



SAHRUDAYA

VASAVYA MAHILA MANDALI



HOME / COMMUNITY BASED HIV / AIDS CARE AND SUPPORT PROGRAMME
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From the Editor's Desk

It is our immense pleasure to bring forth the fourth issue of "Sahrudaya", a bi-annual newsletter. Vasavya has gained experience and geared the efforts to keep pace with the emerging needs and challenges like orphaning due to HIV/AIDS, grannies and grand children's mutual dependency, strengthening of support groups, increased children participation in the program.

We are sure that new initiatives like grannies clubs, children support groups, school support groups and community taking responsibility of child headed families with the support of extended families / grand parents, and process documentation on orphans and vulnerable children in the field of Home/ community Based HIV/AIDS Care & Support Programme will be helpful in the strategic planning.

Your suggestions can improve our efforts in Home/ community Based HIV/AIDS Care & Support Programme.

Your's in service,

G. Rashmi

Executive Director
Home / Community Based Care & Support Programme
Vasavya Mahila Mandali



Voices of grannies

- "Now we are able to take care of our problems after sharing in grannies club. My problem looks very small now" — Rama Rao, 70 years taking care of 2 afflicted grand children.
- "We too have a club for us. We feel happy to be part of it, as we are recognized and are wanted"— Kanthamma, 65 years, a granny club member taking care of 2 grand children.
- "Now here we listen to each other. At our homes nobody is there to listen to our problems."— Chittemma, 75 years an active member is shouldering the responsibility of 2 grand children.
- "I wait for the day to meet my peer group as I feel comfortable in their company." – Veeraiah, 80 year old grand father worry about his 8 year old grand daughter's future.
- "At least we are there for our grand children. There are so many children who do not have even grand parents". — Parvathamma, 60 years taking care of 2 afflicted grand children.

* 65 year old Lakshmi Kantamma is taking care of 2 grand children empowered with grannies club.

GRANNIES TAKING CARE OF GRAND CHILDREN

The HIV/AIDS pandemic in India is making the children and aged more vulnerable with middle generation succumbing to HIV. Hence this has a long-term impact on national and state economic scenario. The current challenge for the nation is “Orphaning” of the children where the grannies are taking care of them.

The emotional bond between the grannies and grand children is making them mutually dependent and supportive. In 10 projects supported by Vasavya Mahila Mandal/ India HIV/AIDS Alliance, it is found that nearly 380 grannies are taking care of 570-orphaned grand children in Coastal Andhra Pradesh.

Lessons learnt Due to geriatric problems, the aged are not able to meet the physical demands of children and due to generation gap they are unable to meet their emotional needs. Lack of financial support and social security for the aged there is increased school dropouts, child labour, beggary, insecurity of future, sibling separation and emotional trauma among the children. Multiple orphaning is having an impact on the children and aged alike. The food insecurity of children and aged is an immediate need to be addressed.



Kumari with her grand mother

“I lost both of my parents, younger sister and grand father for AIDS and now I am staying with my grand mother who is terminally ill with HIV positive status. What I want in this world is my grand mother to be alive. So to feed her I am begging”- Kumari an 11 year old girl from Chilakaluripet of Guntur district of AP. Both granny and Kumari are in a traumatized condition where Kumari is habituated for consumption of “Gutkha” (cocaine addiction). Granny is depressed and worried about the future of Kumari- this is a very bleak condition. Needs Serving Society, Implementing NGO to VMM is providing psychosocial support besides the assistance for medical needs. Kumari represents the children orphaned due to HIV/AIDS who are increasing everyday. She is exposed to the continuous morbidity and mortality in the family having HIV sero positive status in 3 generations- grand parents, parents and her younger sister.

Grannies club

The issue of orphaning and grand parents mutual dependency the situation has demanded for an innovative approach to cope up the circumstances. One such experiment is Grannies clubs. In the implementation programme of VMM in Vijayawada, grannies club was initiated as a pilot intervention with 30 grannies and they are enjoying this club as it is providing them a place to ventilate their feelings and emotions with other members. Their problems are looking small when they listen to others experiences. One granny is providing psychosocial support to another and the peer psychosocial support is giving a positive attitude for grannies to live longer and to give bright life to their grand children.



