

SAHRUDAYA

VASAVYA MAHILA MANDALI



TAP Programme
With the communities- By the communities - For the communities

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Reflections on the Effectiveness of Community Structures

- Prasada Rao, Project Director, YCB

Youth Club of Bejjipuram, Srikakulam is a partner to VMM in TAP program and community structures are formed and efforts are being taken to strengthen since 18 months. The most useful groups for us are Adult and Children Support Groups.

Sri Rama Adult Support Group with 13 Members in Kalingapatnam, fisher village on the shore of Bay of Bengal is exemplary in creating awareness and providing moral support to their peer. They are supporting each other financially also and reduced stigma in the community.

Another woman affected by TB became a positive speaker and is inspiring community to follow the treatment. Members are taking lead in creating awareness on testing, treatment and adherence. The involvement of support group members is increasing the confidence of the TB and HIV affected people and their families. Some are changing the attitudes of people who stopped the treatment and are referring them to DOTS centers and follow up.

Children support group members raised contributions to support 9 fire victim families with rice, school uniforms and dresses. They are planning to get a tri- Cycle to a differently abled child.

It is good to involve the community for sustainability and in TAP programme, the community structures are showing us the way forward.



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In the words of K. Lakshmi

Member in the First adult support group of Vasavya Mahila Mandali in 2003

I suggest to promote support group formation in all programmes as I am the living witness of the benefits of the support groups. I graduated from 'wanting to die' to 'living with dignity'. I got the strength from my peer in the support group and we share all our problems and help each other. We stopped working when our HIV status was revealed to us but with the support of each other, all of us are busy with jobs now. Our thoughts of 'death' are replaced with 'HOPE' and also we became inspiration in the community. We used to suffer in our houses before but now bold and positive in our thinking and still continue to have a productive life. I, on behalf of the support group members; I wish the very best to the members of the support groups formed in the TAP programme.

PROUD TO BE A MEMBER OF ADULT SUPPORT GROUP

"I have a hard life with diseases and loneliness residing in an urban slum in Vijayawada, Krishna district, Andhra Pradesh, India. I have two children: daughter ten and son six years. We are living with my mother after my husband died with HIV in 2010. I was married to a truck driver at the age of 18 and happy with two children till 2005 when my husband repeatedly had illness and was treated by a local doctor. My husband got tested for HIV at ICTC in government hospital. We were devastated with the positive report and I continued to care my husband. He was referred to ART center in government hospital and was on treatment. But he did not take medicines regularly and died. The responsibility of family fell on me and so I started working as a daily labourer earning around INR 3000 per month and it is not sufficient to take care of my children.

My father and mother are supporting me and then my father at the age of 60s was being treated for TB, and I too noticed the same symptoms; cough and fever and screened for TB as advised by a worker from World Vision organisation. I had TB in the lungs and I was provided DOTS by her only for nine months. I thought that I got TB from my father. But only after becoming a member in Adult support group formed by Children Leadership Development Association (CLDA), VMM partner I came to know the facts of HIV and TB that there are more chances of getting TB among HIV positives.

While forming a group, a volunteer of CLDA, regularly interacted with us and motivated us to gather at one place to discuss the problems related to TB/HIV since July 2012. I was surprised to know the modes of transmission of HIV and TB and importance of partner and children testing. My parents and relatives suggested me several times to get HIV test after my husband's death but at that time I didn't give importance due to my ignorance. After knowing about HIV in our support group meeting, I felt that I need to test myself for HIV. I took the help of TAP volunteer, and got tested for HIV and found to be HIV positive. I became bold after becoming support group member and took my children too for HIV testing and thank God they were HIV negative.

The 20 women living in the same area and the persons who suffered or suffering with TB or HIV are part of the support group and we support each other often as we meet every day informally. Monthly once we all gather at one common place to share and discuss about our problems. The staff of CLDA helps us in understanding the treatment and side effects and also the services available in our area.

These adult support groups made me brave in dealing with my life and I will help more people like me and so proud of being a support group member" says Ms. Padma.

IMPORTANCE OF COMMUNITY STRUCTURES

For a sustainable programme through social security net for people living with diseases with a social taboo and implications at family level like HIV and TB, the support groups are promoted with a visible outcome within 18 months of Tuberculosis Initiatives in Andhra Pradesh (TAP) programme of Vasavya MahilaMandali at six partner organisations in six districts: Srikakulam, Visakhapatnam, East Godavari, Krishna, Prakasam and Nellore.

