

Spandana

A Comprehensive Rural HIV and AIDS Programme

**Raichur, Karnataka
October 2009 - June 2012**



Swasti Health Resource Centre



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Contents

Abbreviations	3
1. Introduction.....	4
2. Background.....	4
2.1 Socio-economic and health scenario of Raichur	4
3. Programme Initiatives.....	9
3.1 Village Information Centres	9
3.2 Mobilisation of Volunteers & Creation of Red Ribbon Clubs.....	10
3.3 Mass HIV and AIDS Awareness Programme.....	12
3.4 Demand Generation for Local Health Services	12
3.5 Linking PLHIV to treatment and preventing parent to child HIV transmission	14
3.6 Addressing stigma and discrimination.....	15
3.7 Working in partnership with Panchayaths.....	17
4. Key Achievements, Signs of Change and Challenges	18
4.1 Key Achievements	18
4.2 Signs of change.....	19
4.3 Challenges	21
5. Concluding Observations.....	22
6. Annex: List of people interviewed through field study.....	24

Abbreviations

AIDS	Acquired Immunodeficiency Syndrome
ANC	Antenatal care
ANM	Auxiliary Nurse Midwife
ART	Antiretroviral Therapy
CCC	Community Care Centre
DAPCU	District AIDS Prevention and Control Unit
DBS	Dried Blood Sampling
DOT	Directly Observable Therapy
HIV	Human Immunodeficiency Syndrome
HRG	High Risk Group
IDU	Injecting Drug User
NACO	National AIDS Control Organisation
PLHIV	Person living with HIV
PPTCT	Prevention of Parent to Child Transmission
STD	Sexually Transmitted Disease
STI	Sexually Transmitted Infection
UNDP	United Nations Development Fund
UNICEF	United Nations Fund for Children
VIC	Village Information Centre
WSW	Women in Sex Work

1. Introduction

In October 2009, Swasti commenced *Spandana*, a comprehensive rural HIV prevention programme in Raichur District of Karnataka, India. Funded by the United Nations Children’s Fund (UNICEF), *Spandana* is part of the Link Worker scheme developed under National AIDS Control Programme III. Link workers are introduced at the village level to provide information on HIV and general sexual health and link the rural communities to HIV prevention, care and support services.

This report discusses the implementation of *Spandana* and its key initiatives. It identifies some early signs of change as a result of the intervention and key implementation challenges faced. The report has been compiled following a three day field visit by two members of the Swasti team in May 2011 during which consultations were conducted with project staff, local health officials, ASHA and Anganwadi workers, women in sex work, people living with HIV (PLHIV), self-help groups, Gram Panchayath members and others members of the village. A complete list of persons consulted is provided in the Annex. This report also draws on findings of an assessment of the implementation of the link worker scheme in Raichur, conducted in July 2011 by ICRA Management Consulting Services (IMACS), on behalf of the National AIDS Control Organisation (NACO), UNICEF and United Nations Development Programme (UNDP) (hereinafter, the NACO Evaluation).

The names of certain individuals mentioned in the document have been changed to protect their identity.

2. Background

2.1 Socio-economic and health scenario of Raichur

Raichur is one of the least developed districts of Karnataka, with poor health outcomes, low literacy levels and one of highest HIV prevalence rates in the state. Located on the border of Karnataka and Andhra Pradesh, Raichur is a major transit hub connected by rail and road to major cities like Bangalore, Mumbai, Chennai, Hyderabad, Ahmedabad and New Delhi.¹ Administratively, Raichur has five talukas - Sindhanur, Raichur, Manvi, Devadurga and Lingsugur, 164 Gram Panchayaths and 830 notified villages (see figure 1).²

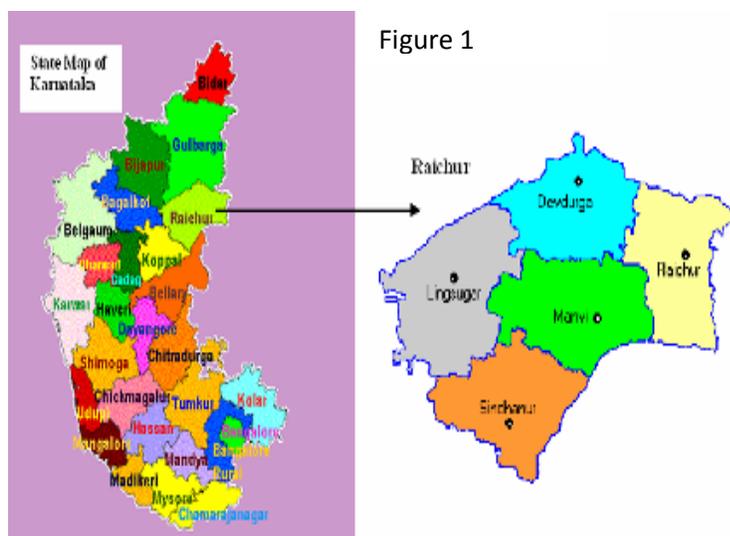


Figure 1

¹ Swasti. *Raichur Comprehensive District HIV/AIDS Programme Proposal*, September 2010.

² NACO, UNICEF and UNDP, *Assessment of Link Worker Scheme in Raichur Karnataka: Report on Top-line Findings*, August 2011, pg 1.

The population of Raichur is 1,924,773 million, with a population density of 228 persons per square kilometre. The population over the past 10 years has grown rapidly at a rate of 15.27% and its sex ratio stands at 992 (females per 1000 males).³ Poverty is high and there are relatively few employment opportunities within the district. The literacy rate is 60% - 71% among males and 49.5% among females.⁴ Health outcomes are also poor, with the district's maternal mortality rate as high as 144 deaths per 100,000 live births and an infant mortality rate of 23 per 1000 live births.⁵

Though there have been some improvements, the HIV situation remains a concern. HIV prevalence among women tested in Prevention of Parent to Child Transmission (PPTCT) centres as part of antenatal care (ANC) in 2003-04 was around 1.25% and continued to record around 1% during 2005-06⁶, but 2009 PPTCT data shows it declining to 0.51%⁷. This decline is potentially due to expansion of PPTCT facilities to low risk areas and changing risk profiles of the women tested over the years. However, 2009 data on HIV positivity among those walking into Integrated Counselling and Testing Centres (ICTC) was higher than previous years- 26% among males and 11% among females.⁸ According to DLHS-3 conducted in 2007-08, the percentage of women with correct knowledge of HIV and AIDS is high, 88.6% of married women and 90.9% of unmarried women. However, this did not translate into a change of behaviour with a very small percentage undergoing HIV testing (less than 20% in both the married and unmarried categories).⁹

