SAHRUDAYA

VASAVYA MAHILA MANDALI

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

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Message

Tuberculosis has emerged as one of the foremost challenges for poverty alleviation and development in our country. TB is prevalent in both urban and rural area. Government of India along with its partner states in the entire country is implementing Revised National TB Control Program to bring early, effective and quality TB diagnosis and treatment free of cost to all the needy.

Over the years Andhra Pradesh has implemented most of the additional components like TB/HIV cross referrals, management of drug resistant TB, engagement of NGO and private sectors, airborne infection control, operational research and involvement of medical colleges both from the Government and private sector. This led to increased accessibility to the TB treatment services.

The state is taking all the steps to further strengthen the accessibility to the TB control services and moving towards the goal of universal access to TB control. In this scenario contribution of partners and NGOs becomes important.

I wish VMM all the success in their endeavors.

T Rani Samyuktha

Dr. T Rani Samyuktha
Joint Director (TB) &
State TB Officer(AP)

Hyderabad
7th October, 2013

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Message from Madhavi, Project Director, PEACE

PEACE, implementing partners of TAP programme, working in five tribal mandals of Vishakhapatnam district focussed on tribal population. TAP project is family centred approach with focus on TB and HIV. While implementing the project we learnt that there are lot of myths and misconceptions on TB and DOTS due to poor knowledge levels on symptoms of TB and HIV. After the initiation of TAP program there is a visible increase in awareness about TB in the community and the community started availing the services with active involvement of the community structures. Tribal villages are sparsely populated; a village is with 15-20 households and meagre transport facilities. Buses ply occasionally and the most common mode of transport in hilly areas are jeeps. On sandy days (a market place arranged at one place weekly once) ply three wheeler auto rickshaws with persons hanging on both the sides with materials purchased. I am really proud regarding the commitment levels of outreach workers and volunteers in identification of suspects and referring for testing centres, walking hundreds of kilometres reaching home for 7-10 days. TAP is the only programme till now worked for tribal people in the unreached areas for TB reduction in Visakhapatnam. Through community structures able to reach the much deserving population. We work closely with government departments such as women and child development in providing nutrition to children from TB families, with Integrated tribal development agency in a drive for smear positive TB identification among 4800 and 280 are positive. PEACE transported MDR drugs in 6 TUs as per the proceedings of District TB officer.

ADVOCACY - TAP

Vasavya Mahila Mandali initiated Tuberculosis in Andhra Pradesh (TAP) programme funded by UK Aid with the technical support from TB Alert. TAP programme aims to reduce levels of TB and TB/HIV co-infection, and increase access to effective health services, through empowered communities and local advocacy in six coastal districts of Andhra Pradesh. TAP is reaching to the tribal population in East Godavari and Visakhapatnam, fisher-folk in Srikakulam and partly in Prakasam, rural folk in Nellore, Prakasam and Krishna, urban slum dwellers in Krishna district of Andhra Pradesh. TAP is initiated from September 2011 up to March 2015.

TAP conducted baseline study at the beginning of the programme (in March 2012) by collecting the data on knowledge, attitudes and practices of the community, patients and service providers at district, facility and community level. This baseline report has analysed the service delivery with access to services and found that there are certain gaps which are affecting the effectiveness and planned those as advocacy plan:

Advocacy targets identified from baseline:

- *The Anganwadi workers (AWW) indicated that referring antenatal (ANC) and Prenatal (PNC) cases is part of their job. Similarly refer every TB and HIV suspected case for screening, testing and treatment but they did not receive training hence TAP need to advocate with department of women development and child welfare (WCD) for including DOTS provision in to the job chart of AWW*
- *Training of AWW on DOTS is another advocacy area for TAP. The project can advocate with AWW training centres located in the district and liaison with them. TAP also need to make provisions for bi-annual reorientations*
- *TAP needs to advocate for double nutrition to TB affected children during treatment through ICDS programme of WCD in par with HIV affected children.*
- *Low levels of knowledge among RMPs/PMPs regarding TB leading to wrong diagnosis and treatment resulting in advanced stages of pulmonary TB. Minimal knowledge levels about extra pulmonary TB leading to non-detection of cases and non-treatment. RMPs / PMPs in rural areas are the most immediate and preferred health service providers who are to be trained in TB screening. As they are also very important and effective referral hubs that the project need to consider improving their information level.*
- *Project has identified that as the diagnosis for extra pulmonary and non-smear TB positive is through x ray screening, x ray services are very minimal in the government sector at primary health services level and mostly available at tertiary care or some CHCs (Community Health Centers). Hence project to identify the x ray service providers in the private sector and make partnership with them to provide x ray services. In order to ensure this the project need to develop a referral system.*

Advocacy is literally defined as any action that speaks in favour of, recommends, argues for a cause, supports or defends, or pleads on behalf of others. Advocacy is speaking acting, writing with minimal conflict of interest on behalf of the sincerely perceived interests of a disadvantaged person or group to promote, protect and defend their welfare and justice by

- *being on their side and no-one else's*
- *being primarily concerned with their fundamental needs*
- *remaining loyal and accountable to them in a way which is*
- *emphatic and vigorous and which is, or is likely to be, costly to the advocate or advocacy group*

Social work advocacy is the exclusive and mutual representation of clients or a cause in a forum attempting to systematically in?uence decision making in an unjust or unresponsive system. (Schneider and Lester 2001 p65) Advocacy involves a person(s), either a vulnerable individual or group or their agreed representative, effectively pressing their case with in?uential others, about situations which either affect them directly or, and more usually, trying to prevent proposed changes which will leave them worse off. Both the intent and outcome of such advocacy should be to increase the individual's sense of power; help them to feel more con?dent, to become more assertive and gain increased choices. (Brandon 1995b p1, cited in Brandon and Brandon 2001)

TAP advocacy issues: Tuberculosis in Andhra Pradesh (TAP) project has focussed on giving voices to the people affected by TB/HIV with community participation, confronting the issue of poverty; advocating for access to TB treatment as a fundamental human right; tackling stigma and discrimination; effective use of resources and utilizing and creating effective networks and alliances. Improved diagnostic facilities for sparsely populated communities with increased accessing of TB and HIV services by women and children were aimed. The most unreached tribal and fishermen communities, the vulnerable urban and rural areas reached through TAP programme. By increased utilization of the services, gaps were identified and advocacy at district, state and national level has taken up. The project in six coastal districts of Andhra Pradesh with district wise focus on different communities was taken up.

1. *Provision of double ration to TB affected children through ICDS.*
2. *DOTS provision in the job chart of AWW*
3. *Provision of X Ray facility at reduced cost in private sector*
4. *Sputum collection and transportation in the remote areas*

ADVOCACY INITIATIVE 1: ADVOCACY WITH WCD FOR PROVISION OF DOUBLE RATION TO TB AFFECTED CHILDREN THROUGH ICDS

TB among Children

The burden of paediatric TB is estimated at 10% of the total TB load. Globally, about One million cases of pediatric TB are estimated to occur every year accounting for 10-15% of all TB; with more than 100,000 estimated deaths every year, it is one of the top 10 causes of childhood mortality.

A child usually gets TB infection from being exposed to a sputum-positive adult. Young children below ten years of age are at risk of becoming infected with TB bacilli. They are also at high risk of developing active tuberculosis because the immune system of young children is less developed.

The chance of developing TB disease is greatest shortly after infection. When children present with active tuberculosis disease their family members and other close contacts should be investigated for TB to find the source of the disease and treat them as necessary.