The support groups are formed within a geographical area with a common interest of a healthy life. All the group members know and interact with each other often to support each other. The groups are very active and utilize the health and social security facilities more and advocate within their own communities and support each other. This increases a conducive environment in the communities to enjoy their health rights. These groups are forming a community within the larger community. They are able to become bold and their life is planned in a better way with the support of the peer accepted by the family and community.

Vasavya MahilaMandali and the six partner NGOs in TAP programme is addressing the community by involving the communities at different levels of the programme. To improve the involvement and to sustain the involvement beyond the programme period, community structures are formed. The various community action groups are,

- 69 Adult support groups
- 51 Children support groups
- 7 Community core groups
- 6 Grannies clubs

ADULT SUPPORT GROUPS

The groups consist of people living with HIV/AIDS and TB, their family members, and one or two key persons in the community. The members gather at a home of the member or a religious place or a community hall available for them. They discuss their problems, and maintain the minutes for follow up. Outreach worker of TAP programme facilitates the process initially and later the group meets independently that shows sustainability of the groups. They identify the people suffering from diseases and refer them to facility centers and appropriate institutions with the support of resource directories. They participate in community mobilization and the programme activities.

The Purpose of adult support groups is to create a platform to ventilate the problems, to own the community, to sustain the programme and to act as a resource hub for the area

Methodology used is participatory using IEC Material and play tools

The outcome of the adult support groups is being reflected in their active participation in the control and treatment of HIV and TB. Improvement in the quality of life is an indicator of the quality of services delivered by the TAP programme.

Tuberculosis activities by adult support groups:

- 158 people with symptoms of TB referred to facility center (Designated Microscopic center)
- 129 tested for TB (81.64%)
- 17 were tested sputum positive (13.17%)

HIV activities by adult support groups:

- 143 people with symptoms of HIV referred to facility center ICTC
- 103 tested for HIV (72.74%)
- 8 were tested HIV positive (7.76%)

The contribution of adult support groups in the total referral is 2.72% (301) after 18 months. Vasavya Mahila Mandali is aiming to increase the role of adult support groups by the end of the programme. Now 40 groups are maintaining the referral book to refer the suspected.



CHILDREN SUPPORT GROUPS

The purpose of children support groups is to provide emotional and psychosocial support, to increase their confidence and sense of belonging by perceiving loss and help them overcome it with a unique approach of play-based activities.

Children support groups are promoted with a group of children affected/living with HIV/TB and the children in the neighborhood. Each group consists of 10-15 members of both gender.

Children support group members also started to contribute to the programme in identification, referral and also follow up. The outcome is,



courtesy: TB Alert UK

Tuberculosis activities by children support groups:

- 35 people with symptoms of TB referred to facility center
- 32 tested for TB (91.42%)
- 0 were tested sputum positive (0%)

HIV activities by children support groups:

- 17 people with symptoms of HIV referred to facility center
- 13 tested for HIV (76.47%)
- 2 were tested HIV positive (15.38%)

The involvement of the children is volunteered in the community and the children started to feel responsible after joining the children support groups. Now 15 groups are keeping the referral book with them for ready use.

Children Support Group Involvement in Positive Prevention

Kameswarao Rao, 34 years aged fisherman from Kothadibbalapalem of EtcherlaMandal, Srikakulam district is living with HIV since 2008. He lived with his wife and two children. They were leading life by taking necessary steps for safe sex for not to increase viral load. His wife started to become weak and was not able to perform her regular domestic chores. Members of the Gandhi Children support group noticed her health condition and alerted outreach worker of YCB. She was referred to nearby Community Care Center and after 15 days she died in 2012.

It is the local tradition to conduct second marriage to the widower within a month so that the soul of died wife rest in peace. KameswaraoRao was ready for immediate marriage and was in search of a bride. As the Gandhi children support group came to know the tradition, they discussed the need for a positive marriage as was discussed in one of their support group meetings. As the children could not deal with this matter, they came to a decision to approach TAP Volunteer Neelaveni and outreach worker Bharathi for further suggestions and action.

Bharathi and Neelaveni visited KameswaraoRao's house thrice to counsel him on the consequences of marriage between two HIV positives and discussed the need to protect another woman. He was very reluctant to the suggestion as he wanted to marry a healthy woman. The outreach worker approached his brother and he too expressed that to serve his brother, he needs to marry a healthy woman.

