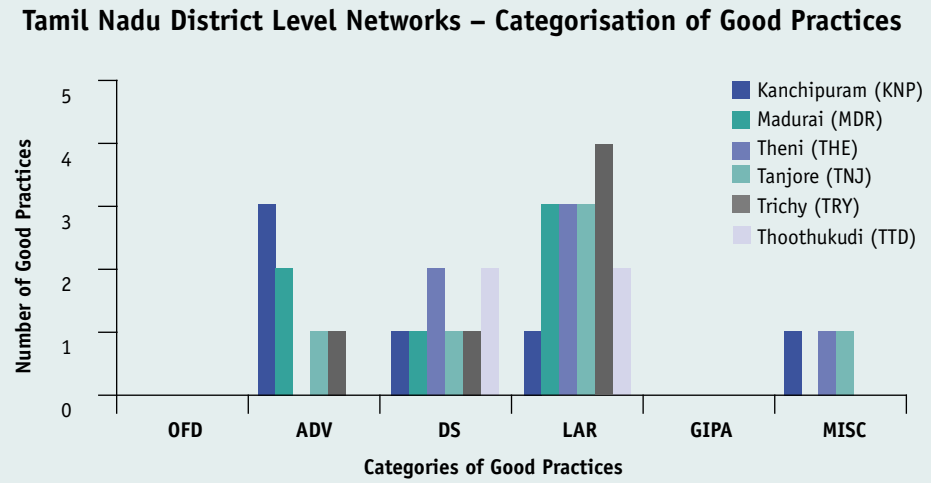
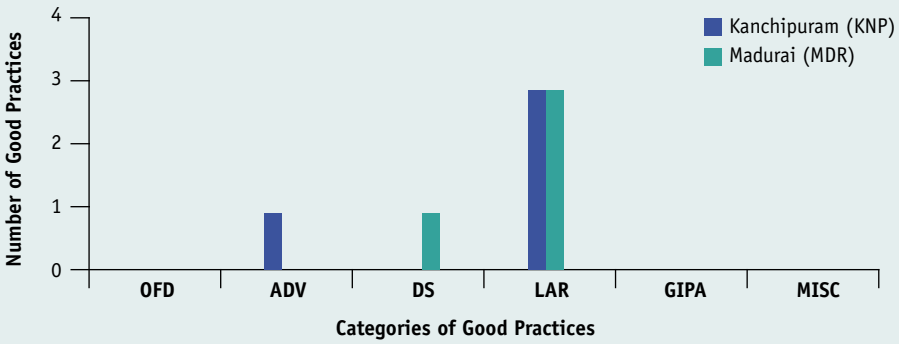


Figure 7: Categorisation of Good Practices in Tamil Nadu TCCs



5.2 Organisational Functioning and Development (OFD)

Good practices in this area may include such practices as sound institutional charter, with concrete objectives and activities, plans for sustainability, development of second-line leadership, innovative strategies to involve members outside of the PLHA community in DLN structure, and good documentation of organisational systems.

Good practices in OFD were identified and explored among DLNs in Andhra Pradesh, Karnataka, Maharashtra and Manipur. Selected case studies are described below:

OFD Case Study 1: Good documentation in Imphal East, Manipur

In brief: Imphal East Network of Positive People (IENP+) has institutionalised good documentation practices in programmatic and administration areas.

Description: The ACT project provided both financial resources and capacity building towards developing systems for documentation practices.

IENP+ is one of the networks that has been able to utilise these inputs for formalising register-based and computerised documentation systems. Some of the documents that existed prior to inception of the ACT project included registers for membership, meeting minutes, stock, cash and ledger, and visitor records. The support group meeting register was one of the important documents that was developed after ACT was launched.

Since initiation of the ACT project, IENP+ has begun maintaining several documents, including records of correspondence, leave, forms and registers for self-help groups, network membership, beneficiaries, counselling, advocacy and referral.

In an interview, the network General Secretary described the rationale for good documentation thus: *"We are maintaining the registers because it is the proof of what we are doing in the network. We need to show the activities to any person who comes to the network. It is a must to maintain documentation for each organisation. With the ACT project we are able to maintain documents in a good and proper way. We have maintained separate files for each activity: leave file, outgoing and incoming mail, notice file, circular file etc. Earlier, for peer treatment educators (PTEs), we did not have any format to report their monthly activities. So we developed field monitoring visit format for the PTEs, which can also be used by other staff, such as outreach workers and others."*

Speaking of the advantages of documentation, he added *"Many people cannot remember all what they have done in the past month or year. That thing can be found out from our documentation. What activities we conducted in the past, we recollect the information from the documents. With the help of these documents new staff can understand the process, past activities of the network, etc."*

Lessons learned: Capacity-building from mother NGOs or donor agencies can help positive networks and other community based organisations strengthen their systems.

5.3 Advocacy (ADV)

Advocacy to reduce stigma and discrimination, secure rights and mobilise resources, constitutes one of the key activities of all DLNs. Targets of advocacy are varied, and include families of PLHA, members of at-risk groups, the general population, professions such as healthcare, law-enforcement, education, government administration, insurance agencies, pharmaceutical companies, elected people's representatives, charitable organisations and fan clubs, to mention a few. Good practices in advocacy were initially identified among DLNs in all states, and were explored in all states but Manipur based on availability of all three levels of evidence. Selected case studies are given below.

ADV Case Study 1: Village level advocacy meetings in Guntur district, Andhra Pradesh

In brief: Advocacy and sensitisation meetings organised by the DLN in villages throughout the district, have demonstrated success in reducing stigma from residents towards PLHA, securing support from local elected body members for the cause of PLHA, and identifying new PLHA who are then facilitated to access care services.

Description: DLN-Guntur organises village level meetings covering the entire district. These initiatives have brought in increased awareness among general population, hike in the disclosure and enrolment levels of new PLHA. In most of the covered villages, as an impact of this initiative, reported instances of stigma and discrimination cases have been reduced.

Initially the DLN struggled to organise these form of meetings in the villages, as no one moved forward in listening to them. Later, after realising that unless myths and misconceptions of the community leaders related to HIV/AIDS are cleared, directly organising the village level meetings would not be effective. Though the entire process of sensitising the community leaders took a long time, it facilitated access and communication with the general public at later stages.

Facilitator: A counsellor working in the DLN observed that rapport building with the village level leaders at the onset is very much essential. Such rapport would help them in accessing the general community and motivating them to listen to them. She also shared that the impact of such meetings had been very high as more and more people are voluntarily coming forward to undergo HIV testing and counselling. This has helped and made easy for the DLN in identifying new PLHA. Holding village awareness sessions at different levels are very much important for community members, she added.

A beneficiary living with HIV/AIDS in one of the target villages added that he had personally benefited from the advocacy meetings, both directly through contact with the network and its services, and indirectly through the reduction in misconceptions and thereby stigma in the village towards people like himself.

Lessons learned: As decentralisation of care and treatment proceeds in India, it is imperative to reach villages with advocacy events aimed at mobilising local support for the cause of PLHA from a broad spectrum of local constituents.

ADV Case Study 2: Advocacy with Sangli ART Centre for increased services to PLHA, Maharashtra

In brief: The district level networks at Satara, Sangli and Kolhapur collaboratively advocated with Sangli ART Centre to make ART services

available six days a week so that people from adjoining districts could avail these services, which had formerly been available for only one day a week.

Description: The Sangli ART Centre is the only public treatment facility for PLHA from Sangli and neighbouring districts such as Satara and Kolhapur. It was earlier only functional for one day a week, during the morning hours of 9 am – 1 pm. Owing to the limited hours, PLHA who went to the ART Centre at Sangli had to return on successive weeks to get various tests done. This was causing tremendous inconvenience to PLHA, including about 140 from Satara district. To address this problem, the Satara DLN contacted its counterparts in Kolhapur and Sangli, and learned that the problem was impacting PLHA from all three districts. The three networks then joined forces with other local NGOs in Sangli and organised a campaign "Doctor aamla jagayacha ahain" meaning "Doctors we want to live too". The primary demand of the campaign and associated rally was to get the ART Centre to be functional six days a week. This campaign received wide media coverage at local and state levels. As a consequence, the Maharashtra State AIDS Control Society intervened and directed the ART Centre to start functioning six days a week, with effect from June 2006. Additional outcomes of the campaign and associated advocacy activities were that a monthly meeting of doctors of ART Centre, district level networks and other NGOs is held every second Tuesday of the month, where any problem or issues regarding PLHA is addressed. Volunteers of NSP+ (Satara), NKP+ (Kolhapur) and Sangli network assist patients at the ART Centre with follow-up and referrals.