The health facilities present in the district include 218 sub health centres, 46 primary health centres, four community health centres and a district hospital. HIV-related facilities include 28 ICTC, 25 PPTCT, six government-recognised blood banks and a sexually transmitted diseases (STD) clinic. Services for PLHIV include a community care centre (CCC), an antiretroviral therapy (ART) centre, 2 link ART centres and a CD4 machine and a PLHIV network.¹⁰

The poor health scenario in Raichur is due to several factors. There is poor access and utilisation of the available health services. This is due to poor transportation and communication infrastructure, lack of qualified staff, irregularity and non accountability of bureaucracy. Moreover, women tend to have children young and have multiple and closely spaced pregnancies. The percentage of girls

³ Census of India, 2011 <http://censusindia.gov.in/2011census/censusinfodashboard/index.html>.

⁴ Census of India, 2011 <http://censusindia.gov.in/2011census/censusinfodashboard/index.html>.

⁵ Government of Karnataka. Karnataka NRHM PIP 2009-10 < <http://stg2.kar.nic.in/healthnew/NRHM/PDF/PIP/Final%20write%20modified%20after%20NPPC%202009-10.pdf>>, pg 74.

⁶ NACO, UNICEF and UNDP, *Assessment of Link Worker Scheme in Raichur Karnataka: Report on Top-line Findings*, August 2011, pg 1.

⁷ India Health Action Trust. *HIV/AIDS Situation and Response in Raichur District: Epidemiological Appraisal Using Data Triangulation*, July 2010, pg 12.

⁸ India Health Action Trust. *HIV/AIDS Situation and Response in Raichur District: Epidemiological Appraisal Using Data Triangulation*, July 2010, pg 15-16.

⁹ Ministry of Health and Family Welfare, Government of India, *District Level Household and Facility (DLHS-3) Raichur District Fact Sheet*, 2007-08., pg 5.

¹⁰ India Health Action Trust. *HIV/AIDS Situation and Response in Raichur District: Epidemiological Appraisal Using Data Triangulation*, July 2010, pg 10.

marrying before the age of 18 is almost 39% and less than half the women (45.5%) using any form of contraception.¹¹ Several factors drive the high risk sexual behaviours and HIV infections in the district. Raichur is a major transit hub and there is significant movement of people in and out of the district. Many of men work as truck drivers or gain employment in nearby cities and return to Raichur periodically.

2.2 About Spandana

The Spandana programme has been operating since October 2009 in a 100 core villages spread across all five talukas of Raichur district. The 100 villages were selected based on population and HIV prevalence. The purpose of the programme is to develop a replicable and sustainable rural intervention model that enables the target population to prevent and manage HIV infections through innovative and multi-sectoral collaborations (see programme design in figure 2).

Spandana's objectives are to:

- Improve access to information, knowledge and skills on prevention of HIV and other sexually transmitted infections (STIs).
- Encourage behaviour change to ensure increased and consistent use of condoms.
- Enhance demand for and utilisation of services (especially ICTC, PPTCT, ART, Directly Observable Therapy (DOT) for Treatment of Tuberculosis and other health services).
- Reduce vertical transmission of HIV from mother to child before, during and after child birth by ensuring access for counselling and testing, care and treatment of mothers and follow up care of mothers and infants.
- Facilitate early infant diagnosis and treatment of infected infants/children and ensure drug adherence.
- Ensure children affected by AIDS have equal access to services and care (family/alternate), without discrimination and at par with other children in their communities.
- Create an enabling environment and reduce stigma and discrimination for PLHIV by working with existing community structures/power groups.
- Effectively advocate for enhanced quality and reach of services available from government departments and catalyse effective interlinks between the services and community.

The programme initially focused on the general population. In January 2011, this changed to specifically target high risk groups (HRG) such as women in sex work (WSW), men who have sex with men (MSM) and injecting drug users (IDU), as well as vulnerable populations, in particular migrants, truck drivers, youth, pregnant women, children affected by AIDS and PLHIV. There are an estimated 2,820 WSW in the district, with 68% spread across three of the five Talukas: Sindhanur (25%), Raichur (24%), Lingsugur (19%).¹² MSM in urban areas are estimated at 412 of which 84% are in three

¹¹ Ministry of Health and Family Welfare, Government of India, *District Level Household and Facility (DLHS-3) Raichur District Fact Sheet, 2007-08*, pg 4.

¹² India Health Action Trust. *HIV/AIDS Situation and Response in Raichur District: Epidemiological Appraisal Using Data Triangulation*, July 2010, pg 21.

Talukas: Raichur (54%), Devadurga (17%), and Sindhanur (15%).¹³ The Spandana team conducted line listing of high risk groups present in the 100 core villages covered by the programme. According to this line listing, there were 698 WSW and 212 MSM identified, which became the targets for the programme (there were no IDUs identified). 90 male PLHIV, 83 female PLHIV and 40 orphaned and vulnerable children were contacted.¹⁴

The programme has approximately 50 link workers who operate in pairs (one male and one female) and each pair is responsible for a cluster of three to five villages. They are supported by four field supervisors.

The link workers:

- Conduct one-to-one and group information sessions on HIV prevention and general sexual health.
- Encourage behaviour change towards safe sex practices including through distributing condoms and demonstrating their correct use.
- Link target populations to health services such as ICTC, PPTCT, DOT and ART.
- Sensitise the community to HIV and reduce stigma and discrimination of PLHIV.
- Participate in Gram Panchayath, youth groups, self help groups meetings to mobilise support of the community.

The Spandana programme had been running for nearly 18 months at the time of this visit and a number of successful HIV awareness and prevention initiatives had been conducted. Village information centres and volunteer groups known as Red Ribbon Clubs have been established in several villages. Mass HIV awareness programs have been carried out in some villages. The project field team has also mobilised significant resources (financial, human and infrastructure) and forged strong partnerships with key stakeholders such as the Gram Panchayaths, district and local health officials, ASHA and Anganwadi Workers. The following section discusses the various initiatives and activities undertaken by the Spandana team.

¹³ India Health Action Trust. *HIV/AIDS Situation and Response in Raichur District: Epidemiological Appraisal Using Data Triangulation*, July 2010, pg 28.