Hence, outreach worker decided to put collective effort with Positive people network to provide information on HIV and its impact. An awareness meeting was organized for the village elders. Children support group members organised the meet and made all the elders to be part of the meet. This meeting brought a positive change in the elders which lead to stop the marriage with a young girl. The elders counseled Kameswararao about his marriage.

Even though marriage did not happen, Children support group members continued to follow up him for a change in his attitude of positive living. Children support group was initiated on 15th March 2012 as titled 'Gandhi' group and they are enthusiastic and observed a change in their own attitudes so decided to organize more meetings, hence 11 meetings were organised.

REFLECTIONS BY CHILDREN

'Gained knowledge and disseminated information to many villagers' - Venkata Lakshmi, 10th Class

'With a series of interactive sessions and counseling, I am facilitating adherence to a TB patient as she stopped taking medicine for two months' - D. Nagamani, 9th Class

'We are going to the houses of TB patients on every Monday, Wednesday and Friday to make them to consume TB Medicines'.

'I learnt about HIV and its associated infections and referred one person to Community Care Center for treatment of opportunistic infection' - Chandra Sekhar, 10th class,

'Prior to Children Support Group only we knew about HIV but now we continue to learn about TB and also about ourselves' - V. Mutyalu, 9th Class



courtesy: TB Alert UK

Based on the advocacy of Vasavya Mahila Mandali to improve the nutritional status of TB affected children or those who are living in TB affected families, the Commissioner Women Development and child welfare department, Government of Andhra Pradesh, Hyderabad issued a Memo on 19 October 2012: "Provide supplementary nutrition to children below six years those who are on DOTS or INH Prophylaxis to improve nutrition and health status." TAP staff educated the grass root functionaries of Integrated Child Development scheme (ICDS) to widely benefit the children.

COMMUNITY CORE GROUP

Community Core Groups

Community Core Groups are formed with Teachers, women self help group leaders, Integrated Child Development Scheme staff, people's representatives and Faith based leaders, Private health providers and leaders in the community and affected persons: one HIV positive, one TB Positive and one Co infected person also are part of the community core group.

The community core groups are visible through promotion of a community core group with children and youth in Children Leadership Association in Krishna district apart from community core group with adults.

Purpose of the community core groups is to create the ownership for promoting health rights within the community, to improve the accessibility of available services and to develop a platform within the community to bring visibility to the issues.

The outcome is visible through increased referrals and support system in the community for the affected persons.

TB activities by community core groups:

61 people with symptoms of TB referred to facility center, 57 tested for TB (94.37%), 7 were tested sputum positive (12.28%)

HIV activities by community core groups:

34 people with symptoms of HIV referred to facility center, 31 tested for HIV (91.17%), 5 were tested HIV positive (16.12%)

The involvement of the members is volunteered in the community and the members started to respond to the needs of the community and in particular the target groups. Now seven groups are keeping the referral book with them for ready use. The children community core group at CLDA is also referring and following the affected persons.

MD Kandrika is a village with 160 houses in Venkatagirimandal in Andhra Pradesh and STEPS is operating in the area. TAP outreach team is in the process of identifying the potential persons to be part of community core group as this village is identified with minimal knowledge of HIV and Tuberculosis. Rajireddy, a model farmer was identified as a potential member having attitude to serve the needy. TAP outreach workers approached him to be part of community core group. He accepted and suggested few other members who can influence the community.

Community core group had been in place with ten persons including Rajireddy on 06th of April 2012. Formally, the group assembled once in a quarter but now more number of times if they need to discuss an issue. The group was oriented on symptoms and modes of transmission of Tuberculosis and HIV and co infection. The group was requested to disseminate the information to their respective community members. The group was provided information, communication and education materials in order to support them in dissemination of knowledge with great enthusiasm.

As a part of his personal work one day Rajireddy visited house of Krishnaiah and found that he was bedridden with cough and high temperature since 15 days. The community core group member assumed that these are the symptoms of HIV and referred him to ICTC for HIV test as well to DMC for TB test. Simultaneously the same information was shared to other core group members; so group meeting was called for, all the members assembled to discuss the possible ways to support to Krishnaiah as he was unable to support his family that was dependent on him only. Rajireddy came forward to provide rice, dhal and other provisions to the affected family.