Grannies in action

Lata, 3year old girl and Rajesh days baby boy, lost their parents to AIDS and both of them are being taken care by 80 years old grand parents, who neither can take the infant into their lap nor able to give artificial feeding. Lata tells, *“Nanamma (granny) is not running with me and is not playing with me” yes it is true. Is the age of granny right to cope up with the needs of her grandchildren?*

PICTURING HOPE - PHOTO SAFARI PROJECT

VMM participation in World AIDS day celebrations at US

Keerthi, Technical support Manager, VMM with Manjula CAA in Picturing Hope, have participated in World AIDS day events in Washington DC and Chicago from 27th November to 8th December 2004.

“Through their eyes”, an exhibit of photo exhibition was arranged followed by media interaction both at DC and Chicago. At DC the events are organized at Capitol Hill and provided an opportunity to meet the senators and celebrities like Jennifer, Miss Universe and had shared with the gathering, the situation of children affected by AIDS in India and particularly in AP. At Chicago, the events are in Abbott Park where the exhibition of “Through their eyes” of Picturing Hope is displayed in 3 wings of Abbott- Marketing, manufacturing and policy & admin wings. The interaction with Abbott employees has provided an opportunity to show them the positive impact of Abbott funding on the lives of CAA in India, Romania and Bokina Faso. An interactive session was arranged with the high level functionaries of Abbott and shared with them the life stories of 3 children Manjula (India), Alex (Romania) and Henri (Bokina Faso).



Keerthi, Technical Support Manager with Manjula (India), Alex (Romania) and Henri (Bokina Faso) in Abbott Park, Chicago, USA.

Chicago Daily Herald

December 9, 2004

Children share emotions through Abbott AIDS exhibit

By Scott Ray Daily Herald Staff Writer

Posted Thursday, December 09, 2004

Dozens of black and white snapshots of people, young and old alike lined a hallway at Abbott Labs on Wednesday to create a sobering message. It is a display designed to bring the AIDS epidemic to light. But the real story is the kids behind the lens who used the photos to express how the dreaded disease has affected their lives. Three young photographers - from countries directly affected by AIDS, such as Romania, India and the landlocked west African nation of Burkina Faso - have been documenting their country's struggle through Abbott Labs' "Picturing Hope" program.

Chicago-area native Craig Bender, a professional photographer who has traveled throughout the developing world to document Abbott's efforts to support children affected by HIV/AIDS and meet their immediate needs with medications and health care, created it. Bender wanted to let children share their emotions and experiences through photographs.

Alex, a 16-year-old Romanian student diagnosed with the HIV virus in May 2000, is featured in the "Through Their Eyes" photo exhibit and said it has helped him see AIDS in a new light. "AIDS is a problem," said Alex, a 10th-grader in Constanta, Romania. "But it shouldn't be seen as a bad disease. You can still have a great relationship with people." Henri, a 16-year-old from Burkina Faso, said the program has helped him emotionally after he lost his father to AIDS when he was 9. "Where I come from, children are never asked about their emotions," Henri said through an interpreter. The photography program has helped him communicate messages to his peers, he said, capturing the emotions through pictures. That is something, he said, that would not be possible in other contexts because most of his peers are illiterate. Manjula, a 12-year-old from Vijayawada, India, who was separated from her parents after they were diagnosed with the HIV virus, also had her photography displayed from her country in the exhibit.

"Some people get numb with the numbers," Bender said of the 14 million kids throughout the world who have been orphaned due to AIDS. "This program gives us a new way to talk about the disease from a personal perspective." Abbott Laboratories, the world's largest manufacturer of drugs designed to help fight the AIDS epidemic, has been circulating the exhibit to help spread awareness of its new program. The photo exhibit has also been displayed in Washington D.C. for World AIDS Day and the International AIDS Conference in Bangkok.



Meroz, a child mentor and Rajesh child volunteer explaining the emotions captured by them to Ms. Reata Roy at Vijayawada.

Children's Participation in picturing hope national and state level media Interaction at Delhi and Vijayawada

Media interaction was organized on 3rd and 6th September 2004, at Delhi and VMM with the national and state level media to share the present scenario of the HIV/AIDS and about HCBCS. In this programme the representatives from Global Care Initiatives, Alliance India and Revathi, Ramu, Pandu and Manjula CAA also participated. Meroz, child mentor has facilitated the media interaction and it had given chance to reach the message to wider community. A photo exhibition was also arranged in which the amateur photographers trained by Mr. Craig Bender, Director Picturing Hope, exhibited their talent.