A beneficiary, Mr. S. B is a 46 year-old man in Satara, and the sole breadwinner of his family, consisting of a wife and three children. When he was diagnosed he came into contact with the positive network NSP+, which referred him to Sangli ART Centre and got his ART regimen started. His economic condition was also not good, earlier he had to come three to four times a month for various services such as CD4 count, sonography, and other tests. The ART Centre was around 95 km from his house and going there every time was expensive. Following the advocacy intervention of the positive networks, he reported that the condition at the ART Centre had improved. As the ART Centre has become functional six days a week he could adjust his time and go there. He began volunteering for NSP+ and assisted in follow-up of other PLHA.

Lessons learned: Advocacy is often effective when agencies with similar demands work in coalition with one another. Visible campaigns and media coverage can assist advocacy efforts.

ADV Case Study 3: Ensuring access to ART through railway concessions in West Godavari, Andhra Pradesh

In brief: Association of Positive People Living with Excellence (APPLE), the positive network of West Godavari district, Andhra Pradesh, has advocated successfully with the Indian Railways to provide travel concessions for

PLHA. As a result, PLHA who were unable to afford to travel monthly to the ART Centres, now have the opportunity to do so.

Description: In interviews with the President and General Secretary of APPLE, it was learned that one of the main reasons that many PLHA living in poverty are unable to continue their ART regimen, despite the free availability of medicines, is that they are unable to afford the cost of monthly travel from their homes to the ART Centre. One of the members of the network, who used to seek treatment from the Tambaram ART Centre, learned of the travel concession schemes available through the Railways in Tamil Nadu. Upon approaching the local (West Godavari district in Andhra Pradesh) Railway officials with a request to offer similar facilities, he was initially turned away. His persistence was eventually rewarded with one of the railway staff members suggesting that he get a disability certificate from a government hospital physician. He subsequently approached the Superintendent of Osmania General Hospital Dr. Bala Raju, and explained the issue.

The physician issued him a certificate stating that he was HIV positive and may be eligible to receive travel concessions. The network then took up the case and assisted the PLHA in further advocacy visits with the railway officials. Four to five months after the initial intervention, the railway offices finally sanctioned railway concessions to the applicant. At the time of interviewing (17–18 August, 2006), only one individual had benefited from the concession: another network staff member had applied for the concession and was awaiting the response.

The **beneficiary** conveyed to the field team that he was contented at the positive outcome after a long struggle.

The APPLE network has also initiated a 'self fund' through which PLHA who were in dire need of funds could have their travel subsidised by their economically stronger PLHA peers.

Lessons learned: Persistent advocacy by PLHA networks and individuals can yield such benefits as railway concessions. This issue, may, however, be taken up for advocacy at a large (state-wide, country-wide) scale by positive networks and their allies, to secure railway concessions for all PLHA who may need them.

5.4 Direct Services (DS)

District Level Networks in all states studied have distinguished themselves through provision of a wide range of direct services, such as accompanying PLHA on clinical visits, facilitating support groups at their premises or within healthcare facilities at district/sub-district levels, assisting with income-generation programmes, training of caregivers for home-based care, positive prevention services, and services for children infected or affected with HIV.

Good practices in direct services illustrate the principles of greater and meaningful involvement of PLHA (GIPA and MIPA), and also establish the credentials of DLNs and TCCs as service providers. Through direct services, the PLHA groups are able to leverage more support and respect from diverse stakeholders involved in care and support from government and civil society sectors.

Good practices in DS are illustrated through the following case studies:

DS Case Study 1: Support group meetings in three DLNs of Andhra Pradesh

In brief: Three District Level Networks (East Godavari, Prakasam and Rangareddy) have been successfully holding support group meetings at different levels regularly. The support group meetings have helped create a common platform to disseminate information, mutually share problems and experiences of the PLHA and address common issues.

Description: Support group meetings have helped in enhancing enrolment rates across all the DLNs. In DLN, East Godavari, the support group meetings among ante- and post-natal women have additionally been significant as a number of women are opting for institutional deliveries now.

Beneficiary 1: Mrs. N, a post-natal mother living with HIV attended a support group meeting organised in her village, Recharlapet in an anganwadi centre. She has two daughters; the first one whom she delivered at home is mentally retarded. After her first delivery, an outreach worker of the DLN, East Godavari approached and invited her to the support group meeting that was organised at the anganwadi centre regularly. She has attended the meetings couple of times and they had been an eye opener for her every time. According to her, she has learned many useful aspects and benefited through an institution based delivery. She had her second delivery with a healthy child. After her own experience, she has been encouraging every married and expectant woman in her locality to visit primary health centres and prefer for institutional deliveries.

Beneficiary 2: Mrs. M was motivated by the outreach worker at a support group meeting to learn about safe pregnancy and delivery. She learned about institutional deliveries, HIV-testing, low cost nutritional food such as taking leafy vegetables, fruits, high-iron content food and medication. Since then she is visiting nearby PHC centres regularly.

SGM Supporter: Mrs. S is an anganwadi worker of a village. She described their activities through the Anganwadi Centre for ante and post-natal care to the women. The centre provides information on low cost supplementary diet, distributes iron and folic tablets to the expectant mothers, publicises the benefits of breast feeding, immunisation etc. Often the centre organises exhibitions on nutritional food where preparation of low cost nutritional

diet is demonstrated. Recently the anganwadi centre organised a breast feeding campaign. She also noted that the centre organises awareness sessions on sexual and reproductive health for adolescent girls, wherein the DLN Outreach Worker provides information on HIV/AIDS. They recommend all ante & post-natal cases to visit Government General Hospital for blood test and medications. She instructs women to take medicines only after due prescription from doctors.

Beneficiary 3: Mr. N, a PLHA and an auto rickshaw driver, while on one of his visits to the ARV Centre of the Osmania General Hospital, learned of the DLN and its activities including the support group meetings. He recollects that the DLN Officer counselled and motivated him to attend support group meetings. He then became a member of the DLN, and started attending the support group meetings regularly, where he was able to exchange views and share concerns with fellow PLHA. Mr. N is a beneficiary of a variety of services from the support group, such as positive counselling, family counselling, positive living training and information on HIV prevention and care etc. He perceives the DLN as a forum that takes care of its community to alleviate emotional stress, provides information on different service delivery points including the care and support services.

Lessons learned: This case study personifies the good practice of forming and developing support groups that function to disseminate information, exchange personal experiences including setbacks and successes.

DS Case Study 2: Support group meetings in Kovilpatti Government General Hospital, Thoothukudi, Tamil Nadu (also illustrative of GIPA)

In brief: Support group meetings in Kovilpatti Government General Hospital assist PLHA by offering a safe and accessible space where they are free of stigma and are able to meet discreetly. Additionally, the hospital venue offers PLHA the benefit of interaction with doctors and paramedical staff.

Description: According to the DLN president, the main criteria for conducting support group meetings (SGM) at Kovilpatti Government General hospital was the convenience and comfort level of the PLHA. Initially, the meetings were being conducted in the Thoothukudi town. Then the DLN realised PLHA were attending the SGM from Kovilpatti and the neighbouring taluks. Since the distance is about 60 km between Kovilpatti and Thoothukudi they had to incur huge travel expenses. To avoid this travel expense, the DLN decided to have SGM at Kovilpatti. Later, through the counsellor's field visit, they came to know from the PLHA that they are not comfortable if SGMs take place in their own villages due to overt stigmatisation.

Then, the DLN Officer after discussing with the counsellors at GH contacted a health department official who in turn advocated with the Superintendent of Kovilpatti GH to provide space for monthly SGM in the hospital.

The ICTC counsellors and the DLN staff worked together to prepare the agenda for the meeting and invited doctors from other departments to participate in the meeting and clarify doubts PLHA may have with regard to treatment. They also indicated that due to this activity treatment adherence is being followed up effectively. Till date four SGMs have been conducted at Kovilpatti GH.

The GH counsellor, technician and DLN staff report the following benefits of conducting SGM in the hospital premises:

- SGM in a hospital setting helps PLHA to collect their medicines without fail
- Medical officers from all departments participate in the SGM.
- PLHA feel that they are not stigmatised and discriminated.
- SGM gives a hope for the PLHA that the government is there to provide care and support for them.

Beneficiary 1: Wife of Mr. G who died of HIV, was motivated by the DLN to undergo testing, when she contacted the DLN following her husband's demise. She tested positive but her children were negative. She started attending SGM at Kovilpatti GH, and came to know more people who were affected. The SGM created confidence within her and helped her to talk more effectively about HIV/AIDS with her relatives. She was even able to persuade her mother to attend the SGM. At present she works as a volunteer for the DLN.

Lessons learned: Despite space constraints at the hospital, the practice of conducting SGM in the hospital premises has been successful at multiple levels. The roles of multiple stakeholders such as TANSACS Consultant, Hospital Superintendent, Counsellors and the PLHA have enabled this practice to be implemented.

DS Case Study 3: Nutrient supplements provided at support group meetings in Kolhapur, Maharashtra

In brief: NKP+, the Network of Kolhapur for People Living with HIV/AIDS, provides free nutritional supplements to participants of the support group meetings (SGM). In addition to the nutritional benefit, this practice also draws large numbers of people to the meetings.