¹⁴ NACO, UNICEF and UNDP, *Assessment of Link Worker Scheme in Raichur Karnataka: District Report*, September 2011,pg 1.

Figure 2

COMPREHENSIVE DISTRICT HIV/AIDS PROGRAMME-LINK WORKERS SCHEME RAICHUR				
Project design				
Goal	To contribute to NACOs efforts to halt and reverse the epidemic in India over the next five years by integrating programmes for prevention, care and support and treatment.			
Purpose	To evolve replicable & sustainable rural intervention model that enables key population to prevent & manage HIV infections through innovations & multi-sectoral collaborations.			
Key objectives	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 33%; padding: 5px;"> <p># Improve (access to) information, knowledge and skills on STI/HIV prevention & risk reduction among rural High Risk and Vulnerable Groups.</p> <p># Encourage behaviour change to ensure increased & consistent use of condoms.</p> <p># Enhance demand for & utilisation of services (especially STI, ICTC/ PPTCT, ART, Directly Observable Therapy (DOT) and other health services)</p> </td> <td style="width: 33%; padding: 5px;"> <p># Reduce vertical transmission of HIV from mother to child before, during and after child birth by ensuring access to counselling, testing, care and treatment and follow up care of mothers and infants.</p> <p># Facilitate early infant diagnosis and treatment of infected infants/children and ensure drug adherence.</p> </td> <td style="width: 33%; padding: 5px;"> <p># Ensure children affected by AIDS have equal access to services and care (family/alternate), without discrimination and at par with other children in their communities</p> <p># Create an enabling environment & reduce stigma and discrimination for PLHIV by working with existing community structures/power groups.</p> <p># Effectively advocate for enhanced quality and reach of services available from the line departments & catalyse effective interlinks between the services & community.</p> </td> </tr> </table>	<p># Improve (access to) information, knowledge and skills on STI/HIV prevention & risk reduction among rural High Risk and Vulnerable Groups.</p> <p># Encourage behaviour change to ensure increased & consistent use of condoms.</p> <p># Enhance demand for & utilisation of services (especially STI, ICTC/ PPTCT, ART, Directly Observable Therapy (DOT) and other health services)</p>	<p># Reduce vertical transmission of HIV from mother to child before, during and after child birth by ensuring access to counselling, testing, care and treatment and follow up care of mothers and infants.</p> <p># Facilitate early infant diagnosis and treatment of infected infants/children and ensure drug adherence.</p>	<p># Ensure children affected by AIDS have equal access to services and care (family/alternate), without discrimination and at par with other children in their communities</p> <p># Create an enabling environment & reduce stigma and discrimination for PLHIV by working with existing community structures/power groups.</p> <p># Effectively advocate for enhanced quality and reach of services available from the line departments & catalyse effective interlinks between the services & community.</p>
<p># Improve (access to) information, knowledge and skills on STI/HIV prevention & risk reduction among rural High Risk and Vulnerable Groups.</p> <p># Encourage behaviour change to ensure increased & consistent use of condoms.</p> <p># Enhance demand for & utilisation of services (especially STI, ICTC/ PPTCT, ART, Directly Observable Therapy (DOT) and other health services)</p>	<p># Reduce vertical transmission of HIV from mother to child before, during and after child birth by ensuring access to counselling, testing, care and treatment and follow up care of mothers and infants.</p> <p># Facilitate early infant diagnosis and treatment of infected infants/children and ensure drug adherence.</p>	<p># Ensure children affected by AIDS have equal access to services and care (family/alternate), without discrimination and at par with other children in their communities</p> <p># Create an enabling environment & reduce stigma and discrimination for PLHIV by working with existing community structures/power groups.</p> <p># Effectively advocate for enhanced quality and reach of services available from the line departments & catalyse effective interlinks between the services & community.</p>		
Expected Outcomes	<p>100% HRG population identified during the mapping /revalidation process reached with information on STI and HIV and AIDS.</p> <p>90% of HRG, 70% of the most at risk adolescents and 50% of the bridge population who are contacted in the core villages in the district know correct mode of HIV & STI transmission and the available services for prevention.</p> <p>80% of HRG use condoms correctly and consistently in every sexual act.</p> <p>40% of most at risk adolescents use condoms correctly and consistently during every sexual encounter.</p> <p>30% of bridge population use condoms correctly and consistently during every sexual encounter.</p> <p>Decreased incidence of STI among rural HRG, youth and bridge population.</p> <p>Increased demand for ICTC service.</p> <p>Decreased incidence of STI relapse and reinfection among rural HRG, youth and bridge population.</p> <p>100% pregnant tested positive to HIV have an institutional delivery.</p> <p>0% children born with HIV.</p> <p>Increased ART adherence among children who are on ART.</p> <p>Increase in number of PLHIV & CABA (& families) accessing social welfare schemes or livelihood support schemes.</p> <p>Decrease in incidents of enacted stigma & discrimination against PLHIV & CABA when accessing needed services.</p> <p>Improved ability of field staff and project team to manage and deliver outputs.</p>			
Geographical Coverage	<p>100 villages of Raichur district (5 Talukas- Manvi, Deodurga, Sindhanur, Raichur & Lingasagur)</p>			
Target Groups	<ol style="list-style-type: none"> 1. Female sex worker 2. Men having sex with Men 3. Injecting drug users 4. Truck drivers/Cleaners 5. Migrant worker 6. Vulnerable young people 7. Young girls/women in women headed households 8. Pregnant women 9. Person infected and affected by HIV 			

3. Programme Initiatives

3.1 Village Information Centres

Through the programme, 104 village information centres (VIC) have been set up. These centres have been established with the support of the local Gram Panchayaths and are located in the Panchayath office buildings. These centres are an easily accessible source of information for the village on HIV prevention and other related health information.



Young boys from a village in Manvi Taluka playing carom outside the local Village Information Centre. The carom board provided through the project contains educational messages.

They contain various visual Information Education Communication (IEC) and Behaviour Change Communication materials e.g. posters, booklets, pamphlets. These highlight how HIV is transmitted, safe sex practices and the importance of taking care of one's health and staying in school. They also have various board games such as snakes and ladders and carom incorporating similar messages but tailored for young people. This is an interactive and fun way to engage the youth.

These centres have helped sensitise the local communities and remove myths and misconceptions on HIV and AIDS.