RECENT HAPPENINGS

Child Centered Programme working committee meet : Organized at VMM with involvement of four implementing partners on 26 August 2004 to identify the gaps in working with children and to develop necessary guidelines for dealing with specific children problems.

During this session the main issues discussed were on the counseling services at VCCTC, which were at present not child friendly. One child expressed during her testing at VCCTC, that counselor had discarded to speak with the child. They took the blood sample and gave the report without saying the status of the report. Based on this participants prepared a list on the concerns of children and that needs immediate interventions.

State level Child centered Review meet : The state level Child centered Review meet was held at Needs Serving Society, Chilkaluripeta of Guntur district on 4th September 2004. Ms. Kate Harrison, from International HIV/AIDS Alliance, Ms. Mamta Panwar, from India HIV/AIDS Alliance, Mrs. Rashmi, Executive Director, staff of LP-Vasavya Mahila Mandali, nine implementing NGOs and 50 children also participated. This meet was organized to discuss the issues related to children affected by AIDS and developing action plans for supporting them in future. The children's active participation in the programme lead to prioritizing issues by children them selves. Key issues raised by the children are: Sibling separation, Grannies taking care of grand children, Educational problems and Death of their Mother.



Abbott, Alliance and VMM team with Children & Staff at Needs Serving Society, Chilkaluripet.

Global Care Initiative Team visit : The team consists of Ms. Reeta Roy, Divisional Vice president Abbott Laboratories, Mr. Jeff Richardson, Executive Director, Step Forward, Mr. Craig Bender, Director Picturing Hope, Mr. Prateek Patnaik and Mr. Mathew Bedella, Abbott Laboratories of Global Care Initiatives (GCI) and Dr Balwant Singh, Country Director, Alliance India and Mr. Sasi Kumar, Director Programmes of Alliance India visited VMM and it's NGOs from 6-8 September 2004

Reflections about VMM work : *"We are moved by the programs of the children and voices of these children carried on to all directors in Abbott"* - Jeff Richardson, after seeing the VMM care and support implementation
"Excellent team work in dealing with children"- Reeta Roy, after seeing the Partnership for Sexual Health project of VMM with street children.

Reflections about Needs serving Society work.

"Excellent work, great results"- Reeta Roy

"Very impressive work, feeling very happy especially in helping the people for their need and children are amazing" -Jeff

"Needs is doing good job in HIV/AIDS care and support and related activities . We will encourage them to continue the good work and also share it with other community based organizations. Thank you for being such wonderful hearts"- Balwant Singh

"Keep up the work, be gentle and take care to new heights"- Sasi Kumar

Retreat : Three days working retreat for the staff of Lead Partner was organized at Araku valley, Visakhapatnam district from 8th to 10th October 2004. The staff got an opportunity to have a break to the routine work and look back at each ones strengths and weaknesses and able to review the futute programme. Staff retreat has enhanced the team building spirit among the staff members.

Programme Advisory Committee meet (INGO) was held for half-day on 30th October 2004 at VMM and Joint collector Krishna district was the chief guest. The aim of the meet is to develop linkages between government and NGO sector that can give a good out come in the developmental work. Joint collector applauded the commitment and the passion shown by the team of VMM towards HIV/AIDS issues and shown concern on stigma and discrimination involved with HIV/AIDS. He told that, will coordinate the sensitization meet with government doctors for easy accessibility of the medical services. And also expressed that there is need to have the liaison officer between the Government and NGO for better coordination between the two for access of the more services from the government. The support group members are shared their involvement in the programme and attitudinal change occurred in them after joining in the programme. During this the children exhibited the IEC material which was developed by children on their own and got appreciation from the participants. Sangamithra Service Society and Rotary Community Service Trust from Krishna District shared their experiences and best practices.

EXPERIENCE SHARING AND LEARNING MEET: The experience sharing and learning meet (ESLM) for the third quarter of 2004 was conducted from 7th –9th November 2004 at Needs Serving Society, Chilkaluripeta on “Quality of Medical Services”. The action plans were developed NGO wise and felt that medical documentation should also to be increased. Besides prophylactic care the NGOs should develop knowledge among the community about ART and also develop linkages with Government for providing ART to eligible PLHA's. 50% of our INGO's are headed by Medical doctors and remaining INGO's by non-medical personnel. Hence in the NGOs headed by non-medical personnel, provision for a Medical doctor to follow up the PLHA's should planned the theme based ESLM was very productive in terms of discussing about the issues linked with medical services.