Description: The impetus for this practice came during a support group meeting when some members requested the network to provide better refreshments during the meetings instead of providing only tea and biscuits. The DLN consulted with PFI state office regarding this, and from December 2005, the network started providing nutritional supplements to SGM participants. The

nutritional supplements include seasonal fruits, dry fruits, cereals, pulses and vegetables (such as tomatoes). These items are purchased by the DLN in bulk and then distributed as small packets among all the participants, including the caregivers and others who accompany the PLHA to the meetings. Some of the participants carry the food packets back home, while others consume the food at the venue, especially if seasonal fruits are given.

During the focus group discussion, DLN staff noted that nearly 40% of the DLN members did not have proper knowledge about nutritious foods. According to them, this distribution of nutritional supplements at the SGM helped to teach the participants about various types of nutritious food items, and their role in maintaining good health.

The network spends the entire budgetary allocation for each SGM, which is about Rs. 1200 –1500, towards nutritional supplements, which are purchased in bulk to avail discounts.

Beneficiaries: M, A and S shared their opinions of this practice in a focus group discussion. M, a male commercial sex worker aged 24; A, a married man aged 28; and S, a 26 years old female commercial sex worker and mother of a four years old child, all expressed satisfaction with the SGM concept as implemented by NKP+. They found the nutritional supplements they received – mainly jaggery, groundnuts, and dates – as well as the educational sessions on yoga, diet, and adherence to be very useful. Above all, they appreciated the fact that all these benefits were available to them in a safe non-judgmental place.

Four other beneficiaries expressed similar sentiments in individual in-depth interviews.

Sustainability plans: The DLN plans to raise donations towards continuing the nutrition supply, and has obtained commitments from private donors towards this. Additionally the DLN has also approached the Merchant Association at Kolhapur so as to get bulk donations of food items such as pulses, wheat and rice. The proposed plan involves the Merchant Association rotating the responsibility for such donations among its member-traders, so that a particular merchant has to give his contribution may be only once a year.

Lessons learned: Distribution of nutritional supplements during SGMs is an innovative practice that serves multiple purposes such as (a) enhancing nutritional status of PLHA, (b) increasing their knowledge and awareness of the importance of diet and nutrition in health, and (c) providing motivation to attend the meetings, during which other practices such as adherence to medication can be inculcated.

DS Case Study 4: Training in preparation and sales of nutrition powder by network in Bellary, Karnataka

In brief: Nithya Jeevana, the network of Bellary district, Karnataka, has trained a positive woman in preparation and sales of nutrition powder. Besides benefiting the local PLHA community at large, this practice has helped the woman get out of debt, and helped raise her self-confidence.

Description: Availability of adequate and affordable nutrition is a key need for people living with HIV. In response to this need, the Bellary positive network Nithya Jeevana trained M, a woman living with HIV to prepare nutrition powder to augment the nutrition supply for PLHA. Through this activity, the woman was able to get out of debt very quickly. Her powder is getting such good word-of-mouth publicity that her neighbours and others are asking for it and buying it. All this has greatly augmented her self-esteem and self-confidence. The network is now exploring possibilities of marketing the powder through mainstream outlets.

The beneficiary of this training, M, conveyed in an interview: *"Nithya Jeevana gave me training to make nutrition packets… I also had to get out of debt…out of manual labour…I was also interested in doing this. Initially, I used 1 kg of each ingredient…now the demand is more, so I am now using 5 kg of each…I manage my finances well on my own… I am out of debt now. My original employees agreed to my working elsewhere to repay their loan, now I have repaid all that and saved about 13,000 rupees. I have gained 5 kg weight. My children are also doing better".*

Another beneficiary, A, was receiving the nutrition powder for her child. She said: *"[My child] calls the nutrition powder 'aapaa'. Whenever he wants it he asks for it. He likes it very much. He has gone from 8 kg in weight to 11 kg now."*

In addition to providing income for the individuals involved in manufacturing the packers, the practice also has psychological benefits in people *feeling* better and *seeing* their children do better. Thus, this is a good practice that helps both physical and psychological well-being of PLHA.

Lessons learned: The nutrition packet project is a very vital and cost-effective method of providing the nutritional support that PLHA need to improve their health. It could easily be scaled up within and across district level positive networks.

DS Case Study 5: Meditation and cultural activities promote psychological well-being among PLHA in Belgaum, Karnataka

In brief: Spandana, the positive network in Belgaum district of Karnataka, involves its members in meditation camps and cultural activities such as talent shows, music, dance and art, as part of its holistic approach to care and support.

Description: Staff of Spandana shared in a focus group discussion that they had encountered high levels of depression amongst PLHA. They observed that information on HIV management, diet, and ART – all serious topics – were not serving to retain interest of PLHA in support group meetings, and there was a consequent drop out of participants at these meetings.

This motivated the network to conduct cultural activities (art, music, dance) during the meetings. These were well received and cause a resurgence of interest in attending the meetings. Art therapy workshops were conducted for children as well.

"People are dealing with a lot of stresses. If they get only serious information at the SGM also they will soon become tired [of it]. They also need to have some enjoyment. This makes them feel a little lighter. It helps them receive the serious information. It also helps them understand that there is hope, that they should be happy and have fun." – **beneficiary,** also staff member.

Spandana also conducted a three-day meditation camp, following the Osho method. V, a private donor who sponsored the camp, shared his thoughts thus: *"The meditation camp helped boost morale and confidence. I plan to hold one every year from now on. In a group, tensions will go away. Once tension is gone, [the feeling sets in that] we are among others like us... Meditation technique is Osho's method. It helps in people getting better balance (centering). Frustration is reduced."*

Lessons learned: Meditation camps and cultural activities are part of holistic approach taken by Spandana in rendering services to PLHA. Collectively, these activities benefit members in terms of stress-reduction and relaxation. This is seen by the network as important not just for itself, but also as a necessary pre-condition for other care services the network provides to PLHA.

DS Case Study 6: Combining medical camps with support group meetings increases access to care and treatment in Bellary, Karnataka

In brief: Nithya Jeevana, the positive network at Bellary, has evolved the practice of combining medical camps with support group meetings (SGMs) at the taluk level. These have increased uptake of network services by PLHA.

Description: Focus group discussions with Nithya Jeevana staff revealed that travel costs were an impediment for PLHA in remote parts of the district to seek medical services and attend support group meetings. In collaboration with World Vision, a faith-based organisation operating in the district, Nithya Jeevana decided to decentralise the support group meetings from the district headquarters to the taluk level, and combine them with medical camps.

At the SGMs, medicines for opportunistic infections, information and help for getting ART, follow-up for those on ART, counselling people to get tested for HIV, and referral help for medical care are provided. Also provided are support and advice on income generation programmes, family/social support, and combating stigma and discrimination. A government doctor, supported by World Vision, assists in the medical camp on a part-time basis.

Travel to these meetings is subsidised, and food expenses met. More women, especially widows, than men attend these meetings. This practice started off with 40 members in January 2005. New members come via referrals from the local Voluntary Counselling and Testing Centres. Over 60% of attendees are in the 18–30 age group, about 40% are over 30 years old. Each month, 40–50 members join in the district as a whole. The taluk-wise break up of the members attending as of July 2006 was: Hospet: 80+, Siriguppa: 60+, Kudligi: 50+ (with drop-in centre of WV) and Bellary: 150+. World Vision and the Freedom Foundation are among the organisations helping with in-kind donations and subsidies.

In an interview with the network president, he said: "*Initially, we had about 25-30 people. They used to get medicines with the support from World Vision... As the numbers increased, we thought if we could buy medicines wholesale, we could save some money and buy more medicines for a larger number of people... It was also difficult for us to conduct one large meeting for the whole district. It is difficult for the people also. So, we decided to conduct the meetings in the taluks. Then we consulted a doctor and asked him if he would come to taluks and conduct medical camps. He agreed.*"

A beneficiary, who found out that she was HIV positive when she had gone to Freedom Foundation to get tested for tuberculosis, was referred to Nithya Jeevana by a peer educator. She said: *"I attended the SGM in Siriguppa... There I saw that I am not the only one. There are so many people like me. Moreover, the [World Vision] coordinator offered me a job... as field worker."*

Lessons learned: The many kinds of interventions provided through these combined SGM-medical camps augment both mental and physical (health) components of quality of life for the PLHA. In addition, they also build solidarity and strengthen what Nithya Jeevana president calls *aatma-dhairya* – self-confidence.

DS Case Study 7: Village level mapping identifies care and support resources for PLHA in Madurai, Tamil Nadu

In brief: The Madurai District HIV Positive People Welfare Society (MDPS+) has initiated village level surveys to map resources for PLHA, and this has also enabled rapport-building with the concerned agencies and individuals.