The central location of the centres

means that anyone in the village can easily access them. In one of the villages, the village library is located next to the VIC and as result all members of the village readers association have visited it and received an orientation on HIV and AIDS.

The VIC space is often used for other purposes such as meetings of seniors' and women's groups. These groups inevitably pick up some knowledge about sexual and reproductive health and HIV during their visits to the centres. According to the NACO Evaluation, the VICs can be further strengthened, with different information displayed and distribution of IEC materials, such as posters, leaflets, maps, as well as availability of contact numbers for emergencies and for different Government schemes.¹⁵

¹⁵ NACO, UNICEF and UNDP, *Assessment of Link Worker Scheme in Raichur Karnataka: Report on Top-line Findings*, August 2011,pg 7-82011.

3.2 Mobilisation of Volunteers & Creation of Red Ribbon Clubs

The Spandana team has been effective in mobilising volunteers at the village level, particularly during village level awareness events. They talk to the villagers about the Spandana programme- its goals, objectives and benefits and highlight how as volunteers they can help to contribute to their local communities. A total of 1,295 volunteers have been recruited. The Spandana team educate these volunteers on HIV and other STIs, high risk behaviours and where and how to access necessary health services. These volunteers are then responsible for transferring the acquired knowledge to the people in their respective villages, help distribute condoms and encourage people to go ICTC for HIV testing. Most of these volunteers are young and members of vulnerable populations.



One of the Spandana volunteers sharing information on sexual health and HIV to young people from his village.

Young volunteers have also formed youth clubs, known as Red Ribbon Clubs, with the support of the Spandana link workers. By the end of the project's closure in June 2012, a total of 114 Red Ribbon Clubs have been established, with approximately 1295 members in total. The youth clubs meet twice a week and assist in conducting health camps, organising games for the village youth, identifying members of high risk groups and maintaining the village information centres.

Similar to the link workers, the Red Ribbon members are a bridge between the community and health service providers. However, unlike the link workers who travel from village to village, the Red Ribbon Club members are generally always present in their villages and therefore individual/s can approach them at any time to ask questions about HIV, how it is transmitted and how it can be prevented.

Moreover, they are better known to the villagers than the link workers and therefore, some of the villagers may feel more comfortable discussing their issues with Red Ribbon Club members than with the link workers. For example, the young men of one of the Azad Red Ribbon Club in Manvi taluka expressed that before they hesitated to discuss personal matters with their friends but the club has provided them with a nice platform for sharing their concerns and clarifying any doubts they have on sexual health related issues.



Members of the Azad Red Ribbon Club in Manvi Taluka

At first, there was a lot of community opposition to the forming of the Red Ribbon Clubs. People did not like that the youth were openly discussing sex and condoms. However, there was consistent effort on the part of the link workers, their supervisors and the Red Ribbon Club members themselves to help the people of the village understand the purpose and benefits of the club. Now, according to one of the members of the Azad Red Ribbon Club, the villagers have realised the value of the club and are supporting it.

The Red Ribbon Club members are proud about the work they are doing and how it is benefiting their local communities. The clubs are always recruiting new members and seeking to do more. As *Mr. Zeelani, President, Azad Red Ribbon Club* stated:

“We want extra support from Gram Panchayath, health department and the government. We have the zeal to do more work but financial support is very important to conduct any programme. We have a vision to reach other villages. Each Red Ribbon Club member could educate five others and even go to other villages, but we need bus fare. Finance is the obstacle to initiate any creative ideas.”

Mobilising volunteers from the village and setting up the Red Ribbon Clubs is a crucial step in ensuring the long-term sustainability of Spandana beyond the interventions of the link workers. However, as noted by the NACO evaluation, in order to retain the support and build ownership, the capacities of the volunteers needs to be built up more.¹⁶

¹⁶ NACO, UNICEF and UNDP, *Assessment of Link Worker Scheme in Raichur Karnataka: Report on Top-line Findings*, August 2011, pg 11.

3.3 Mass HIV and AIDS Awareness Programme

In order to raise awareness about HIV and sensitise the local population, a number of campaigns have been conducted at the village level, particularly in the large villages. The Spandana team conduct rallies in the village, enlisting the support of school children, health workers, Anganwadi workers, Red Ribbon Club Members, Gram Panchayath members and other village elders. They also mobilise the community to one place and conduct stage programmes or plays to raise awareness about HIV. The team tend to stay overnight in the village making door to door visits the day before the awareness programme to inform and encourage the village residents to attend the event.

In Thurvihhal in Sindhanur Taluka, the Gram Panchayath and their friend circle contributed Rs 30,000 of their personal funds to conduct a mass HIV awareness programme. The Spandana team strongly promoted the programme, making door to door visits to inform people about it. This resulted in approximately a 1000 people attending, mainly ladies and helped make the programme a success. In August 2010, a mass HIV awareness programme was conducted at another village which was attended by more than 200 adults, of which nearly 150 were adolescents.

On World AIDS Day, the Spandana team collaborated with the Raichur District Administration, Zilla Panchayath, District Family and Welfare Department, District AIDS Control Unit, Population Services International, Samuha Samraksha, Hosabelaku positive network, Nation Service Scheme and National Cadet Corps Unit and other government departments, to organise a rally to raise greater awareness of HIV and AIDS. 400 individuals participated in the rally.

In addition to the above events, the Spandana team organised a youth programme, Yuva Jagrutti. The Spandana team also supported another NGO's efforts to conduct a street play on HIV prevention and awareness by spreading word about the street play and encouraging people to attend.

Through these mass programmes, the Spandana team has been able to educate large masses of the population on HIV prevention and non discrimination of PLHIV. The awareness programmes have also provided visibility and momentum to the Spandana intervention. According to the NACO Evaluation, these awareness programs have provided a platform to create awareness about the link worker scheme and an entry point into the villages.¹⁷

3.4 Demand Generation for Local Health Services

The link workers are supporting the public health system in a number of ways. Through their outreach in the villages, they have helped create awareness among the local population about the health services available and encouraged them to access these services. The link workers create awareness about the various government health programmes such as immunisation and eye camps

¹⁷ NACO, UNICEF and UNDP, *Assessment of Link Worker Scheme in Raichur Karnataka: Report on Top-line Findings*, August 2011,pg 7.

and encourage the villagers to actively participate in them. According to many of the local medical personnel, there has been increased utilisation of health services such as ICTC and DOT since the Spandana intervention. The ICTC counsellors indicated that client loads have increased at the ICTCs and the link workers are helping the counsellors reach their targets. According to the project staff, more PLHIV are accessing ART and many women especially those in high risk groups are seeking HIV tests as part of ANC.