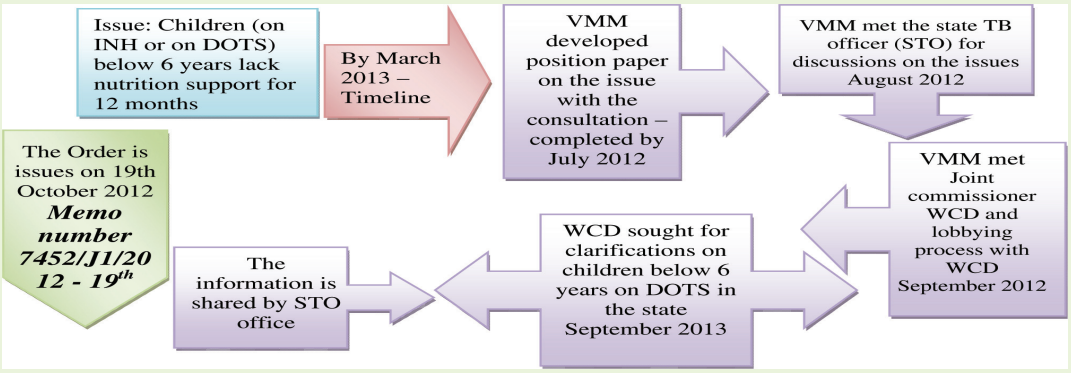
Factors that put children at risk:

- Any child living in a setting where there are people with infectious TB can become ill with TB, even if they are vaccinated.
- TB illness in children is often missed or overlooked due to non-specific symptoms and difficulties in diagnosis, such as obtaining sputum from young children.
- Children with vulnerable immune systems, such as the very young, HIV-infected or severely malnourished, are most at risk for falling ill or dying from TB.
- Infants and young children are at increased risk of developing severe disseminated disease associated with high mortality, such as TB meningitis or miliary TB.
- Adolescents are at particular risk of developing adult-type disease, i.e. often sputum smear positive and highly infectious.
- Children with TB are often poor and live in vulnerable communities where there may be a lack of access to health care.
- New-born children of women with TB are at increased risk of contracting TB. Risks are very high for HIV-infected mothers and children.

Need for Double nutrition to TB affected children and children from TB affected families:

Nutrition is the key requirement for successful outcome (Cure) of TB treatment to children and to improve the immunity levels among the children in vulnerability from TB affected families. Provision of double nutrition is in place for HIV affected children through ICDS programs, but TB affected children and children from TB affected families are not included in the program. In a few cases it is leading the children to become school drop outs. The TB affected children / children from TB affected families are not getting proper diet from families although the children are on DOTS or on INH Prophylaxis. The TB and HIV affected persons and their family members are under nourished that increases the non-adherence. So to improve the adherence among children on DOTS / INH prophylaxis and to have a normal growth of the child double nutrition from ICDS will be beneficial.

Double ration for HIV affected children (below 6 years) through ICDS programme of women and child development is already in place vide Departmental order (DO) number: 2052/J3/2009. Vasavya Mahila Mandali advocated with Department of Women Development and Child Welfare through state TB cell for provision of double ration to TB affected children and thankful to the department of WCD, government of AP for releasing the government order.



The result of the double ration GO is demonstrated through the case story in remote tribal village Sanyasammapalem of Hukumpeta mandal, Vishakhapatnam district. The village consists of 75 households with a population of around 350. In this village one Anganwadi centre is available. Through TAP programme identified seven suspected persons for TB and HIV and referred them to testing centres (ICTC and DMC) at Hukumpeta and Paderu. Among the referred two persons found TB positive one with pulmonary and another Extra-pulmonary and kept on DOTS with the regular monitoring by ASHA worker. The person with pulmonary TB is having two children; both of them are aged below 5 years and attending to anaganwadi center in their village. With the Doctors advise the youngest child of 18 months is provided INH prophylaxis. The child is under weight10kgs.

The TAP outreach worker met the Anganwadi worker and shared about the information of double ration GO, the same is shared to AWWs during the cluster level meetings. After continuous visits made to the center and sensitised the worker. The sensitised AWW provided double ration to the youngest child of the TB affected family. The child is receiving the nutrition support (for 25 days in a month) worth of rice 1.040kgs, Dhal - 465gms, Bencyravva 900gms, Oil - 295gms and Eggs twice a week.