Description: MDPS+ initiated the village level surveys with the objective of collecting information on treatment resources such as hospitals and laboratories, and developing linkages with these institutions to facilitate referrals. After initiating the survey, the staff reported that they were getting almost five to ten new cases every month referred by the agencies that they had mapped. The mapping exercise helped the staff members carry out some sensitisation with such stakeholders as doctors, NGOs, self-help groups, police, and panchayat leaders.

One of the **key informants,** M, worked as a peer educator in the network, and was part of the team conducting the village level surveys. She reported that as part of the mapping exercise they try to get appointments to meet the key contact persons, describe the network and its functions, and give them their contact details. In the meeting itself the staff disclose their positive status. Through this survey almost 17 of the agencies mapped have referred PLHA to the network till now. At the time of interviews, a resource directory was under development.

Lessons learned: Resource-mapping, a direct service of networks to their community, is an important strategy that can promote referrals from and to agencies.

DS Case Study 8: Coding bottles with symbols helps PLHA remember their medicine dosage and timing, in Kolhapur, Maharashtra

In brief: The Network of Kolhapur for People Living with HIV/AIDS (NKP+) enables PLHA who are illiterate or semi-literate to recognise their drug dosage timings through a system of coding medicine bottles.

Description: Many of the network members are either illiterate or semi-literate. Consequently, when medicines are given to PLHA by the ART Centre, the clients are often unable to clearly understand written instructions regarding dosage and timing.

The network has assisted its members by devising a system of symbols to mark the medicine bottles. A single mark on a medicine bottle indicates that it has to be taken once a day. Two marks or symbols on the medicine bottle indicate that the medicine has to be taken twice a day (once in the morning and once in the evening). Similarly three marks on the bottle indicate that the medicine has to be taken thrice a day.

Three beneficiaries stated in their interviews that the system helped them immensely. Two of the three were married couples, both on ART. The husband and wife spoke highly of the patient literacy provided by NKP+, which included information on ART side effects and how to cope with them, and a telephone number to contact in case of emergencies. According to them, the symbols were a boon for people who lacked a formal education, such as themselves.

Lessons learned: The system of marking bottles, though a simple innovation, can greatly enhance client-friendliness of ART provision. This good practice is worthy of immediate replication in other centres.

DS Case Study 9: Volunteering for Family Health Awareness campaign strengthened linkages with primary health centre in Kanchipuram, Tamil Nadu

In brief: In the year 2005, the Kanchipuram Network of People living with HIV/AIDS (KNP+) volunteered with the Family Health Awareness Campaign (FHAC). This helped them mobilise clients for the health camps, and strengthened linkages with the Saathanur Primary Health Centre.

Description: The Family Health Awareness Campaign, launched in 1999 by the National AIDS Control Organisation (NACO), is an effort to address reproductive health issues in the community, especially in rural areas. It aims to improve early detection and treatment of Reproductive Tract Infections (RTI) and Sexually Transmitted Infections (STI) through community involvement (Acharya et al. 2006). Health camps are the strategy through which community members are mobilised for STI/RTI treatment.

In 2005, two KNP+ members voluntarily assisted healthcare providers at Saathanur Primary Health Centre (PHC) in recruiting clients for a 15-day camp for RTI treatment. According to PHC physician Dr. Arun Prasad, the familiarity of the volunteers with STI/RTI syndromes, and their willingness to discuss sexual histories, helped them in identifying cases and recruiting clients to the camp.

The volunteers for KNP+ shared their contact information with the PHC. At the time of the interview, the physician reported having referred six cases to the network.

Lessons learned: Involvement in the FHAC, besides constituting a direct service to clients, helped in building bridges between a Government Primary Health Centre (PHC) and the network.

5.5 Linkages and Referrals (LAR)

The continuum of care for PLHA involves services and activities that extend far beyond clinical care and treatment. The role of PLHA groups, whether DLNs or TCCs, is critical in facilitating access of community members to the range of care-continuum services through referrals and linkages.

Good practices in LAR include, but are not limited to, producing directories of services and resources, referring PLHA to clinical and psychosocial care providers, forging linkages with educational, financial institutions and employment generation schemes (often with advocacy as a critical pre-requisite), services for orphans and vulnerable children, and links with providers of other services.

Instances of good practices in LAR are to be found in all states where DLNs and TCCs were visited. Few practices are described below:

LAR Case Study 1: Linkages for widow pension and income generation in Guntur, Prakasam and Vishakhapatnam, Andhra Pradesh

In brief: District Level Networks in the above districts have developed good linkages with the government bodies like DRDA and Scheduled Caste/Backward Caste (SC/BC) Corporations that helped in accessing grants for initiating income generation ventures and pensions for widows living with HIV/AIDS.

Description: These linkages grew in response to the acute felt needs for financial support to widows living with HIV/AIDS, many of whom were younger than the lower age limit for eligibility to the widow pension scheme. Through rapport and linkages built between the DLN and government bodies such as the DRDA and SC/BC Corporation, monetary relief and disbursements have been made available to families affected by HIV. Women living with and widowed by HIV/AIDS have been receiving pensions and have been able to mobilise grants to send their children to regular schools and obtain low cost nutritional food. Grant assistance to initiate income generation programmes for the widow PLHA have also been significant in securing the lives of their children.

Specific instances: In Guntur, in 2005, seven widow PLHA received grant assistance from Scheduled Caste Corporation of Rs. 10, 000/- to initiate viable income generation ventures. Similarly in 2006, around 20 widow PLHA were sanctioned grants worth Rs. 2,000 and a monthly pension of Rs. 200/- each from District Rural Development Agency (DRDA). Twenty women have been sanctioned widow pensions in Vishakhapatnam as of year 2006, and one woman in Prakasam has been able to avail of the scheme.

Beneficiary 1 is a PLHA widow with two children who benefited from interventions by the DLN staff with the Mandal Development Officer (MDO), who is the concerned official sanctioning grants to the widow PLHA. On World Women's day in 2006, the department issued Rs. 2000 /- initially as a seed grant and Rs. 200/- towards monthly widow pension. The grant of Rs. 2000 was invested in setting up of a beauty parlour at her home and procuring related cosmetics and equipment. Now, with part time engagement with the beauty clinic, she is able to earn some money to manage her family including the children's education. According to her, the widow pension schemes have been helpful for the widow PLHA to establish similar self-employment ventures ensuring them to sustain a self-dependent life. It has been an opportunity wherein every woman even without an educational background can earn livelihood and sustain her family.

Facilitator: Mr. Kaleb, Former Project Director, Joint UN CHARCA (Coordinated HIV-AIDS Response through Capacity Building and Awareness) Project,

mentioned that the project had been working in close relationship with the DLN in Guntur. CHARCA project assisted the network in approaching Government agencies including banks for accessing grants/loans for the PLHA. CHARCA also facilitated the DLN in holding an advocacy event with the State Level Bankers Committee to access loans/grants, District Officials for old age pensions, DRDA for grants. Mr. Kaleb recommends that district networks approach the District Collectors at the outset, to familiarise them with PLHA issues and set the foundation for linkages with the government system.

Lessons learned: This case study illustrates the benefits of linkages (following prior advocacy) with government bodies like the DRDA, Scheduled Caste/ Backward Class Corporations etc. for financial assistance to widow PLHA and families affected by HIV.

LAR Case Study 2: Resource mobilisation through linkages in Guntur, Andhra Pradesh

In brief: The Guntur DLN has been successful in mobilising monetary and in-kind support for PLHA living in poverty through linkages with private individuals and non-governmental organisations in the area.

Description: During a focus group discussion with DLN office bearers, a respondent shared that in most counselling sessions, the clients who were from poor socio-economic background requested the network to fulfill their acute financial needs, and to provide educational and nutritional support to their children. This overwhelming demand was raised at the DLN board meeting and consensus reached on the need to develop strategic linkages for resource mobilisation.

Mobilisation of local resources was not a new attempt as far as the DLN effort is concerned. Even at the inaugural ceremony of the DLN on August 29th 2004, Mr. Roshan Kumar, director of a local NGO named SEEDS suggested they mobilise funds for infrastructure strengthening by approaching philanthropists in the district. Mr. Roshan Kumar initiated the activity, agreeing to donate two fans and two chairs instantly. As days went by, the DLN members leveraged different resources for its infrastructure development and mobilised support to the PLHA members from diverse sources. To indicate a few, AMG India International, an NGO with varied activities in and around Andhra Pradesh contributed educational and nutritional support to 125 children of PLHA. M, a neighbour of DLN office and a philanthropist donated Rs. 10,000/- and also agreed to provide a piece of land in the near future to the DLN to construct a shelter home for the PLHA. Ramesh Babu, the DLN President, expressed the view that the practice of mobilising local resources is a continuous process and the DLN is expecting to target and mobilise more resources either in cash or kind. The next attempt will be to develop its own building rendering care and

support to all PLHA requiring shelter, psychological support and treatment under one roof.

