



SAHRUDAYA

VASAVYA MAHILA MANDALI



HOME / COMMUNITY BASED HIV / AIDS CARE AND SUPPORT PROGRAMME
SUPPORTED BY THE INTERNATIONAL HIV/AIDS ALLIANCE IN INDIA
FUNDED BY : ABBOTT FUND STEP FORWARD PROGRAM, USA

Volume : 5

December 2005

Issue : 6

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From the Editor's Desk

It is our immense joy to put forth the sixth issue of "Sahrudaya", bi-annual newsletter. Vasavya has gained experience, geared the effort in the pace with the emerging needs and challenges like orphaning due to HIV/AIDS, community strengthening through support groups, more involvement of children in decision-making and monitoring levels.

We are sure that new initiatives like community fostering, education and life skills for children and adolescents, psychosocial support to children through a module, child centric programming, positive speakers, e-newsletter, focus on operational research, documentation and publications will show new pathways for all those in the field of Home/ Community- based HIV/AIDS Care & Support Programme.

We express our heart-felt gratitude to all our readers who have responded by writing to us. This will certainly help the newsletter to improve its content. We also expect your valuable suggestions to improve the lives of millions of people living with HIV/AIDS, their families and children.

Yours in service,

G. Rashmi

Executive Director

Home / Community Based HIV/AIDS Care & Support Programme

Vasavya Mahila Mandali



Children sharing their issues with Chief Minister of Andhra Pradesh



Children with U.S. acting Consul



Megastar Chiranjeevi with Children



Mr. Rosaiah, Health Minister issuing the Cheque on World AIDS Day



Children Intra Support Group Interaction

Issue Focus

STIGMA

AND

DISCRIMINATION



Vasavya team interacting with Ms. Ann Veneman, Executive Director of UNICEF at UN, New York

STIGMA AND DISCRIMINATION (S&D) IN HIV/AIDS:

The act of stigma & discrimination is shown in various ways: Blaming and finding fault with the persons for their HIV positive status. Treating them like untouchables. Looking them down and making fun of them. Showing no priority to People living with HIV/AIDS (PLHA) by family members. Cursing PLHA by their own family members and community members.

Levels/areas of stigma & discrimination in the operational areas: Denying them permission to draw water from public water tap; people of their own community avoiding them. Not allowing children affected by AIDS to play with other children in the community playground and denying admission in schools. Isolating PLHAs by their own family members and some of PLHAs were left alone by their spouses; sending out PLHAs from work place.

Strategies for reducing stigma & discrimination : Stigma can also be termed as self-acceptance and, discrimination as community rejection. The self-acceptance is seen more frequently among those PLHAs who are not empowered and community rejection often seen in communities where there is a lack/incorrect information/knowledge about HIV/AIDS transmission. Awareness/sensitization campaigns with cultural teams through role-plays; rallies on HIV/AIDS; establishment of study-cum-recreation centers and utilization by all the children in the community and picnics. Support group meetings by involving the community people has reduced stigma, as they are educated about myths and misconceptions on HIV/AIDS. VMM has initiated the strategy of educating the communities not only the modes of transmission but also how HIV won't transmit; this knowledge empowerment has been achieved regularly through exhibitions, pamphlets, posters, street plays etc. This has made the community to think of stigma and brought an attitudinal change.

Vijaya reflected that before Home/community-based Care and Support programme we were ignorant of how HIV won't affect. Hence I used to keep away my sister from me and my children. I never served them food in our plates. Later, I came to know that HIV won't spread even if we share a plate or a glass. Now I stopped hurting my sister and her family. Now we all dine together and the vessels are common.

Impact of home and community based HIV/AIDS care and support programme in reducing Stigma & Discrimination (S&D): It was very much evident in early days that S&D was high in the programme areas where PLHA and their children were discriminated by the community. The people in the community had a lot of myths and misconceptions about HIV/AIDS. So people were even afraid of touching PLHA. Among PLHA self-stigma was also very high by isolating themselves from the community and if anyone is gossiping they assume that the others were talking of them only and again if somebody did not talk to them they take it in a negative sense. Before initiation of the programme stigma and discrimination prevailed in the communities against people living with HIV/AIDS and children affected by AIDS.