The Anganwadi worker has expressed that, "The work of the PEACE (Implementing NGO partner of VMM in TAP project) is reaching to tribal people and more number will benefit through the scheme, thereby we can increase the immune system of the child with healthy nutrition diet". In her words the orders has to be availed to all the needy and service providers for better accessibility, similarly educate the Anganwadi workers to deal issues of stigma and discrimination.

VOICES OF A YOUNG VOLUNTEER...

Santhosh Kumari, a young volunteer in CLDA TAP programme, is from HIV affected family. She expressed that through TAP project I have learnt many things apart from the TB disease. I really convey my sincere thanks to the project staff. Through capacity building programmes in TAP project, I learnt communication skills with officials, with other stakeholders, community and how to motivate clients for testing centres, in one word my communication skills were improved a lot. Similarly I am able to support the clients emotionally; I became an effective counsellor and available round the clock to the clients and their families.

My uncle died due TB few years ago, at that time I didn't have enough knowledge on the disease, but he was always telling me about support people require, even a soothing word helps the TB patients to get relief and don't expect money. My uncle words made me to start supporting the needy persons to go for testing, even sometimes accompanying and paying for their travel charges too.

I am associated with CLDA since 2007; I was much moved with the aims and objectives of the organization. I worked as child care guide in HIV/AIDS stigma and discrimination reduction programme. I continued to work with the organization. Now, I am working as volunteer in TAP project. I am monitoring the health of ten TB and TB/HIV co-infection clients, with regular home visits and monitoring their health needs especially adherence monitoring of clients on treatment. I feel very happy while doing this type of services to the people.

With the formation of the community structures (adult support groups), my half job is taken over ie., identification of suspects for testing is done by the members of the groups, I used to do home visits and provide necessary counselling to patient and the family. Projects like TAP are much need for the urban slum communities where we live. In the community which I live people lack knowledge on the services at the government, now I became a source of information for them on services available at the government with contact details of the service providers.

ADVOCACY INITIATIVE 2 : INCLUSION OF DOTS PROVISION IN THE JOB CHART OF AWW

DOTS providers in Andhra Pradesh

DOT provider is trained health care worker or other designated individual (excluding a family member) gives the prescribed TB drugs under Direct observation. It is observed that people take medicines till they get relief of symptoms but not till the disease is cured. So the Directly observed therapy is monitored by the DOTS Provider. Studies show that 86-90% of patients receiving DOTS, complete therapy, compared to 61% for those on self-administered therapy. DOTS help patients to complete TB therapy in the prescribed period. DOTS help prevent TB from spreading to others. DOTS decrease the risk of drug-resistance resulting from dropping out of treatment or irregular treatment. DOTS decrease the chances of treatment failure and relapse as the treatment is monitored by DOTS provider. There are 1, 11,195 TB affected persons in AP in the year 2011. There are 62,000 identified DOTS Providers that administer medication for the TB patients. Majority of the ASHAs and AWW are trained in DOTS Provision at the district level.

DOTS provider delivers the prescribed medication, identify for side effects, monitor the medication, document the visit and increase the knowledge of the patient and the family.

Findings from TAP Baseline on DOTS Providers

Anganwadi Worker (AWW), ANM and ASHA are the key DOT providers identified by the facilities across the districts. Though there is scope for converting RMP, PMP, PLHIV, TB affected, NGOs, and local teachers as DOT providers none of the facilities have attempted so far. The DOTS provision is not yet officially incorporated into the job charts of AWW. Most of the DOTS providers are oriented about the TB and DOTS during the trainings, but there is need to conduct repeat trainings.