CHILDREN CONSULTATION: Children's consultation on HIV/AIDS draft policy is organized at VMM in collaboration with Lawyer Collective on 21st November 2004. This is the only consultation with children among the 20 consultations organized, the other are with NGOs, PLHA net works, SACs, Bilateral and UN agencies. This meet is very fruitful in terms of children contribution to the draft policy, and is being placed before Indian Parliament for making into legislation.



The issues and concerns shared by children are with regard to Confidentiality, Discrimination, Orphaning and Staying with extended family and **Education** : As care givers they are not able to attend to school in time so they want a parallel schooling to be developed in the evening hours like regular schools; as the attendance in schools is not sufficient they are keeping fine hence this has to be waived to CAA, when the scholarships are awarded to some students they are not able to open bank accounts due to firstly not having INR 300.00 to open an account and secondly as all are children in the house in the absence of legal guardian they cannot open an account, at home the environment is not conducive to study hence some community places to be developed to children as study centers.

Consent while testing for HIV: The age of consent should be 14 years, their unresolved issues are when children are infants and become orphans who has to give consent? **Health:** When the parents are HIV positive, the children's health is neglected hence it is the duty of Government and community to protect it. **Property:** Guardianship, testament of WILL **Fostering/adoption:** Proper guidelines to be developed.

Interaction with Media personnel conducted on 29 November 2004. During these representatives from print and electronic media interacted with 5 positive speakers from VMM implementation. It was discussed that how the positive change came in the media compared to earlier years of the programme for example projection of HIV/AIDS cases as a sensational issue earlier and as a life sustaining issue now, as expressed by Mrs. Vedavathi Station Director, All India Radio. In this they were sensitized on issues of confidentiality and projecting the positive stories rather than the negative on HIV/AIDS. All the media representatives showed their anxiousness in interacting with positive speakers where some of the media was able to do so for the first time.

Programme advisory committee meet (PAC) (Lead Partner) held on 27th December 2004 under the leadership of Mrs. K Damayanthi, IAS, Director, APSACS, at APSACS office, Hyderabad. This PAC meet has provided a wide range of opportunity to work in collaboration with government and bilateral agencies. APSACS has collaborated with VMM, for selection of coordinating NGOs for providing free ARV through government general hospitals. APSACS came forward to telecast care and support issues pertaining to children, grannies, PPTCT and young widows

Dissemination of publications: has held on 29 December 2004 at VMM auditorium. Dr. Sambasiva Rao, vice chancellor AP University of Health Sciences, Vijayawada and Dr. Jagannadha Naik, DLO & District Nodal Officer (AIDS) are the chief guests and released the three books, Moving forward, Stay Fit Feel Good and Good Food for Good Health (Nutrition). VMM developed these books in collaboration with International/ India HIV/AIDS Alliance.



from left G. Rashmi, Dr. Jaganadh Naik, Ch. Vidya, Prof. Dr. Sambasiva Rao, Dr. G. Samaram and Keerthi are in the Moving Forward book release function

Orientation workshop to the II cohort NGOs (Byrraju Foundation, Rotary Community Service Trust and Vasavya Mahil Mandali) was held from 26th to 31st December 2004 at VMM in order to equip the new NGO staff with thorough knowledge on HCBCS, OVC, OIs and other such issues involved in HCBCS. This workshop is an inclusion of two days exposure visit to AIRTDS, Tenali and Vasavya Mahils Mandali, Vijayawada in order to train the new NGOs with field back up. One of the participants response - "I had lot of myths and misconceptions prior to this training. But after attending to this training and interacting with some of the positive people, I realized that I should change my attitude."

IEC workshop (VMM INGO) - The Information Education and communication (IEC) workshop was organized with 15 children for two days at VMM in order to develop IEC material with children from a child's perspective. During the workshop, children came up with various ideas and designed IEC material from their own perspective, which can be developed and published for educating the communities. The entire material belongs to children and there is no adult interfere in the concepts developed during the workshop. This material will be shortly published and disseminated.