Now the total scenario is changed because of the consistent community sensitization through one to one and one to group and even group-to-group discussions/meetings. Regular field visits of staff, and community mobilization by involving Community-Based Leaders (CBLs) and different stakeholders has also contributed in reducing stigma. Now PLHAs are empowered through support groups and now they are addressing their own issues by exploring their live stories in the public meetings, training camps and workshops. Now CAA (Children Affected by HIV/AIDS) are at the fore front of the programme. They are given knowledge through children support groups meetings, psychosocial support workshops and peer education training including care giving and coping mechanism.

In the first year the participatory community reviews (PCR) were conducted at NGO office but now the PCRs are taking place at community places. Even the community people are also actively involved in PCRs, nutrition demonstrations etc. Positive attitude among PLHA and CAA has been developed and is visible. Percentage of school dropouts came down due to the sensitization of teachers and school support groups. At least 70 per cent of dropouts are back to school due to the enabling environment in schools. Reduced suicidal tendencies of PLHA, and they are providing psychosocial support to newly identified PLHA. They improved their health standards by taking locally available low cost high nutritive food. They have developed confidence and hope in their lives and also positive speakers came up with confidence to help fellow PLHA in the community. Support groups are their strength and the place to share their feelings with their friends. Children are actively involving in the programme and some of them became child ambassadors to advocate their issues with officials and carrying out the issues of children.

Lessons learnt: It is realized that someone should initiate to pool out the good in each person. Giving lead to community-based leaders gave the positive response in the community, which helped a lot to improve the quality of PLHAs' lives. Voluntarism by PLHA, CAA, and community leaders brought positive results in reducing stigma, discrimination, myths and misconceptions.

Best practices: Working with PLHA, CAA, Family members Affected by HIV/AIDS, Self Help Groups and other stakeholders for the better implementation of the programme; Initiation and functioning of support groups with PLHA and CAA; Conducting training camps and workshops to strengthen PLHA and CAA and regular follow up; Understanding and assessing their situations and problems within the community; Initiation and strengthening of support groups with PLHA & CAA, involvement

STIGMA AND DISCRIMINATION IN PPTCT :

of Community-Based Leaders, spiritual leaders and other stakeholders like self-help group leaders for the mainstreaming of the PLHA it is also very effective. Improving care giving and coping mechanism systems; mobilizing communities to reduce stigma & discrimination; children becoming change agents. Focus on orphan and children involved in child labor.

Laxmi's (Name changed) husband worked as a mechanic and died of AIDS. Later Laxmi was also diagnosed HIV positive. She has two children and was upset and depressed after knowing her HIV status. None of her relatives allowed her to stay with them or to help her in any manner. She had undergone mental agony and was living only for the sake of her children. In spite of all those trials and tribulations she looked for work to feed her children and at last got a job in a hotel on daily wage basis of INR 20/- per day. She could feed her little kids with that meager amount that she was earning. Later on owner of that hotel came to know Laxmi's HIV status through a customer and removed her from the work. She was also asked to vacate the rented house. With children she survived in a bus shelter for two days. Third day she could manage to have a small hut on the roadside but neighbours did not allow her to stay there. Then she left the place and went to a new area where she could get a rented shed and worked as a domestic servant. Neighbours in the new area also came to know her status and she was asked to leave the place.

Meanwhile Sanghamitra (one implementing NGO) staff and volunteers came to know this situation and approached her and gave counseling and then sensitized the community by giving knowledge on HIV/AIDS. Now community members are providing food material and moral support to this family.

IMPACT OF STIGMA AND DISCRIMINATION IN PREVENTION OF PARENT TO CHILD TRANSMISSION

Stigma and discrimination within the family and community is having a negative impact on the prevention of parent to child transmission of HIV. Rural and slum dwelling women in the programme areas have the disadvantage of illiteracy, ignorance, lack of equal place in the family, domestic violence and the attitude to learn and understand their own lives. With such background the hurdles to prevent transmission of HIV from parent to child are many which directly relates to stigma and discrimination.