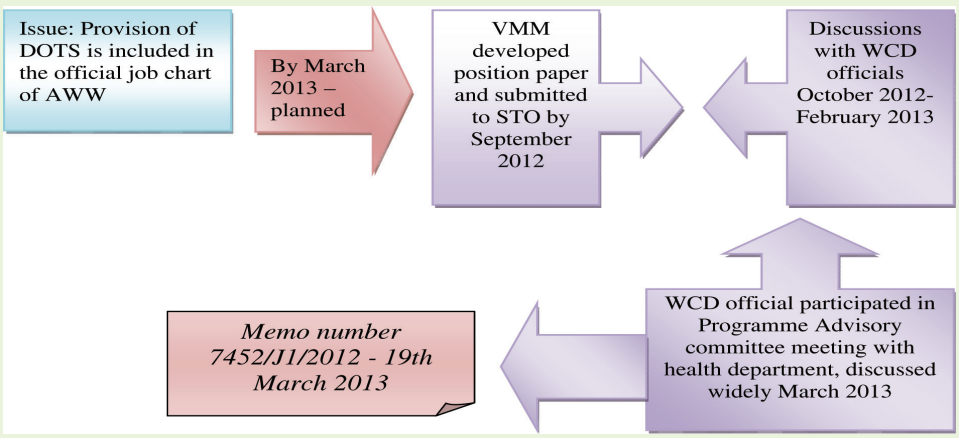
Anganwadi worker as DOTS Provider in TAP operational area

There are 2170 Anganwadi workers in TAP operational areas among them 259 are DOTS providers. Most of them have not under gone training that is required to provide quality services as DOTS provider.

Need for inclusion of AWW as DOTS Provider in Job chart

40-50% of Anganwadi Workers and ANMs are the key DOT providers identified by Senior Treatment Supervisors of the Tuberculosis Units in the project area. AWW is informally supporting and associating with DOTS provision. DOTS provision is not in their job chart hence in the monthly review their role of DOTS provision is not included. Most of the Anganwadi workers were not oriented on TB and role of DOTS provider. Proper orientation can be given to ICDS staff to make them effective about referral, testing, treatment and adherence. So that early identification leads to reduced mortality and improved adherence for quality of life. Secondly the AWW are not capacitated on TB as they do not have it in their AWW training curriculum.

Vasavya Mahila Mandali advocated with Department of Women Development and Child Welfare to Include: DOTS provision in the official job chart of Anganwadi worker (AWW) so that they under take TB referrals and follow up of children, antenatal and postnatal women and act as DOTS provider and to include TB along with HIV in AWW training module. The process if presented in the flow diagram:



Dissemination:

Disseminated the two government orders to the ICDS and WCD functionaries from village to district level (in six districts of TAP presence). TAP project staff are participating in the district/mandal level meetings of ICDS project by educating them on TB symptoms, treatment along with adherence monitoring of clients on treatment. Till June 2013 (From April 2013) the dissemination meeting with knowledge on TB is provided to 1120 WCD and ICDS staff (1091 AWW, 17 Supervisors, 6 CDPOs and 6 PD WCD). The information on TB with snake and ladder game (soft copies) is shared to WCD to print it in AWW's Dairy in March 2013.

With the knowledge gained, 479(235 for TB and 244 for HIV) persons were referred to facility for TB and HIV testing. Among them, 40 are positive for TB and 20 for HIV. Now the picture has changed that the referrals by the AWW has increased and directly referring the suspects for testing centres and later informing the same to the TAP project staff. As the AWWs are informed on importance of DOTS providers' role, now the AWW as DOTS provider is supervising the treatment.

ADVOCACY INITIATIVE 3: X RAYS AT REDUCED COST FROM PRIVATE HEALTH CARE PROVIDERS FOR SMEAR NEGATIVE CASES

TAP implementing NGOs have conducted 28 sensitisation and networking meetings with 430 private health care providers (PHP) in 18 months. 7 PHPs have entered MoU with TAP NGO for providing services of x ray at 20-30% reduced cost for the smear negative cases referred from TAP. In 18 months 219 patients were referred for X ray among them 170 were provided x ray screening by PHPs. In the total patients 119 were X ray positive among them 54% (64) are from private sector support services.