Krishnaiah found reactive for HIV and negative for Tuberculosis. The family was devastated with the news and became insecure about their livelihoods, property and also their daily needs. Community core group members noticed the distress and counseled the family members. Members did regular home visits and also arranged ten kilos of rice per month from an individual donor and supported travel expenses to health facility from the group.

Community core group members discussed and included Krishnaiah as a member of the community core group to reduce stigma and discrimination for HIV and TB. Krishnaiah regained respect and dignity as a member of this group in the community. The group matured with knowledge and commitment with an outcome of :

4 persons referred to Designated Microscopy Center (DMC) for TB testing, 2 persons were tested TB positive (50%), 9 persons referred to Integrated Counseling and Testing Center (ICTC) for HIV test, 1 person as reactive (11.11%) and linked to CD4 test and kept on ART Medicine.

GRANNIES CLUBS

Senior Citizens need family support to share their sorrows and responsibilities. In Home and Community Based HIV/AIDS care and support programme Vasavya MahilaMandali identified families where aged persons and children were living together and the middle generation was missing due to the diseases. The old persons were taking care of many children living with HIV also and this lead to many issues like generation gap, livelihood challenge and trauma of both generations. The adherence to treatment of the children was a great concern to the community.

Vasavya Mahila Mandali initiated 'Grannies clubs' with aged persons for providing moral support and also to educate them to monitor their grandchildren's health. The members used to meet regularly with the support of outreach worker. The grannies in the group shared their feelings and the meeting became a platform for psychosocial support through peer. The grannies expressed that the meetings were very helpful for them to reduce strain in their lives. Basing on the experience VMM, replicated 'Grannies Clubs' in TAP programme.

The partners formed six groups one group at NGO level. 15 to 20 members formed as a club. These groups were initiated in January 2013 in TAP programme. During the club meetings, the outreach worker and volunteer provided knowledge on self-care and home care to grannies for an hour. In the meeting the group members share their problems and events that happened at home regarding their grandchildren and children. The grief was shared and also jokes to get over their sorrows and worries. The grannies clubs are new to the communities reached. Then the outreach worker will share few new things about self-care and home care and medication along with jokes to retain their wish.

The major challenges of the grannies are

- **Livelihood:** as they have to be the bread earners of the family but they are too old to do jobs and became unproductive. The responsibility of sick made it more difficult to bear the medical expenses and to feed them.
- **Care taking:** as they themselves are dependent on medicines, they have to take care of their grandchildren, which is very difficult to monitor the health conditions of their grandchildren.



VASAVYA IN ACTION...

- 11 October 2012 International Day of the Girl Child: Women and men from rural villages and urban slums were sensitized on importance of girl child and investing on them by saving girl child, curb child marriages. A poster is released on determining child sex and responsibility of MAN scientifically.
- 07 November 2012 National Cancer Awareness day: A seminar is organized by VMM and TNP+ at Hyderabad on Cervical cancer among women living with HIV and key population - Emerging Trends.
- 01 December 2012 World AIDS Day: Breakfast meet of children with Mr. Budha Prakash Jyothi District Magistrate and Collector, Krishna to provide an opportunity to hear to the concerns and issues of children
- 01 December 2012 A poster on Pap Smear test for Cervical cancer among women living with HIV at ART centers is released by Dr. Ravindra Reddy, Hon'ble Minister for Health Government of Andhra Pradesh
- 08 March 2013 International Women's day: Observed the day with Mrs. P. Usha Kumari, Joint Collector Krishna by honoring women achievers at communities working on TB, HIV, violence against women and girl child.

TAP PARTNERS



CHILDREN LEADERSHIP DEVELOPMENT ASSOCIATION (CLDA)

KRISHNA DISTRICT



COASTAL NETWORK OF POSITIVE PEOPLE (CNP+)

EAST GODAVARI DISTRICT



MAHILA MANDALI (MM)

PRAKASAM DISTRICT



PEACE EDUCATIONAL AND RURAL DEVELOPMENTS (PEACE)

VISAKHAPATNAM



SERVE TRAIN EDUCATE PEOPLE'S SOCIETY (STEPS)

NELLORE DISTRICT



YOUTH CLUB OF BEJJIPURAM (YCB)

SRIKAKULAM DISTRICT

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