Beneficiary: An elderly woman narrated the situation of her five-year old HIV positive grandchild who lost both of his parents to AIDS around a year back. A few months after the mother's death, the DLN approached the grandmother seeking details of the child such as the birth certificate and HIV status report. For the last five months, the child has been receiving educational and nutritional support through the DLN that were mobilised from different individuals and agencies. Additionally, a monthly educational support of Rs. 250/- is being provided by the DLN. While concerned about the future of the child after her eventual demise, the grandmother is confident of the DLN's support to her grandchild continuing into the future.

Supporter: M, a neighbour of the DLN office, shared that he initially used to observe the activities of the DLN and kept enquiring about its commitments and activities. Learning of his goodwill, the DLN office bearers approached him for support to poor PLHA. After an initial donation of Rs. 5000/-, he felt so motivated that he continued his philanthropy. At the time of the interview, he was planning to request other well-off neighbours and relatives to come forward and help the PLHA.

Lessons learned: Linkages with well-wishers and NGOs are key to sustainability of support to PLHA living with HIV. They also help to expand the support base and reduce reliance on external sources (e.g. grants from donor agencies).

LAR Case Study 3: Mobilisation of medicines through linkages in Kadapa, Andhra Pradesh (also DS)

In brief: Through linkages with NGOs, private doctors, medical representatives and stockists, the DLN Vimuthi Positive People's Network (VPPN+) in Kadapa district has been able to mobilise drugs for treatment of opportunistic and sexually transmitted infections. These benefit those PLHA who are hesitant to procure medications from government healthcare facilities for fear of being stigmatised.

Description: Medical care is the prerequisite for all the PLHA. DLN feels that meager counselling services are not adequate particularly for the poor PLHA who had always been on request for medicines. The DLN hardly had any financial aid and projects during its initial period of establishment. In 2005, during the Kadapothsavamela fair, Mr. Rajendar, a Condom Stockist, met Mr. Sameer, the President of VPPN+ and was moved by the services provided to the PLHA. He introduced Mr. Sameer to Mr. Prasad, a field staff from Population Services International who provided certain insights on the options of mobilising medicines for the PLHA from various donors. He

suggested developing and distributing brochures/pamphlets among hospitals, clubs, associations and interested individuals in seeking donations.

Facilitators: Mr. Rajendar and Mr. Prasad introduced the DLN to different donors including certain medical representatives and medical agencies that provided general medicines including for STIs. Private doctors issued free samples of drugs for mouth ulcers. Medical representatives contributed vitamin and antibiotics and government hospitals provided Oral Rehydration Salts (ORS) to the DLN.

Facilitators-cum-beneficiaries: Four PLHA had advocated with the doctor and nurses of the AASHA programme to contribute general medicines giving assurance that, those will be used for poor PLHA. The mobilised medicines were stored and distributed from the DLN office. According to the interviewees, they face grave discrimination and stigma at the hospital setting particularly from the healthcare providers and therefore had also put forward a proposal before the DLN to provide a full time doctor and supply of free medicines.

After providing medicines, there has been a significant increase in enrolment rate of PLHA into the network.

DLN office bearers plan to visit and seek medicine contributions from the general households. PLHA have been informing the general public on the medicine support rendered by others and motivate them through awareness sessions. PLHA have also been contributing medicines, which they have collected from the AASHA programme. DLN is expecting to gain effective outcome from this activity.

Lessons learned: In the words of VPPN+ president Mr. Sameer, "seeking alternative and self-mobilisation initiatives for resources will ensure the sustenance of any activity. Without the support from the general population, PLHA cannot be mainstreamed".

LAR Case Study 4: Facilitating linkages among PLHA in neighbouring districts, the ART Centre and NGOs, in Churachandpur, Manipur

In brief: The Manipur Network of Positive People (MNP+) has assisted PLHA in other districts facilitating CD4 testing and ART services in Churachandpur by facilitating appropriate linkages.

Description: PFI state office, earlier this year (2006) had requested the DLN to help clients from other districts as those districts do not have proper CD4 testing facilities and ART services.

For the last two to three months (from the date of data collection) the DLN has started helping clients from other districts as well. Till date the DLN had referred about 44 clients (from other districts) to Churachandpur

ART Centre, and there are more clients from other districts who have gone directly to the ART Centre without first coming to the DLN.

Beneficiary: In an interview with a beneficiary from the adjoining Bishnupur district, he said: *I am a 36 years-old man from Bishnupur district. I live in a nuclear family with my wife and two children. I was tested positive five years ago. Due to the various health complications, I visited doctor and he prescribed me medicine for ART. But in the Bishnupur district, there is no ART Centre. So, I have to go either to Imphal or Churachandpur. Geographically, Churachandpur is near to our home compared to Imphal. So, I visited ART Centre Churachandpur and where I met the counsellor of the Churachandpur DLN. She advised me to come and visit the DLN for more services and support. With their help I got free ART from the centre. They also advised me to visit the DLN every month when I come for my medicine. The DLN has also helped me obtain medicines through [an NGO] Shalom.*

Now, my health condition has somewhat improved. I can work in the field for my children's education. Earlier for my treatment, we had spent all our resources and my children could not go to school.

Lessons learned: While decentralisation of care and support at the district level is ideal, the pace of decentralisation may not be uniform across districts. Hence DLNs can play an active role in supporting PLHA from districts where services are not available.

LAR Case Study 5: Linkages and Referrals with counselling services in NGOs and VCTC in Prakasam, Andhra Pradesh

In brief: Referrals among the DLN, VCTCs and key NGOs in the district provide effective linkages to a variety of counselling services for people living and/or affected by HIV, including couples counselling, child counselling and peer-counselling.

Description: A Focus Group discussion with the DLN staff of Positive People Network (PPN+) in Prakasam, revealed the process of building effective linkages with local NGOs and VCTC Counsellors. In May 2005, the DLN engaged in a resource mapping of the district to identify and prioritise different service delivery points in the district for its member PLHA. The DLN initiated rapport and networking with different NGOs. PASCA (Planned Action Service Committee for Achievement), an NGO engaged with HIV/AIDS prevention activities, played a vital role in strengthening the DLN services through counselling the referred PLHA from the DLN.

The VCTC associated with the Government General Hospital referred PLHA for enrolment to the DLN after testing and counselling services. In turn, the DLN was able to refer their members to the VCTC for such couples' and child counselling.

Facilitator: Mr. Veeraiah, the Project Manager of a local Ongole based NGO PASCA briefed about his organisation and its HIV/AIDS related services since the year 2000 for the vulnerable groups including the street and migrant children, commercial sex workers and PLHA. The operational area of PASCA is Tangutur and Ongole mandal of Prakasam district. He shared that, in initial period, as part of organising a medical camp in Ongole, the DLN approached PASCA to render support and involve in its referral activities. The PASCA team extended the fullest possible support to the DLN initiating a networking system with other NGOs too in the district. PASCA and the DLN mutually coordinated referral services that brought in effective service delivery to the PLHA. PASCA referred many PLHA to avail services of the DLN at its drop-in-centres. In this way, the DLN and PASCA succeeded in reaching hitherto unreached PLHA in the district.

Another NGO, Lakshmi Development Society also refers PLHA from commercial sex workers background to the DLN for availing services like psychosocial support and positive peer-counselling.

Lessons learned: Effective networks with the local NGOs and VCTC in the district have improved the mutual referral systems wherein the PLHA enrolment rate increased and follow up through service linkages have been made effective.

LAR Case Study 6: Multiple networks in Tamil Nadu are linked with shelter and educational institution for children infected and/or affected by HIV/AIDS

In brief: Five district level networks. Thoothukudi (TTD), Tanjore (TNJ), Trichy (TRY), Theni (THE), Madurai (MDR) have developed linkages with a residential institution named "Reaching the Unreached" (RTU) at Vethalagundu (Theni district) where children (infected and/or affected by HIV/AIDS) are given care and educational support till their graduation.

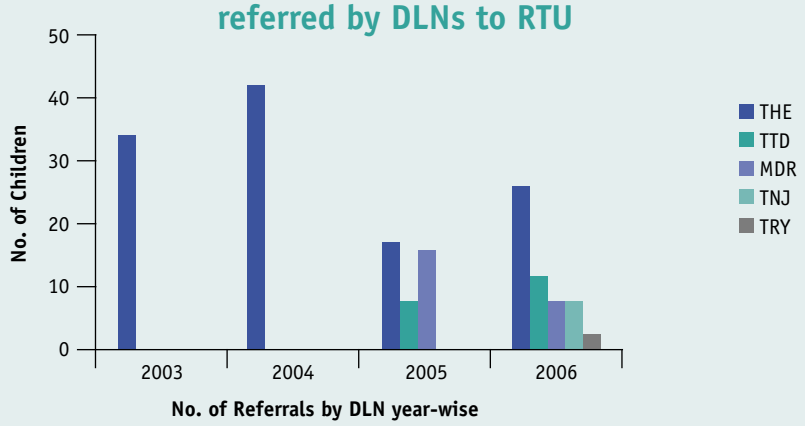
Description: This good practice evolved out of an initiative by Mr. Pitchaimani of Theni, who, in 2000–2001, first made contact with RTU in order to admit his own child, as he was facing financial difficulties. After forming the Theni HIV positive network in 2001, the network started referring children from Theni. The agency (RTU) originally began as a shelter for destitute women, including widows. It is these women who eventually took on the role of caregivers to children infected and affected by HIV.