In East Godavari district, CNP+ TAP partner has partnered with Ramakrishna Mission, faith based organisation who runs a mobile medical camp weekly once on Sunday and screens smear negative TB for X ray besides for other screenings. As in the tribal areas of East Godavari, those services are very helpful for smear negative patients, hence 87 were referred and 43% (37) are TB positive. TAP has felt as in the recent past RNTCP is also focussing on smear negative cases, the innovative partnership with private sector contributing in TB reduction. Ram Mohan Project Director CNP+ expressed that the tribal patients wait for Sunday x-ray services which are at very reduced cost and the smear negative patients with TB were referred to DOTS. For the eight tribal mandals this is the only service available from private sector. The patients need specialised services are referred by Ramakrishna mission and transport them to Rajahmundry for specialist advice. The turnout on Sunday health camp is about 300 patients that is more than the weekly outpatient in CHC at Rampachodavaram.

A medical doctor from Venkatagiri is doing yeomen service for smear negative cases by contributing his professional expertise in screening for X ray. 89 of TB smear negative were screened for TB by the particular PHP and among them 42% (37) are positive.

ADVOCACY INITIATIVE 4: SPUTUM COLLECTION AND TRANSPORTATION IN THE REMOTE AREAS

As per RNTCP each DMC is located for 40-50000 population but keeping in view the unreached tribal and fisher folk areas, TAP programme has proposed to provide a service of sputum collection from the symptomatic TB patients and transportation to the nearest DMC. Hence in the project area about 30% of the patients TAP reached were tested through sputum collection in remote tribal and fisher folk areas. TAP has planned to access to partner NGOs three sputum collection and transportation scheme in three locations i.e., Visakhapatnam, Srikakulam and Prakasam districts. Regarding these, initiated advocacy meetings with the district TB officers and represented on the need to provide support to patients. Still this is yet to take a shape.

Local advocacy: In order to provide area specific interventions the TAP partners with VMM guidance have taken up three advocacy initiatives. In five districts TAP partners have entered MoU with local DTCO for having mutual coordination and cooperation for reduction of TB.

- **Messages on fish boats in collaboration with Fishermen cooperative society:** In Srikakulam district sensitised the fisher folk communities and boat owners. As their workplace is mostly Fish boats, VMM discussed the matter with YCB, implementing partner and sensitised boat owners and disseminated information regarding TB symptoms and testing on 90 boats through radium stickers. The outcome of this community friendly information and education has led to made 38 referrals among them nine were positive for TB and one for HIV. In the first phase the expenditure is 100% from TAP for stickering. After a few months again provided write up on boats. Then in second phase sensitised the Fishermen cooperative society members and they told every year for Sankranthi festival (falls in the second week of January) they paint the boats and write some matter hence they told from 2014 January they write the slogans on TB and they will meet the 100% expenditure. They asked the project support in providing them the matter to be written. This shows the community commitment for the cause.
- **Women involvement in TB reduction:** Throughout the six projects intervention districts of TAP, advocated with Mahila Samakhya, a forum for Women self-help groups working on micro credit and thrift. Capacitated 2142 SHG members in 170 SHGs on TB symptoms, testing, treatment and follow up and 1673 SHGs are actively taking part in TAP programme and managing referrals from their villages. SHG members have referred 474 patients for TB and 320 for HIV among them 66 are positive for TB and 25 for HIV. The story of SHGs involvement in TAP is recognised by RNTCP as a good model of mainstreaming with community and published in RNTCP 2013 report.
- **Drug Transportation for MDR CAT-IV patients:** Among the tribal population PEACE, partner NGO of TAP has identified that many patients do not have much of understanding about the repercussions due to non-adherence to MDR TB. The issue was discussed during the district review meetings and based on the need to provide timely supply medication to MDR patients; DTCO Visakhapatnam has sanctioned MDR medicines transportation under RNTCP non funding programme. PEACE has extended the services of transporting MDR TB CAT IV drugs from treatment units (TU) to PHCs and PHCs to DOTS providers in five TUs: Pendurthi, Chodavaram, Paderu, Arakuvalley and Yelamanchili. Medicnes were transported to 26(19male and 7female) patients for the period May 2012 to February 2013.