The Medical team from one of the local primary healthcare centres in Thurvihal, Sindhanur Taluka, Raichur

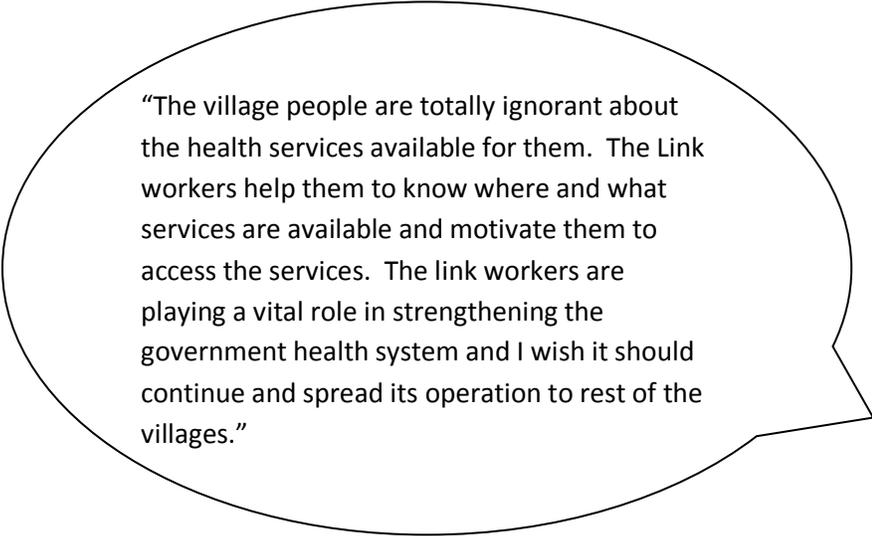
The link workers are also supplementing the efforts of the ASHA and Anganwadi workers. The ASHA workers are generally already stretched focusing on ANC cases, so having link workers operating at the village level means that the villagers have an additional contact person who they can go to for HIV and broader health-related information. Also, through the combined efforts of both link and ASHA workers, more and more people who had previously considered going to the hospital are now willing to go for HIV and other tests, visit the dentist and seek other health services. One of the ASHA workers said:

“If there was no link worker, I feel the percentage of the infection would have increased due to lack of awareness and knowledge on HIV prevention measures and protection”.

The Spandana team has managed to build strong partnerships with local doctors at the Taluka Hospitals and Primary and Community Healthcare Centres. As a result, they have been able to access facilities such as meeting halls and support for conducting group meetings, activities and programmes. Medical personnel such as the ICTC counsellors and lab technicians participate in site

camps organised by the Spandana team, enabling greater reach of health services. In Sindhanur, the Spandana team together with the Primary HealthCare Centre organised an ICTC site camp in one of the villages. Through which 61 people underwent HIV testing and three tested positive.

In these various ways, the Spandana programme worked with, and strengthened the local health system. This was also observed by the NACO Evaluation team who indicated that team had been working closely with the district level health related institutions, with the Spandana District Resource Person attending the meetings convened by the District AIDS Prevention and Control Unit (DAPCU) on a regular basis and link worker supervisors meeting ICTC counsellors, Auxiliary Nurse Midwife (ANM), ASHA and Anganwadi workers during their monthly meetings and supervisory visits to the villages.



“The village people are totally ignorant about the health services available for them. The Link workers help them to know where and what services are available and motivate them to access the services. The link workers are playing a vital role in strengthening the government health system and I wish it should continue and spread its operation to rest of the villages.”

Dr. R.S. Hulamani, Medical Officer,
Community HealthCare Centre

3.5 Linking PLHIV to treatment and preventing parent to child HIV transmission

There is also a concerted effort to link PLHIVs to ART centres and preventing parent to child transmission through dried blood sampling (DBS) follow-up. The link workers have been successful in identifying and reaching out to a number of PLHIV. They have motivated them to access and continue ART and followed up to ensure adherence to treatment. The link worker supervisors are regularly provided lists of individuals who have dropped out of taking ART and followed up with them.

Aadvika is one of the PLHIV that has benefited from the Spandana intervention. She is aged 40 and has two children and her husband passed away four years ago. When interviewed, she said:

“I was totally bedridden, not able to move, eat or do anything. My son approached one of the Spandana link workers. The link worker visited my house, saw my condition, and facilitated health check-ups including a blood test. My report declared me as a HIV positive. Continuous effort and encouragement from link worker is what has enabled me to stand before you today. I can now do housework.”

‘I believe there are so many people are suffering like me in society. They should all get benefit. I request you to continue this great effort.’

The female link workers together with the ASHA workers have also been very effective in encouraging pregnant women to undergo HIV tests. For those who test positive, the link workers help them to minimise the risk of HIV transmission onto the child during pregnancy, labour and delivery, or breastfeeding. They encourage the mother to deliver the child in a hospital where the necessary HIV prevention drugs can be administered during delivery. Once the child is born, they follow-up to make sure the child is also tested. They provide advice and information on nutrition and how to breastfeed the baby correctly so that HIV is passed onto the child. These efforts have resulted in a number of successful PPTCT cases.

Gangana tested positive for HIV during an ANC visit. A female link worker counselled her and helped her access PPTCT services. She advised her on nutrition during and after pregnancy and taught her to breastfeed in a way that minimises the risk of HIV transmission. The link worker also linked her up with various social welfare benefits such as Yashashwini scheme (medical benefit in government hospital), Madilu Kit (Delivery kit) and Poustikahar (Nutrition scheme). Her baby is non-reactive to HIV.

3.6 Addressing stigma and discrimination

The HIV sensitisation efforts, especially the mass HIV awareness programmes of the Spandana team have resulted in successfully addressing some of the stigma and discrimination associated with HIV and AIDS in the village communities. On World AIDS Day, the Spandana team conducted a specific signature campaign in which 300 people vowed not to discriminate against PLHIV. This initiative is part of a larger signature campaign through which over 1.5 lakhs signatures have been collected so far. In addition, when the Red Ribbon Express train (a national initiative aimed at promoting AIDS awareness) visited Raichur, the Spandana team conducted a three day programme to reduce stigma and discrimination associated with the disease. They sought permission for the district commissioner to organise a stall at the entrance of the Red Ribbon train. This included a signature campaign in which they collected more than 12,000 signatures and a local Member of Legislative Assembly, Member of Parliament and several government officers participated in the programme. Swasti directly provided Rs 20,000 for this event.