Later on, in the year 2005, when Mr. Pitchaimani moved to a leadership position at the State Level Network, he arranged an advocacy meeting at RTU with the help of members from other district networks such as Tirunelveli, Thoothukudi, Perambalur, Chennai, Kanchipuram, Trichy, Dindikul, Madurai and Pudhukotai. The purpose of the meeting was to sensitise the RTU staff on issues of HIV infected and affected children and also to inform the

networks about the service availability at RTU. So from that year other DLNs began referring children of economically weaker PLHA to RTU.

Testimonies from members: During focus group discussions with staff of five District Level Networks (Thoothukudi, Tanjore, Trichy, Theni and Madurai), there was unanimous acknowledgment of the role played by Mr. Pitchaimani in establishing contact with RTU, and catalysing referrals of children from various district level networks.

Figure 8: Number of Infected and Affected Children's referred by DLNs to RTU



Beneficiary 1: *"I have been a member of Thoothukudi District Level Network for the past one year. I have two children and my husband doesn't take care of the family well. I met the DLN staff in the government hospital when I went for a check up during my second pregnancy, where they assisted me and accompanied me to receive the hospital services at the GH. With the help of the DLN I have participated in the support group meetings conducted by them in the hospital. Attending the support group meetings and the meeting at the DLN office gives me psychological support. Though my first son is not infected with the virus, my second child is HIV positive. In the meetings, I have shared with the DLN my inability to bring them up and they told me about this institution. It was then that I felt that at least my children could receive good care and proper education for a bright future. RTU has helped my children in manifold ways, my second child was sick most of the time before moving to Reaching the Unreached, but now the child is doing fine after his/her shift to the institution."*

Beneficiary 2: *"I have two children: the first one, my daughter, is 5 years old and HIV negative, and is studying at RTU. My son who is 3 years old is HIV positive and is living with me. Initially when the Thoothukudi network told me about the institution, I was very much upset and confused about the prospect of admitting my child to the institution. My family members were also against the idea of admitting the child into the institution. Against all of their wishes I decided to admit my daughter into RTU to provide her a good education and ensure her bright future. I am sure my daughter will also*

understand that I have done this for her welfare only. My daughter is also enjoying the environment and she is very happy with the women who take care of her."

Challenges: As the graph shows, the majority of referrals to date have been from Theni. This is partly a consequence of the challenges imposed by long-distances, inhibiting referrals from networks situated farther away from the care centre.

Lessons learned: This case study illustrates the good practice of referral and linkages, and also the benefits of sharing information across positive networks. It stands as a testimony to the impact of advocacy.

LAR Case Study 7: Government-Positive Network linkages benefit women living with HIV/AIDS in Aurangabad, Maharashtra (also ADV, DS)

In brief: The Network of Aurangabad District People Living with HIV/AIDS (NAP+) has successfully developed linkages with the Aurangabad Municipal Cooperation for donations of sewing machines, that have been distributed to women from the PLHA community, and are additionally being used by the network for training members in sewing. Links with the Government Polytechnic have enabled the network to avail the services of a lecturer who conducts classes in sewing and social marketing at the network premises.

Description: Since the inception of NAP+ in June 2004, women members – many of them widows—had been actively seeking means of income generation. In the process of making enquiries they came to know that Aurangabad Municipal Cooperation (AMC) was granting free sewing machines to women below poverty line. At that time, the standard protocol was that local leaders (Nagar Adhyaksh) could recommend two women each, to the AMC Mahila Bal Kalyan Samiti department. The network president Mrs. Sunita Kathar approached the President of Mahila Bal Kalyan Samiti, Dr. Gyanda Kulkarni and told her about the organisation. Following several repeat visits for advocacy and strengthening linkages, the network, with the guidance of Dr. Gyanda Kulkarni, submitted a grant proposal for 41 sewing machines to AMC in August 2004. With continuous follow up the DLN succeeded in obtaining sewing machines in January 2006. The network then distributed 31 machines to women members who had skills and interest in sewing. The network retained nine sewing machines at the network premises to provide training to others who wanted to learn sewing. Through links with the Government Polytechnic, the network has been able to avail the services of a teacher who conducts classes at the network premises six days a week, from 3 pm to 5 pm. Under the training programme, the lecturer also provides them training on social marketing.

Facilitator 1: Dr. Gyanda Kulkarni, Education Officer and President of Mahila Bal Kalyan Samiti, stated in her interview that she had always wanted to do

something to assist women with HIV, and when DLN president Mrs. Sunita Kathar approached her, she was willing to help her. She assisted DLN in developing the proposal for the machines.

Facilitator 2: Dr. Thorat, Principal of Government Polytechnic Aurangabad, helped the network to get free sewing classes under a Central Government programme aimed at generating employment opportunities. The only criterion was that there should be more than 30 students per batch. So when DLN approached him he was more than willing to help them.

Beneficiary 1: Mrs. K became a member of the DLN in January 2006. Her financial condition was very bad as she was the sole breadwinner and had lost her husband to the disease. The DLN then gave her a sewing machine and also provided her training on basic sewing which included making petticoats, blouses, salwar kameez, frocks, curtains, falls, etc. She underwent two months of training following which she was able to supplement her family income through sewing. She is in all praise of DLN, and now wants DLN to help her scale up the business through making school uniforms.

Key informant interviews with five other women revealed similar narratives.

Challenges: More initiatives for social marketing of the finished garments are needed to strengthen the income generation component of this activity.

Lessons learned: Resourcefulness in learning about existing government schemes and advocating with the concerned departments can help foster strong linkages. The linkages need not be restricted to monetary or in-kind donations, as illustrated by the practice of having free classes donated by the polytechnic. These good practices may be considered for replication by networks in other districts.

LAR Case Study 8: Linkages with private pharmaceutical company helps in procurement of ART at concessional rates in Aurangabad, Maharashtra.

In brief: DLN developed linkages with pharmaceutical company CIPLA for ART drugs at the concessional rates with 20% discount, and around 25 people have benefited till date.

Description: Prior to the availability of ART from the state network NMP+ at Pune through the TAAL project, the situation in Aurangabad was such that most of the Aurangabad network members needing anti-retroviral therapy had to go to Mumbai for ART treatment. Following meetings with one of the medical representatives of CIPLA, the Aurangabad network was able to partner with CIPLA for obtaining ART drugs at 20 % discount.

Beneficiary 1: Mr. T is 33 years old and was diagnosed in 2006, under the PPTCT programme. He was referred to the DLN from the PPTCT centre. When his CD4 count was discovered to be below 200, he had to be put on ART and was sent to Mumbai. The tedious process and travel involved made him turn to a private practitioner in Aurangabad; however he was not able to afford the market rate for ART. The network enabled him obtain ART from CIPLA at the discounted rate. He was so satisfied by the help that he started volunteering for DLN as a peer counsellor at the Government Medical College Hospital PPTCT Centre. Subsequently he joined as the Treatment Education Officer at the DLN.

Three other beneficiaries reported similar benefits of the linkage with CIPLA in their key informant interviews.

Lessons learned: In districts where ART Centres or government/network-aided free ART is not yet available, linkages with pharmaceutical company can benefit those who are unable to afford the retail price of medicines.

LAR Case Study 9: Linkages with counsellors from VCTC and PPTCT strengthen services to people infected by or at risk of HIV in Theni, Tamil Nadu, and Aurangabad, Maharashtra

In brief: Through effective linkages and rapport with counsellors from VCTC and PPTCT centres, the Theni District Network for HIV Positive People (TDNP+) and Network of Aurangabad by People Living with HIV/AIDS (NAP+) have been able to increase referrals, counselling, and follow-up services.

Description: TDNP+ and NAP+ have developed strong linkages with the counsellors from VCTC and PPTCT centres in the district.

In Theni, the network initially invited counsellors from VCTC and PPTCT to explain the network activities. At present, the network members attend monthly meetings of counsellors organised by local NGOs. TDNP+ staff assists in management of hospital attendees. Counsellors refer PLHA to the DLN. They also help with follow-up of ICTC attendees diagnosed positive. Counsellors refer PLHA to the TDNP+. In focus group discussions, the counsellors testified the effectiveness of their links with the positive network.

In Aurangabad, the network NAP+ was formed initially at the VCTC of Government Medical College Hospital, Ghatti. The doctor in charge of the VCTC (Dr. Bajaj) helped to initiate the network, and spread word of the activities of the network to other doctors. The close association between the network and the VCTC continues to be sustained through linkages maintained by staff of the respective units.