At individual level : The impact starts with the husband's high-risk behavior and HIV positive status, which is not revealed to the wife who is becoming vulnerable. • The husband's insecurity prevents the wife from undergoing test. • Lack of cooperation from the husband to plan protected sex increases the viral load. • The husband avails the health services but the same is not encouraged for the wife as it "attracts attention" and is a 'financial burden' to him.

At household level : The need to become pregnant soon after marriage at the insistence of the in-laws is the priority of the newly married couples and the women fear ill treatment if the pregnancy is delayed as the 'barren woman' title is difficult to bear and these women are ostracized in the community. • The choice of pregnancy is by the husband/in-laws and so the women cannot avoid the untimely pregnancy. • Fear to disclose the HIV positive status to the in-laws/parents due to stigma and discrimination is further reducing the chances in availing the possible resources. • The women do not favor temporary methods of birth control, as the urgency for confirmation ability in child bearing is the priority. • Pregnancy confirmation at fifth or sixth month of antenatal period is delaying the treatment modalities.

At community level : Stigma attached to HIV/AIDS has been hampering women from learning about the disease. • Termination of pregnancy is still looked down in the community so the women continue the pregnancy even after knowing the risk of transmission of HIV to the child.

At facility level : Lack of regular antenatal check up is delaying the chance to protect the child by taking the possible precautions. • Lack of attitude to go for institutional delivery as more deliveries are by local untrained practitioners or 'experienced' women in the local community. • Lack of institutional delivery facilities. • Fear of attending the prevention of parent to child transmission centers as it may disclose their HIV status to the neighbors. • Fear of going to far away Prevention of Parent to Child Transmission center (PPTCT) instead of local health worker as it may attract the attention of the local community. • The less sensitive staff at PPTCT centers discourages women in availing the services of PPTCT.

At family lack of knowledge : The women are affected by stigma and discrimination at various stages of their lives from knowing about HIV to availing the services. So the women are exposed to higher risk of transmitting the HIV to the child.

"What can I do when my husband wanted to have a child? It is better to get HIV rather than to experience the beating every day at home. Let me die with him."

-The agony of Lakshmi who is HIV negative living with a positive husband.

There are so many such women who are not given a chance to protect themselves and unless the stigma towards HIV reduces, the chances of self-protection are questionable.

WORLD AIDS DAY OBSERVATIONS

“It is agonizing to know that my son is HIV positive and it is very bad to know that he got that through me. I feel responsible for his death at such a tender age.”

—The pathos of losing a son

Many women try to avoid getting a HIV positive child if they are given a chance in this stigmatized world.

“I went to PPTCT center and I wanted to die there as the burden of HIV was felt more there.”— The words of Mani who delivered a baby in PPTCT center.

“I did not know about PPTCT and so my child was born at home and is tested positive.”— The agony of a mother living with HIV and rearing a HIV positive sick child.

“We are from upper caste and so we did not go to PPTCT even though we know about it. Alas!! Now we have a HIV positive child who is very sick.” - The pathetic cry of a father who is bound by social layers and stigma.

The impact of compartmentalization of social structure is very visible while working in the community in relation to stigma and discrimination. The multidimensional impact of stigma and discrimination on the prevention of HIV transmission to child is making the success of PPTCT skeptical.

It is very important to reduce the stigma and discrimination to increase the success of the prevention of transmission of HIV from parent to child. As it is very difficult to change the social structures and relocate the culture, it is very important to concentrate our efforts in reducing the stigma at different levels in the community to reduce the vertical transmission of HIV.

World AIDS Day Observation

As part of World AIDS Day observation, VMM has taken up an event of children Intra-support group interaction on the premises of VMM. Twenty-six school support groups with 627 students and 52 teachers attended the interaction meet to discuss the forthcoming plans and strategies to be followed at school level.

The main purpose of this meeting was to reduce the stigma and discrimination from the young learning hearts towards the affected and infected children and to create an enabling environment in the schools and by providing psychosocial support to them. It was observed that there existed discrimination towards those unfortunate children who are the victims of HIV/AIDS. It was the need of the hour to sensitize children and to give them proper awareness and knowledge regarding the issues related to HIV/AIDS. It is easy to mould the children, which would become a tiresome job as they grow older. Through this gathering of children, Lead Partner could analyze the knowledge of children in the field of HIV/AIDS. Different group discussions were carried out and the group leaders from different schools were given opportunities to share the activities being done in their schools. Children were also asked to share their knowledge regarding HIV/AIDS, and their attitudes towards the children who are infected or affected by HIV/AIDS.