The SNAKE –LADDER game is designed to depict from the child's perspective the most serious concerns for HIV/AIDS prevention linked care. and Support (Telugu Language) One of the interesting issue from this IEC is that children prioritized mother to child transmission as their major concern among all the other issues as many of them are practically experiencing the trauma of siblings getting infected with HIV/AIDS in their own families and getting separated from them in their families.



Peeter, a Child Volunteer demonstrating through Puppet the HIV/AIDS issues to Mr. Sampath Kumar, Joint Collector, Krishna District and G. Rashmi.

STUDY CUM RECREATION CENTERS IN HCBCS

According to WHO, "HEALTH" can be defined as the "physical, mental and social" well being of an individual. Recreation plays a major role for psychological well being of the individual. As today's children are tomorrow's citizens, they deserve proper knowledge, guidance, training and educational and recreational facilities in order to mould them into healthy future citizens. In the context of HIV/AIDS, Children are more traumatized and stigmatized leading to the deprivation of basic facilities like education, health and recreation.

Keeping in view of the importance of recreation in the lives of children afflicted by HIV/AIDS, Green Vision, from Visakhapatnam, one of the partner NGOs of VMM in HCBCS Programme, initiated study cum recreation centre at Kobbarithota, one of the largest slums in Visakhapatnam with one lakh population of poor and marginalized communities.

Children living in these slums are deprived of basic amenities apart from recreational and educational facilities. Study cum Recreation Centre in this area became a real boon for the children in accessing the educational and recreational facilities for psychological relief.

The Study cum Recreation Centre is equipped with Indoor & outdoor games, Library with magazines, books, periodicals, a newspaper and educational material on health, hygiene, and civic sense, a teacher to provide educational guidance (private tuition classes) and help the children to complete their homework at the center with proper lighting, which is lacking at their homes, free tailoring classes for young widows and adolescent girls, Classes on painting, mimicry and singing are available at the center to bring out the inherent talents of these children.

Study cum recreation centre is a tool to reduce the stigma and discrimination in the community. Communities are sensitized and encouraging their children to access the centre. There is a lot of reduction in stigma and discrimination among children after the initiation of Study cum Recreation Centers.

By seeing the positive results from of the study cum recreation center, the programme is replicated by the other implementing partners. The center has become a focus point for integration-afflicted children with normal children and providing an opportunity for child development.

The life story of Ramdas reveals the success of the centre. Ramdas who is an infected child, registered in the Programme at the age of 8 with eye infection, non healing ulcers, skin manifestations, depression, cynical and non communicative. He became very healthy, regained his health, developed confidence, self-esteem, more communicative, jovial, and became a child leader at the center after joining in the centre. He organizes sports and events with lot of initiative and drive developed at the center with encouragement from his peer groups. He takes lead in community resource mobilization and facilitating for celebration of National festivals.

CONFERENCES ATTENDED

Break fast meeting with World Bank chairman: Mr. Wolfenson, Chairman, World Bank, has called 10 NGOs for a break fast session on 18th November 2004 during an official visit to India. Out of the 10 NGOs participated, 9 NGOs are working with their respective state governments funded by World Bank and VMM is the only NGO who worked directly with World Bank for conducting an operational research. VMM has explained the HIV/AIDS situation and the orphaning issue.

National Consultation on Nutrition Security in the Prevention, Management and Treatment of TB and HIV/AIDS: A two days National consultation on Nutrition Security in the Prevention, Management and Treatment of TB and HIV/AIDS was organized by UN World Food Programme, New Delhi on 2nd and 3rd December 2004. Mrs. Rashmi, Executive Director, VMM, had been invited as a resource person along with a paper presentation on the integration of nutrition in to TB and HIV/AIDS care and support program. In continuation to this consultation, World Food Programme is planning to develop a publication based on the findings of the consultation. In this context, VMM has been asked to develop 20 pages write up on “Enhancing the Nutrition of People Living with HIV/AIDS through a home based approach”, which is in progress.

Consultation meet at APCRAF: As a part of initiating OVC (Orphan and Vulnerable Children) policy in Andhra Pradesh, APCRAF (Andhra Pradesh child rights advocacy Foundation), organized a one-day meet on 18th October 2004 in order to study and review the Goa Children’s Act so as to adapt it to AP Scenario. Ms. Vijaya Kumari, Programme co-coordinator, VMM had participated and shared the field level experiences with regard to the legal issues pertaining to the children afflicted by HIV/AIDS for incorporating into AP Children’s Act.