Doctors from the VCTC and the newly formed ART Centre in Aurangabad conduct information sessions for NAP+ members on OI, STI, importance of

hygiene, etc. Most members enrolled at the network are referrals from VCTC and PPTCT centre of GMCH. Effective monitoring of PLHA is possible through the efforts of NAP+. Space has been given by the VCTC to peer-counsellors and volunteers from NAP+. The VCTC counsellor reported that the presence of peer counsellors has also alleviated his own counselling load.

The Treatment Education Officer at NAP+ testified the relevance of the NAP+-VCTC linkages in his own life. He was diagnosed positive at the VCTC and referred to NAP+. Soon he became a volunteer for the network and used to work informally at the VCTC as a peer-counsellor. Eventually he gained employment in the network as Treatment Education Officer.

Lessons learned: HIV Counsellors play a key role in motivating individuals to get tested, and in providing support to people diagnosed positive. Maintaining effective linkages between counsellors and district level network can benefit PLHA in areas of follow-up and other services.

5.6 Greater Involvement and/or Employment of Positive People (GIPA)

While the very existence of PLHA groups such as DLNs is evidence of the GIPA principle in action, in this section we consider specifically the involvement and/or employment of PLHA in Regional/National Positive Networks, District AIDS Advisory Committees, NGOs, Counselling and Testing Centres (PPTCT/ ICTC/ VCTC), NGOs (HIV/AIDS Prevention and Care & Support projects), and in capacity-building for healthcare providers.

GIPA Case Study 1: GIPA through placement of DLN staff in hospital in Belgaum district, Karnataka

In brief: Placement of a Public Relations Officer of Spandana, the Belgaum Positive Network, in the government hospital, has helped increase uptake of counselling and testing services at the hospital.

Description: Spandana, the DLN, initiated this practice. The placement of the PRO has had a very good impact both on the membership of the network, as well as with regard to access to the services offered by the hospital. It has been very helpful that the PRO is (a) a PLHA, (b) a member of Spandana staff, and (c) present at the hospital where HIV positive people come into contact with the VCTC services of the hospital. The referral process has been stronger because of the PRO's presence.

As one of the DLN staff members puts it "*Before we set up the PRO at the hospital, we had very low registration with Spandana. After setting up the PRO, there are about 60 referrals per month. Of this, about 60% are actually registering with us…The PRO is the first and public face of Spandana.*"

A member of the PPTCT staff at the hospital substantiated this increase in uptake of services by acknowledging that about 80% of her clients agree to meet the PRO, and that there is an increase in number of clients availing PPTCT services because of PRO's presence.

Lessons learned: This case study illustrates the importance of the "first and public" face of a DLN being present at the hospital when people find out that they are HIV positive. The counselling process is helps in confidence-building when another person is able to say "I am also a PLHA", and offers oneself as an example. This gives considerable boost to the morale, hope, and comfort of the clients.

GIPA Case Study 2: Involvement of Positive Network at women's sub-jail programme in Tiruchirapalli, Tamil Nadu, enhanced uptake of VCTC services

In brief: The District Level Network in Tiruchirapalli district, Tamil Nadu, partnered with a private hospital at an awareness programme in the women's sub-jail, which motivated several inmates to go in for voluntary counselling and test.

Description: A private hospital – American Hospital – has been conducting HIV awareness programmes at the district sub-jail every Friday. One of the problems faced by the group was the indifference of the prison inmates to information on HIV, resulting in low rates of voluntary counselling and testing. Consequently, the counsellor Ms. Elisabeth, then associated with the hospital approached the positive network with a request to depute a member who could motivate the prison inmates for VCTC through positive speaking. In an interview with the field-team, she recalled that the programme involving the positive speaker drew an unprecedented audience of approximately 300 prison inmates.

Positive speaker Ms. Latha shared that she had been assisted by the network through its support groups and also helped her with CD4 testing. This had developed her faith in, and commitment towards, the network. When the network was approached by the hospital for positive speaking, she readily agreed. During the programme she engaged the audience intensely, and received many queries about HIV. After the programme many women came forward voluntarily for HIV counselling and testing, and also enquired about the positive network. Eleven women tested positive.

Lessons learned: Greater involvement of positive people can motivate VCTC uptake in such populations as prison inmates. Positive networks located in towns and cities where prisons exist, can potentially get involved in prison interventions, as they are likely to have great success in engaging the prisoners and motivating them for getting counselled and tested.

GIPA Case Study 3: Involvement of PLHA in support to women availing PPTCT services at Kovilpatti General Hospital, Thoothukudi, Tamil Nadu

In brief: All women attending the ante-natal mother programme at Kovilpatti are being counselled and tested for HIV. DLN staff is providing supportive services to those testing positive. This good practice has enabled DLN to be recognised by the hospital staff as a provider of useful services, and illustrates GIPA in action.

Description: Peer field staff of the DLN are following up women who have undergone voluntary counselling and have tested positive. From the initial stages of being tested and until the delivery of the child, peer staff accompany the women throughout their hospital rounds. Upon delivery, they conduct monthly follow-up until the child gets tested for HIV at 18 months. If the child is confirmed to be positive the DLN helps them to receive medical and other assistance from government and NGOs. According to DLN staff, the objective of assisting pregnant women at the ICTC is to facilitate timely access to clinical tests, help identify new HIV infections, and illustrate the role of the DLN as a service provider. The role of the DLN has been commended by counsellors at the hospital and by women who have benefited from their support.

Beneficiary 1: Ms. E has been a member of this DLN for the past year. She has two children and reports being neglected by her husband. She first met and was assisted by DLN staff in the government hospital during her second pregnancy. The DLN staff helped her in receiving the hospital services at the GH, and enrolled her in support group meetings. When the second child was diagnosed HIV positive, the DLN assisted the mother in admitting him into a care and educational institution 'Reaching the Unreached' as she lacked the resources and support system to raise the child herself.

Lessons learned: While the primary objective of the described activity was to enhance the identification of PLHA, it has additionally helped the DLN to build up a good relationship with the hospital staff and improve service delivery for the PLHA. This good practice also illustrates the benefits GIPA can have in program functioning within clinical settings.

GIPA Case Study 4: Network helps build capacity of doctors in HIV Management in Thanjavur, Tamil Nadu

In brief: The Thanjavur district level network has helped organise a training programme for doctors from Primary Health Centres (PHCs) and Taluk level hospitals in the district. This programme has resulted in increased referrals from these institutions to the Thanjavur ART Centre.

Description: With support from Arockiaagam, an NGO, the Thanjavur network initiated and facilitated a training programme on HIV/AIDS for about 80 physicians from the primary and secondary health care facilities in

Thanjavur district. The purpose of the training was to provide an overview of HIV and OI management, publicise the services of the newly opened ART Centre, and promote referrals to the centre.

The network first consulted with the Deputy Director of Health Services, who recommended that they get permission from the District Collector. After securing the necessary clearances and permissions, the network conducted the programme, which was inaugurated by the Collector, and involved ART physicians from Madurai and Thanjavur as resource persons.

The doctors who attended the training programme were aware of the basics of HIV/AIDS, and also had theoretical knowledge on HIV/AIDS clinical management. However, they lacked practical experience in clinical management of HIV/AIDS cases. The training programme focused on clinical management of OIs and STIs at PHC level, referring the cases to the district hospital for ART. The resource persons also informed the physicians of the diverse range of services available at the district hospital for PLHA.

According to resource person Dr. Parthasarathy, ART Medical Officer, Madurai, the participation and involvement of the Deputy Director, Health Services and Joint Director, Medical Services, contributed to the success of the programme.

A staff member from the supporting NGO Arogyam noted that the Thanjavur network was one of only two in the state that been able to carry out the training programme and utilise funds effectively.

Dr. Jayaseelan, ART physician at the Thanjavur Medical College Hospital, who was one of the resource persons at the training, reported an increase in effective referral of PLHA from the PHC and Taluk hospitals to the ART Centre; approximately 8 – 10 cases referred from each facility every month.

Lessons learned: Involvement of positive people and networks in capacity-building initiatives for health care providers serves the dual purpose of increasing knowledge levels, decreasing stigma and raising the profile of the community. Inclusion of the District Collector, and key health/medical officials was pivotal to the success of the programme.

5.7 Miscellaneous (MISC)

In this category are included practices and systems such as the development of a positive speakers' bureau as an advocacy tool, and positive marriage bureau.

MISC Case Study 1: Positive Speakers' Bureaus of East Godavari and Guntur districts in Andhra Pradesh

In brief: The DLNs of East Godavari and Guntur have institutionalised Positive Speakers' Bureaus each comprising around 70 PLHA members at

the district level. Interactions with the staff of both networks revealed that there was an unanimous acknowledgement of the role played by the Positive Speakers' Bureaus in establishing rapport with the general public, in encouraging the newly identified PLHA to be part of the DLNs and also enhancing their knowledge by disseminating information on HIV/AIDS. The Positive Speakers' Bureau further plays a significant role in positive prevention amongst PLHA.