It was easy to gather sufficient information since the children were so participatory and open in revealing their knowledge and attitude. The impact of the programmes conducted in different schools was also assessed in the meeting. The way the children took it and carried to their houses and nearby localities were also found through this meeting. The children also explained the functioning of support groups and the different activities of the support groups. The difference that support group could make in their locality also figured in the meeting.

Taking into consideration the opinion and concerns expressed by the children as well as the teachers a future action plan was designed in the meeting. The action plan was made with a clear-cut objective considering the areas where there is need for further improvement and where it was applied successfully. The children and the teachers were also given sufficient information regarding the action plan and what are the strategies and steps to be followed in the process.

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Ms. Siva Kumari receiving revolving fund of 1 lakh from Honourable Health Minister K. Rosaiah, Andhra Pradesh Government, on World AIDS Day.

This is the result of SHADOWS, Chirala an implementing NGO of Vasavya Mahila Mandali, advocacy with District Collector, Ongole and other officials concerned. Advocacy and sensitization programs facilitated by Dr. A. Davidson S Solomon, SHADOWS and led by Support group members.

ADVOCACY INITIATIVES

Meeting with Chief Minister of Andhra Pradesh and Megastar Chiranjeevi

It was a unique experience for the children from the implementing NGOs to visit Megastar Chiranjeevi, a well-known film star, in India on 13th November, 2005 and spend time with him more than two hours and another great personality Dr. Y.S. Rajasekhara Reddy, Honorable Chief Minister of Andhra Pradesh on 15th of November, 2005.

The main purpose of visiting Chiranjeevi and Rajasekhara Reddy was to give an assurance to the children that they are not neglected and there are people who are willing to spend their time with them. It also served the purpose of giving courage to the children and helping them to feel that they are really wanted and there will always be somebody to spend time with them.

The way Chiranjeevi spending time with the children was something appreciable. As it is natural for a person like him to be engaged with something or the other and to have some hectic schedule, was same in the case of Chiranjeevi too. But once he came to know the purpose behind the visit of these children, he whole-heartedly agreed to be available for the children.

Chiranjeevi found sufficient time to listen to the voices of children which represented the issues of children affected by HIV/AIDS and then the activities of VMM. He was amazed by the voices of children who are bold enough in expressing their issues and he appreciated their boldness. He was also much impressed by the activities and the way the children are cared and supported. Photographs of Chiranjeevi being with the children were also taken in the process. He called one by one near to him and asked to share their life stories and their sorrows and pains with him.



Chiranjeevi assured them that he was there for them to support always. He told all the children to be strong enough to face the realities in our lives and to continue education. He also asked all the children to be confident to go ahead with studies to stand on their own feet, inspite of all struggles.



Dr. Y.S. Rajasekhara Reddy also could spend some time with children inspite of his busy schedule. Children explored their issues to him. Then he assured all the children that government will take care of children who are in dire straits. Responding to the issue raised by Mrs. G. Rashmi, E.D., with regard to issue-based scholarships, he assured the delegation to sanction scholarships to orphans and vulnerable children. And then he had a photo with children, which was covered by leading print media.

It was really a wonderful experience for the children to be cared and supported by somebody whom they have seen only in the multi-media and photographs. The children were also surprised to see influential personalities like Chiranjeevi and Rajasekhara Reddy really spending time with them.

All of them agreed that they could never dream of being with a film star and Chief Minister and those were some of the moments to be cherished off throughout their lives.

Children's Interactive meet with U.S. Acting Consulate Mr. Ravi Candadai

Children affected by HIV/AIDS across Coastal Andhra Pradesh gathered at Vasavya Mahila Mandali to have an interactive session with U.S. Acting Consulate (Chennai) Mr. Ravi Candadai. Children explored their live stories during the interactive meet, Acting Consulate emotionally responded positively to the live stories of children who have been suffering from different problems of AIDS epidemic. Mr. Ravi Candadai assured children that they are not alone and their country is always ready to help the needy.