International conference on child labour: Ms. Vijaya Kumari, Programme Co-coordinator attended for the International conference on child labour organized by MV Foundation at Hyderabad on 4th and 5th November 2004. Nearly 7000 delegates from 28 countries participated in the conference. One half-day session was focused on Children afflicted by HIV/AIDS and their impact on child labour.

International conference on Care and support, Mumbai: Mrs. Rashmi, Executive Director and Mrs. Deeksha, Medical Director from VMM had participated in the International conference on care and support organized by Nirmala Nikethan, Mumbai from 7th to 9th December 2004. Dr Deeksha had presented a paper on Support groups, which includes child-to-child approach that was highly appreciated by many of the participants.

National conference on Role of social work institutions and organizations-their adaptability to the present scenario: Department of Social Work, Maris Stella college, Vijayawada, with the technical assistance from VMM organized a two day National Conference on s in the two day national conference on “The Role of Social Work Institutions and their adaptability to the present scenario” on 5th and 6th November 2004 . Mrs. Rashmi, Mrs. Keerthi, Ms. Vijaya Kumari and Mr. Srinivas Reddy from Lead Partner, VMM and seven partner NGO representatives took part in the conference and presented abstracts on care and support issues.

“Our Implementing Partners...”

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3.	Sanghamithra Service Society, Vijayawada, Krishna	K. Vani	sanmitra@netlinx.com
4.	AIRTDS, Tenali, Guntur Dist.	Y. Sambasiva Rao	airtds@airtds.org
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8.	Byrraju Foundation, Bhimavaram, W.G. Dist	Dr. Ravi Raju	ravi_c@byrrajufoundation.org
9.	Rotary Community Service Trust, Vuyyuru, Krishna Dist.	P. Bhaskara Rao	vjwvyr@sancharnet.in
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A.Vijaya Kumari

Programme Coordinator

KASNKV Prasad

Administrative Officer

RECENT HAPPENINGS AT VASAVYA

1. **Eliza Jones, Programme officer, Lepra Society, UK** Visited Vasavya Home/Community based HIV/AIDS care and support programme and appreciated the support group members for making an impact on the community in reducing stigma and discrimination. She requested to replicate the support group concept in Krishna Health Intervention Programme which is funded by Community fund UK and Lepra Society
2. **World AIDS day celebrations:** World AIDS day celebrations on 1st December 2004 were celebrated by VMM and INGO's. NGO partners participated in the rallies conducted by the Local self Governments / District authorities. At VMM, in collaboration with All India Radio, an open forum with well-known doctors, NGO representatives and community people was organized. The community people cleared their doubts and concerns regarding HIV/AIDS. The views were recorded and broadcasted in All India Radio (AIR), Vijayawada for 4 days continuously. The support group members' interviews were broadcasted. A continuous two months programme is taken up by All India Radio, Vijayawada in which our NGO partners and LP are involved and sharing the experiences.
3. **VMM is establishing a Home "SWADHAR" with basic amenities and skill development and health needs of 100 women (Affected or infected with HIV) with the assistance from Ministry of Human Resource Development, Department of Women and Child development, Government of India.**

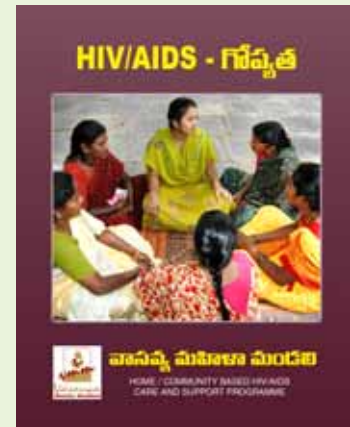
PUBLICATIONS

Publications by VMM- Contact online / phone for orders:

- S Stay Fit and Feel good (Telugu)- a guide for PLHAs and care givers/ field workers
- S Moving Forward (English)- a report on pioneering responses to CAA in AP
- S HIV/AIDS - Confidentiality (English)- a broucher on confidentiality issues.

RECENT PUBLICATIONS

- S Good food for good health (Telugu)- a book on nutrition with values and recipies.
- S HIV/AIDS - Confidentiality (Telugu)- a book on confidentiality issues.
- S HIV/AIDS - Counselling (Telugu) - a book on counselling skills.



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