The link workers, through their one-to-one and group sessions, have clarified myths and misconceptions about HIV and AIDS. For example, they showed the villagers that HIV is not transmitted through eating on the same plate as a PLHIV. According to the President of the Gram Panchayat, Thurvihal where a massive HIV awareness programme aimed at reducing stigma and discrimination was carried out, stigma and discrimination of PLHIV has reduced significantly since the Spandana intervention started.

Below are some specific examples of stigma and discrimination being addressed by the Spandana link workers:

In Thidigodu village, there is a cook employed by a mid-day meal programme run by the government. She was thrown out of the service due to her HIV status. One of the Spandana link workers received the news, met her and provided her moral support. The Spandana team also advocated for her to regain her livelihood, which she eventually did.

A four year old child was attending an Anganwadi. The child had a skin infection which when diagnosed, also led to the diagnosis of the child being infected with HIV and as a result was subsequently banned from the Anganwadi. A Spandana link worker intervened and took the child to the ART centre for treatment which helped save his life. Moreover, the Spandana team's advocacy efforts targeted at the Anganwadi teacher resulted in the child being accepted back into that Anganwadi. Now, the Anganwadi teacher supports and participates in all Spandana activities.

Kaajal's parents abandoned her when they discovered that she had HIV. They made a hut for her in the field for her to stay due to fear and stigma associated with HIV and AIDS. Upon hearing about the Spandana programme, Kaajal went to see her local link worker and shared her problems.

The link worker visited her parent's house, spoke to them and her sister, brought them to Kaajal's hut in the field. Kaajal was having lunch when they reached there and the Link Worker to the shock of the others immediately sat and ate with her.

Then, the link worker convinced the others to sit with Kaajal and explained the modes of HIV transmission and helped them understand that HIV does not spread by talking, eating together, shaking hands, staying together, wearing the same clothes or by sharing the same toilets. The link worker dispelled all the myths and misconceptions that the family had and today Kaajal no longer lives in hut. She is back living with her family who are taking care of her health.

3.7 Working in partnership with Panchayaths

The Spandana team has been very effective in building strong relationships with the Panchayaths in many of the villages. From the onset of the programme, the Spandana team invested time in orienting Panchayaths on the goal and objectives of the programme, its key activities, expected outcomes and the roles that they can play in contributing to the project's success. Panchayaths members were invited as guests at village level awareness events. In this way, they sought the support of the Panchayath members. Moreover, through participation in Gram Panchayath meetings, link workers educated the Panchayaths members on HIV prevention, sexual health, high risk behaviours and on the importance of supporting village level HIV awareness programmes aimed at reducing stigma and discrimination associated with the disease. Changes in the behaviours and attitudes of Panchayath members as a result of these efforts are clearly evident.



Gram Panchayath in Thurvihah, Sindhanur Taluka, Raichur

Some of the Gram Panchayath members indicated their willingness to sit down and eat with PLHIV and support them in whatever way they can. However, they noted that self stigma is preventing the PLHIV in their villages from coming forward and seeking their help.

Realising the value of the intervention in their villages, some Panchayaths extended their support to the programme in a number of ways. Many Panchayaths have provided a room in the Panchayath building to house the village information centres. Some Panchayaths assist in recruitment of link workers and volunteers through identifying suitable individuals from the villages.

The Gram Panchayath in Thurvihah, Sindhanur Taluka went as far as mobilising and donating Rs 30,000 to undertake a village level mass programme on HIV/AIDS awareness. According to the link workers in Thurvihah, the Gram Panchayath's support for the Spandana intervention is largely attributed to the fact that it is a young, enthusiastic and open-minded Panchayath.

Building effective partnerships with Panchayaths has been crucial in creating an enabling environment for the link workers to carry out HIV awareness and prevention activities at the village level.



Members of one of the Gram Panchayaths standing with a Spandana link worker on the left outside a Village Information Centre.

4. Key Achievements, Signs of Change and Challenges

4.1 Key Achievements

Between January 2010 and June 2012, the Spandana programme reached out to 891 members of the high risk population. This includes 762 women in sex work and 129 men who have sex with men. This covered more than 100% of the estimated 698 WSW in the project areas identified at the start of the project and 60% of the estimated MSM – majority of the remaining 40% of MSM were covered by the district targeted intervention. The project team also reached out to approximately 75% (27,973) of the vulnerable population.

Achievements of the programme are reflected in terms of progress has been against the following output indicators:

- 20,709 people were referred to ICTC, of which 11,931 (58%) underwent HIV testing.
- 891 (98%) members from the HRG tested for HIV and 891 (95%) tested from STI.
- 224 people were referred to the ART centre and 143 joined the PLHIV network.
- 195 free condom depots and 38 social marketed condom depots have been set up. More than 386,500 condoms were distributed through these depots or directly by the Spandana link

workers and volunteers. Though, according to the NACO Evaluation, interactions with village functionaries indicated a need for more number of condom outlets in the villages.¹⁸

- 104 Village Information Centres and 114 Red Ribbon Clubs have been established as well as 1,295 volunteers mobilised.

4.2 Signs of change

In June 2012, it was agreed with UNICEF (the funding agency) that the implementation of the Spandana Programme would be transitioned over to District AIDS Prevention and Control Unit (DAPCU). Accordingly, Swasti prepared a project transition plan in consultation with UNICEF and in September 2012, at a meeting with UNICEF and DAPCU, the project handover was done.