US acting consulate Mr. Ravi Candadai with Children

Picturing Hope

Mrs B Keerthi received an invitation along with three children to participate in World AIDS Day observation hosted by Asia Society in New York in November/December, 2005. With Revathi, Ramu and child mentor Meroz, B. Keerthi participated in the World AIDS Day events, 2005, held in New York, Washington D.C. and Chicago, the United States of America in November/December 2005. The aim of the Picturing Hope programme is to improve the lives of children affected by HIV/AIDS. The children who participated in the meet revealed their hearts and narrated their heart-rending stories. They presented the photos taken by them on various occasions. They also gave an avid picture of **Picturing Hope**.

Ann Veneman from UNICEF who was invited as special guest appreciated the efforts of children in participating in the meet. She said that so far UNICEF had been concentrating on African countries and it would henceforth spread its activities in Asia also. She has appealed to the Asians in the US to support for the children affected by AIDS in Asia particularly in India. Visakha N Desai of Asia Society said that the Society is opening soon its office at Mumbai to help the Indians in all aspects of life. Reeta Roy of The Abbott Fund appreciated the work done by NGOs like Vasavya Mahila Mandali in India and hoped it would go a long way in doing great service to the suffering children who became orphans due to HIV/AIDS.

Craig Bender of Picturing Hope explained the involvement of children in Picturing Hope in capturing the agonizing moments of orphans. The highlight of the meet is the interaction of Students of 21 International school in New York with the Picturing Hope children which turned out to be very interesting.

MAINSTREAMING RAO THROUGH EDUCATION

Nageswara Rao, a 13 years orphan, is a school dropout at 6th standard and became the key bread winner of the family. By foregoing his childhood, he has shouldered the responsibility of taking care of grand mother and grand father who are at 70s, terminally ill mother due to AIDS and himself. The family of Nageswar Rao is in such a vulnerable state due to grand father who is physically challenged by hearing impairment, stigma attached to AIDS, loss of father at a tender age and continuous morbidity and mortality in family.

Rao's mother is provided with medicines for opportunistic infections and the quality of life of family is improved a lot due to the psychosocial support being provided to the mother and also to other family members by NGO and also through support group members.

The on set of sunshine starts him with fetching water, washing clothes, buying fire wood and provisions including vegetables and milk. Day in and day out Rao's schedule is busy in managing the family and coordinating various activities of household chores and livelihood.



Rao, washing the clothes and his sick mother pity at him



Rao, cooking the rice. Mother and grand father are visible



Rao, pulling the cart of aluminum and stain less steel products

Rao pulls a cart from the age of 11, after his father's death. He sells plastic and stainless steel vessels on a mobile cart and he drives 12 kilometers to sell these products. He leaves home by 8.00 hrs and return back by 15.00 hrs. As he is young to manage the unit, his grand father accompanies him to business center by sitting on the cart and Rao pulls him. Rao is learning managing the enterprise from his grand father. He earns INR 50 per day (A little more than one USD). After having lunch again he goes alone to buy the products weekly twice.



"I want to go to school like all other children but my grand father beats me if I insist on going to school" says the little Rao. So he is directed to attend for non formal education (NFE) centre at Vambey colony being supported by VMM/EDC. Rao returns from his work at 15.00 hours and attends the NFE centre by 16.00 hours. He was provided with text books, note books, guides from the project. The sensitized communities came forward to support Rao by a teacher contributing additional one and half hour providing extra coaching as he is appearing for 7th standard Government certification examinations, through a private school, commencing from 15th April 2006. Besides that the teacher is providing education support to 19 children including Rao for another 2 hours a day.

He is one of the happy boys now by balancing his personal responsibility of family and as well as fulfilling his quest for studies. "He is a very studious boy and concentrates on his studies well" says the teacher.



He is the leader among his peers and is an active children support group member. (Rao, in the center)

"He is very active now as he is able to appear 7th board exams. He finishes his work at home fast and runs to the school to study. It makes me very happy to see my child at this again" says Rao's mother.

"We hope that he secures first class in 7th exams"- the hope of staff of Vasavya HCBCS.