Beneficiary 1, a member of the Positive Speakers' Bureau, (East Godavari) was cheated by quacks and lost Rs. 1 lakh or two for his HIV treatment. After learning the DLN and its activities, he enrolled, and started attending the support group meeting. He then also readily accepted the offer to join the Positive Speakers' Bureau. Now he is actively involved in disseminating information on HIV/AIDS. On many occasions, participants of the support group meeting expressed doubt of his positive status considering his outwardly healthy physique. However, he was able to convince them all by explaining that initially most people with HIV positive status appear outwardly healthy, but become sick if they do not start to take medicines and become self caring. He has thus helped dispel stereotypes of PLHA through his PSB activities.

Beneficiary 2, a female PLHA, underwent depression and trauma upon learning of her status. The Counsellors at Government hospital, Guntur referred her to the DLN, Guntur where she was initially oriented on HIV/AIDS. She got opportunity at the DLN in getting to learn more about other PLHA and their conditions. Later, she underwent training under the AASHA campaign and has served five mandals of Guntur district as a Positive Speaker. As a positive speaker, she is very much involved in advocacy, and attributes therapeutic value to her training and experience as a positive speaker in helping her overcome personal grief.

Lessons learned: Information received through the positive speakers' bureaus benefit the PLHA directly, and indirectly through sensitising the general community. Mandal level activities of the PSB further aid the project of decentralisation of care and support services.

MISC Case Study 2: Positive Speakers Academy in NTP+, Thane district, Maharashtra

Since December 2005, NTP+ has been implementing activities in positive speaking, with support from a UNICEF project. PSA was originally developed as a means of sustainability for NTP+. Members themselves have developed a curriculum and course content for the Positive Speakers Academy, which includes such areas as personality development, sex and sexuality, myths and misconceptions. NTP+ has also trained one or two positive speakers in other districts such as Satara and Pune.

Key members of the DLN have been involved in PSA activities, and are very outspoken about their status and the need to reach out to other PLHA and society at large through the PSA.

Ms. S, a member of NTP+ first made contact with the group in 2005. Inspired by the support she received at the network, she became a regular member and participated in trainings and counselling sessions. Driven by the conviction *Majha sarke mi ekti nahi yein pan ajoon lok aheinthein jein majha sarkhein cha ahein* (I am not the only person, there are also other people who are like me), she grew passionate about speaking in public. The issues she addresses as a speaker include: positive living, health and hygiene, diet and adherence to medication. Among her achievements as a PSA member is an interview in Loksatta newspaper in which she spoke about her child's negative status, and shared her tips on healthy living. She feels PSA training has given her enough confidence to speak in front of 1000 people. She reports that she has gained confidence in speaking to friends and family from her experience with the PSA.

Ms. B, the DLN staff member, said that PSA training had helped her a lot in building her confidence and in answering questions. She illustrated this with the example of an event organised by MSACS on 'World AIDS Day' attended by the Maharashtra Chief Minister and other dignitaries. She was asked to make an impromptu speak, and was able to do it, the result of confidence built through the training she has received through the PSA.

In addition to positive speaking at advocacy events like Larsen and Toubro's work place awareness and sensitisation programme, Central Board of Workers' Education (CBWE) etc., members of the PSA also give interviews in newspapers, radio shows and on television in which they also publicise their email and other contact information. By doing so, they have been successful in raising the profile of the organisation, generating awareness and understanding, and letting other PLHA know of their services.

An event in which PSA members were involved: the Dabbawala Campaign on World AIDS Day 2005.

Lessons learned: This case-study shows how capacity building at community level and positive speaking can help in mainstreaming, thus helping in reducing stigma and discrimination faced by PLHA and in improving their condition.

MISC Case Study 3: Positive Marriages in Kadapa, Andhra Pradesh

" … Sure, we cannot predict of what will happen tomorrow, however, we can certainly plan carefully for our future".

Leading a life without a spouse is very difficult for PLHA, many of who are young widows with children. Keeping this concern in mind, the DLN President

Mr. Sameer thought of the option to perform marriages among the positive people. He discussed this issue in different support group meetings and invited suggestions from the members as well as from the general community. Most of the PLHA appreciated the opinion of performing marriages among the positive people. After ten days of the proposal, a positive woman and man came forward and sought help from the DLN in getting married. By June 2006, four such marriages among four positive couples had been facilitated by the DLN.

Some women PLHA were worried about the fact that they had already lost their first husband and were not sure of risking a second bereavement if they got married. The DLN staff sought the help of a counsellor at a private hospital in convincing them. DLN received enormous support from certain members from the general public. The DLN has a plan to perform more marriages among the positive people in the future at the district level.

Beneficiary 1 Mrs. C lost her husband in the year 2003 to AIDS when she was not aware of her positive status. In the year 2004, when she learned about her sero-status, she became depressed and contemplated suicide. Meanwhile, she met the DLN president, whom she had known for quite long, and subsequently became a member of the DLN. A neighbour of Mrs. C was HIV positive and caring for his terminally ill wife and two children. He approached the DLN President and communicated his intention of marrying C since she was also a widow. The same proposal was also presented to his wife who too agreed to the idea. The DLN staff took one-month time to mobilise support for the general community, and finally performed the marriage in mid 2006.

Facilitator: Mr. K, a photographer by profession works for several print media in the district, and is also involved in a fan association. Once in the year 2003, he happened to meet the DLN President, and was inspired by DLN's services and assured to render possible support to the network. In the year 2005, when the DLN President decided to perform marriages among Positive People, he discussed the same with K and requested for possible support in performing such marriages with out any problems and obstacles from general community. Mr. K made his presence at the marriage function and mobilised media to cover the event in newspapers and telecast in visual media. Mr. K has been a constant source of external support to the endeavour.

Lessons learned: *Positive marriages are a way to enhance quality of life and mutual support for PLHA. They require broad community and family support to be successful, and the DLN can help facilitate the process.*

6 Recommendations

Despite downward revisions in national estimates of HIV prevalence, ensuring universal access to care and treatment remains one of the most pressing issues on India's HIV/AIDS agenda.

A recent study on access to care carried out by the Maharashtra Association for Anthropological Sciences (MAAS-CHRD 2006) in three districts of Maharashtra, Andhra Pradesh and Orissa, recommended the following ways in which access could be measured:

- Studies of enablers and barriers to care
- Situational analyses using qualitative methods
- Studies of disease burden and coping mechanisms
- Studies to document needs of PLHA at different stages of illness
- Studies to determine response of public, private, and NGO sectors to needs of PLHA.

The present study identified enablers of care that had been developed by District Level Networks in 25 districts. It examined several activities in the areas of networking, direct services, linkages, referrals and advocacy that are worthy of continuation and replication by other DLNs.

The activities varied with respect to the degree of impact, and scale of replicability. While activities such as the support group meetings were high on both criteria, others such as the marking of symbols on medicine bottles clearly need to be scaled up to benefit communities with low levels of literacy. It is hoped that the selected case studies will allow DLNs learn from the collective experiences and enable transfer of good practices across states and districts.

Through our examination of district level networks in this study, some themes were found to be associated with high numbers of good practices. These include:

- ***Presence of charismatic and committed leaders*** at the district and state levels (too many to mention).
- ***Existence of other projects in addition to the Access to Care and Treatment project***, enabling synergy and resource-sharing across projects. Examples include the UNICEF project for positive speakers that strengthened advocacy

in the Thane network in Maharashtra, and projects being supported by Faith Based organisations in northern Karnataka and Manipur.

- ***The role of key external individuals*** such as physicians and government officials who leveraged their own resources or skills to enhance the access to care and treatment through linkages with the networks.

- ***Information sharing and collaboration across networks***. Strong examples are the advocacy involving multiple networks (Satara, Kolhapur, Sangli) that resulted in enhanced hours and access at the Sangli ART Centre in Maharashtra, and the information sharing across networks in Tamil Nadu that has resulted in over 100 children infected or affected by HIV being referred to the care home 'Reaching the Unreached'.

With India's National AIDS Control Plan (NACP-III) emphasising both **decentralisation of care** and **increased involvement of communities** in managing interventions, the need to strengthen the capacity of district level positive networks is high. The present study offers the following **recommmendations** for organisations involved in building capacity of DLNs:

- Help build and strengthen leadership, both first and second line.

- Actively involve DLNs in development of additional programs (e.g. through training in planning, proposal writing)

- Promote district level experience sharing and review meetings of DLN staff with diverse stakeholders

- Promote inter-DLN exchange at state (and national) levels

- Invest in initial and periodic institutional assessment of networks, including visioning exercises and SWOT analyses

- Enhance skills in documentation and communication for DLN staff.

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