Advocacy meeting with RNTCP, Delhi

VMM management have met the Additional Director General of RNTCP and explained to them on TAP programme, outcome of advocacy initiative i.e. double ration to children affected with TB. Discussed on involvement NGOs in TB reduction, replication of double ration to TB affected children of Andhra Pradesh model throughout the country, need for more DMCs in tribal sparsely populated areas, discussed on training of Anganwadi workers DOTS providers, and including of DOTS provision, referral of clients in their job charts.

Training for implementing NGOs on advocacy techniques

In the first quarter of the programme initiation, trained 45 staff (39 Outreach workers and 6 Project Managers) on advocacy skills building that helped the grassroots level programme staff to take up advocacy initiatives.

Lessons learnt in Advocacy:

- The success of the advocacy activity comes only when the purpose is consistently tracked and able to give clarifications at each level.
- Secondly with regard to double nutrition to TB affected children, for government nutrition is on their agenda.
- Continuing the process of advocacy, the order from the concerned government department was circulated to all the district and project officials in addition to Anganwadi workers for better service provision to the children.
- Sharing the IEC material on TB developed in the project to WCD so that the WCD officials can explain to their staff during sector meetings. So it is mainstreamed.
- Capacitating the staff at all levels on advocacy and lobbying skills to take up interventions at all levels for enabling environment.
- Dissemination of the advocacy initiatives helps in replication and scale up.
- Visibility for advocacy outcome through sharing in national forums, district reviews and website.

I AM HAPPY TO BE VOLUNTEER

Appa rao, a primitive tribal youth associated with PEACE in TAP in educating their community on TB and other diseases. He said "TAP project has really made a change in our attitudes towards health among our communities by getting clarity on the taboos. They have poor knowledge on health seeking behaviour. Tribal people mostly depend on barefoot doctors, and are superstitious. With the capacities provided through TAP project I am able to know more about the TB disease- symptoms, referral for testing, treatment facilities and completion. I referred six suspects to the testing centre, which I feel a challenging task in my area as they never want to get diagnosed and always follow the suggestion by barefoot doctors. I became popular in my areas, if anyone has cough they come to me and with no cost getting testing and treatment at government health facility. I sincerely convey thanks to PEACE organization for selecting me as volunteer and providing me training. Even after the TAP programme I will continue to provide services to my community, I am happy that I was also involved in reduction of TB."

VASAVYA IN ACTION...

- Vasavya MahilaMandali is accredited to International HIV/AIDS Alliance, UK
- 'Abhaya' counseling center for women and girls is initiated with the support of Unniti Foundation
- Pap smear test for detection of cervical cancer is facilitated by VMM at government health facility in five districts of AP among 336 key population: wives of men sex with Men (MSM), female sex workers and women living with HIV. Among them 36% are with severe inflammatory smear.
- Advocacy meeting with Project Director, AP State AIDS Control is conducted on 13 August on screening for STI during ART enrollment. The order is issued by government and circulated to Superintendents of all District hospitals.
- Provided sponsorship for higher education to 166 orphan and vulnerable children and 24 for nursing.
- District Collector and Magistrate of Krishna with AGM NABARD and Project Director DRDA visited 'MaaThota' tribal development project at A Konduru.
- VMM participated in various national and international conferences: DrKeerthi presented paper in International conference on Aging women - challenges in SAARC countries; Vijaya Kumar presented in National conference on Tribal Health; Ch. Prabhakar presented in International conference on torture victims.

Mike, CEO of TB Alert interacting with children at Anganwadi center in Sanyasammapalem village in Hukumpeta mandal, Visakhapatnam

Dr. Deeksha suggesting on treatment adherence to community at G. Sundruputtu village in Pedabayalu Mandal, Visakhapatnam.

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