While, it is too early to assess the impact of Spandana, signs of change as a result of the programme include:

- *Greater awareness of HIV among the village communities.* As Praveen, one of the Red Ribbon Club members noted: *“HIV awareness and the concept of protection and prevention of HIV came up only after the Spandana intervention.”* The NACO evaluation also conducted personal interviews and focus group discussions with members of HRG and vulnerable population and found that all respondents were aware of HIV/AIDS through the Spandana programme and majority were aware of the four correct modes of transmission.¹⁹
- *Reduction in high risk behaviours.* For example, one of the women in sex work said that she now always has condoms on hand and insists that her clients use them. Some of the men indicated they no longer utilise the services of sex workers as they have realised the risks associated with it.
- *Evidence of health-seeking behaviour* (including increased willingness to undergo voluntary HIV and STI counselling and testing). As one Gram Panchayath member noted: *“before the Spandana intervention, people were reluctant to undertake voluntary counselling and testing –now they are willing to go.”*
- *Signs of reduced stigma against PLHIVs.* All of the respondents contacted by the NACO evaluation team for its sample study, said that they had not been subjected to stigma and

Saakshi aged 35 years, has five children and works as a coolie. When her husband expired few years back and she turned to sex work. She spoke about how she has benefited from the Spandana intervention:

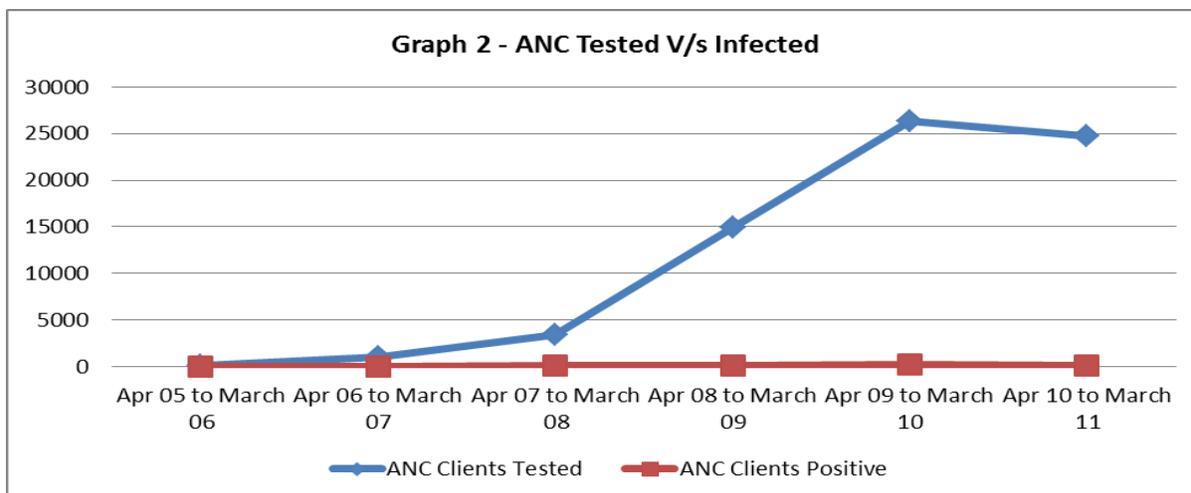
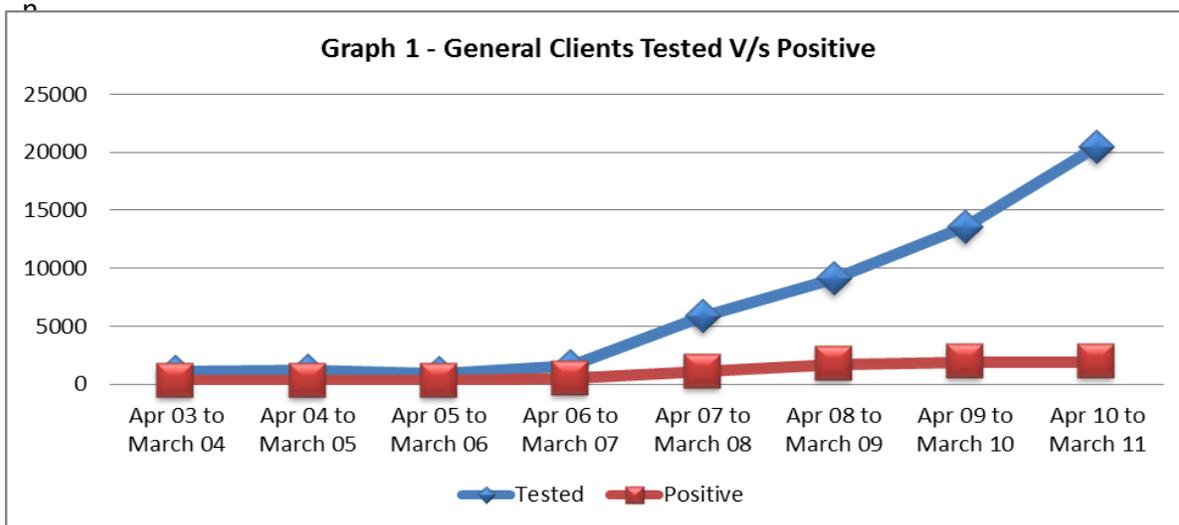
“The link workers have supported me, giving me preventative counselling, motivating me to send my children to school and providing free condoms and health information on any issue. I keep a condom box in my house and always insist my customers practice safe sex.”

¹⁸ NACO, UNICEF and UNDP, *Assessment of Link Worker Scheme in Raichur Karnataka: Report on Top-line Findings*, August 2011, pg 8.

¹⁹ NACO, UNICEF and UNDP, *Assessment of Link Worker Scheme in Raichur Karnataka: District Report*, September 2011,pg 13.

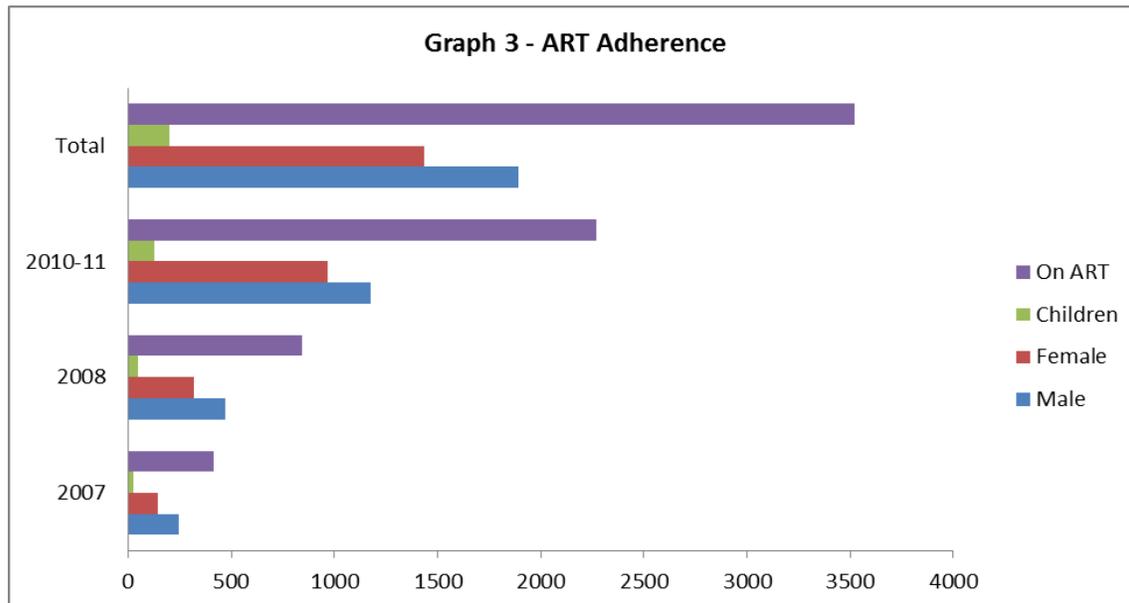
discrimination so far and indicated that the Spandana team had been instrumental in creating a non-stigmatic and non-discriminatory environment in the villages. Of the respondents contacted, 50% of respondents expressed that the link workers had linked them up with support group and with community care centre.²⁰