Thanks for the kind gesture of Alliance and EDC which has reformed the life of Rao.

MEDIA SUPPORT

Recent happenings:

- ❖ Mega children's Camp ❖ Peer education children's camp at Delhi ❖ Experience sharing and learning meet (ESLM) ❖ Children's Picnic at Hyderabad ❖ Child to child approach workshop ❖ Follow up work shop on Peer education ❖ Follow up work shop on Leadership ❖ Programme Advisory Committee Meeting at Andhra Pradesh AIDS Control Society, Hyderabad

MEDIA

- ❖ **BBC News** broadcasted the programme with title of "Indian women face peril of HIV/AIDS in 'Millennium developmental goals'" on 22nd September 2005.
- ❖ **Door Darshan** telecasted half an hour programme called "Matladandi Please" with different people's opinion in the field.
- ❖ **NDTV** telecasted the children voices in the month of Nov, 2005.
- ❖ **TV 9** telecasted the programme through "Young Tarang and Praja Paksham" in the month of Oct, 2005 and 18th & 20th Feb, 2006.
- ❖ **Sibar, E-TV, ZEE TV** and **Siti** cable are covering and telecasting the programme regularly.
- ❖ **All India Radio** is regularly broadcasting the activities of the programme.
- ❖ **Germany News Paper** coverage – Marie Prott a journalist from Germany visited the programme and impressed by a typical child headed family–Master Nageswara Rao at Vambay colony, Vijayawada. Then developed his case study and it was covered by Germany News paper called **Markshe Allgemeine** on 1st December 2005.
- ❖ **Canada News Paper** – Yashley Ward from Canada visited the programme and gave attention to innovative approach of community foster care and developed a beautiful note on it and it was published in Canada News paper called **The Inverners Oren** on 7th December 2005.



Participation of President and Medical Director of Vasavya Mahila Mandali in Vaartha Daily News paper initiative to create awareness on HIV/AIDS.

Press clippings both in English and Telugu.



REFLECTIONS

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January 25, 2006

Mrs. Chennupati Vidya
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India

Dear Vidya:

It was an absolute pleasure and honor to meet you and your wonderful family. VMM is doing outstanding work to improve the lives of children and families. We appreciated the opportunity to meet children, grandparents and women whom our programs are helping. It was extremely gratifying and exciting to move ahead with the night shelter and vocational education workshop. We thank you, Keerthi, Rashmi, Deeksha and everyone at VMM for making our time so insightful and inspiring. Everyone's dedication and passion for fighting HIV/AIDS at VMM is commendable and most appreciated. We look forward to working with you in the years ahead.

Sincerely,



Cathy Babington, President, Abbott Fund



Reeta Roy, Divisional Vice President, Global Citizenship and Policy

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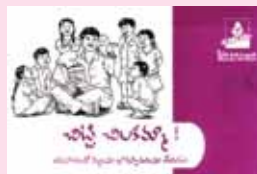
PUBLICATIONS



Prevention of HIV/AIDS from Parent to Child Transmission



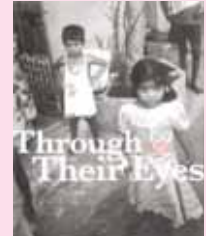
Child Protection Policy



A Guide for people starting to work with orphans and vulnerable children with different energizers



Children Voices



Picturing Hope



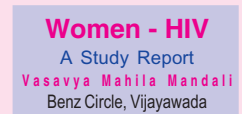
Psychosocial support to children (CAA) (Telugu)



HIV/AIDS- counselling (Telugu)



Stay Fit and feel good- a health guide for caregivers &volunteers (Telugu)



Women - HIV

A Study Report
Vasavya Mahila Mandali
Benz Circle, Vijayawada



HIV/AIDS- Confidentiality (Telugu)



Good food for good health- Nutrition education with 100 recipes (Telugu)



Periodical News Letters (E-Version and Printed)



Moving Forward, a report on pioneering responses to CAA in Andhra Pradesh

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Edited & Published by G. Rashmi on behalf of Vasavya Mahila Mandali. DTP at Viswa Type Institute, VJA. For Private Circulation Only.