- *Greater uptake of local health services e.g. immunisations, ICTC services.* Graph 1 below shows a significant increase in number of general clients being tested for HIV at the ICTCs between 2003 and 2010, with a particularly large increase in 2010. Similarly, there is a large increase in number of ANC clients visiting ICTC in 2009 and 2010 as evident in graph 2 below. These increases could potentially be attributed to the HIV awareness raised by the Spandana i



²⁰ NACO, UNICEF and UNDP, *Assessment of Link Worker Scheme in Raichur Karnataka: District Report*, September 2011,pg 17.

- *Increased accessing of, and adherence to ART by PLHIVs over the years as evident in graph 3 below:*



- *Increased community acceptance of link workers.* Initially, the local communities were hesitant to listen and accept the advice offered by the link workers. Now, there is much goodwill towards the link workers among the community members. In fact, some of the field staff said they joined as link workers when they saw how the other link workers were helping their local communities. Similarly, one of the ASHA workers, Saroja said that: *“seeing the work of the link workers motivated me a lot. My friend and I planned to join the Spandana team, but at the same time we got a call to join as ASHA workers”.*

4.3 Challenges

The programme’s achievements have not come without challenges. Key implementation challenges include:

- Challenges in getting PLHIV and HRGs to accept help due to self stigma.
- Difficulties in making the Village Information Centres (VICs) fully functional, 24x7. The NACO evaluation observed that VICs are yet to be owned and managed by community and that knowledge about the existence of the VICs (4%) and Red Ribbon Clubs (12%) is limited among the HRGs.²¹

²¹ NACO, UNICEF and UNDP, *Assessment of Link Worker Scheme in Raichur Karnataka: Report on Top-line Findings*, August 2011,pg 7-8.

- Financial and logistical difficulties prevent many villagers from accessing necessary health services. Financial and logistical difficulties also acts as a major barrier for many PLHIVs in continuing ART, as, there are only three ART centres in the whole district and accessing them requires significant travel.
- Recruiting and retaining of programme managers with the right levels of skills and experience to provide the necessary operational leadership.
- Transition of the implementation of the Spandana programme to DAPCU in 2012 was challenging as DAPCU was reluctant to take it over, without clear directions for the Karnataka State AIDS Prevention Society. This has implications for sustainability of the programme.



Two female link workers from Manvi Taluka, along with their supervisor in the centre and members of a local Red Ribbon Club on the right.

5. Concluding Observations

18 months on, it is evident that the Spandana link workers are playing a vital role in their respective villages; educating communities about HIV risk reduction, encouraging adoption of safer sex practices and condom usage, and reducing stigma and discrimination associated with HIV.

The factors behind the programme's success include:

- Recruiting individuals from the local community as link workers and Red Ribbon Club members means that the people in community have someone who is not alien to talk to discuss intimate human relations and practices of sex and sexuality.
- Use of female link workers has been effective in reaching women, as women feel they can share their experiences.
- Investing in building effective relationships with stakeholders at all levels:
 - Panchayats
 - Health officials (doctors, ASHA workers)
 - Village people (especially the more vulnerable members of the communities, including adolescents and women)
- Successful mobilised additional resources (human, financial and infrastructure)
- Commitment of link workers and the supportive supervision provided by many of the link worker supervisors. This is evident through the interactions with the link workers themselves and the low turnover rate among the link workers).

In sum, the Spandana programme to date has had some significant benefits to the communities it reaches. Almost all the individuals that were interviewed – health professionals, Gram Panchayath members, ASHA workers and members of both high risk groups and the general population – requested that the Spandana programme keep running and be expanded to other villages currently not covered by the project.

6. Annex: List of people interviewed through field study

Sl. No	Name	Designation & Location
1	Sharana Basava Radder	President of Gram Panchayath, Thurvihah
2	Shivappa	Former member of the Gram Panchayath, Thurvihah
3	Kariyappa	Member of the Gram Panchayath, Thurvihah
4	Mallappa	Member of the Gram Panchayath, Thurvihah
5	Dr. Manjunath	Ayush Doctor, Primary Health Care Centre, Thurvihah
6	Veersh	Link Worker Supervisor
7	Shantha Moorthy	Link Worker
8	Sridevi	Link Worker
9	Dr. Hulamani	Medical Officer
10	Mr. Zeelani	President of Azad Red Ribbon Club, Manvi District
11	Saroja	ASHA Worker
12	Sarashwathi	ASHA Worker
13	Mahantamma	ASHA Worker
14	Rajesh	ICTC Counsellor, Community Health Care Centre
15	Mr. Ramakrishna	Farmer
16	Mr. Ramanna	Farmer
17	Venkatesh	Farmer
18	Shivappa	Gram Panchayat Member
19	Udaya Kumar	Link Worker
20	Rajeshwari	ICTC Counsellor
21	Girish	Lab Tech
22	Chowhan	Link Supervisor
23	Praveen Kumar	Member of Azad Red Ribbon Club, Manvi District

24	Sharanu	Member of Red Ribbon Club
25	Sunil	Member of Red Ribbon Club
26	Anuradha	Anganwadi worker
27	Chandrashekhhar Gowda	Director, Swasti
28	Rajendra R.	Programme Manager, Swasti