HEALTHY MOTHERS & HEALTHY BABIES

Making a difference in the lives of Pregnant and Breast Feeding mothers in Mumbai



Process Document of Technical Assistance provided by VHS Project to Prevention of Parent to Child Transmission (PPTCT) of HIV program in Mumbai

December, 2017













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About VHS

The Voluntary Health Services (VHS) was established in 1958 by Dr. K.S. Sanjivi, an eminent physician, distinguished teacher and visionary leader. VHS is a 465 bedded multi-speciality tertiary teaching hospital guided by the philosophy of "unto the last".

VHS is registered as a non-profit society under the Registration of Societies Act, 1860. VHS offers affordable medical care services to low income groups and people belonging to deprived backgrounds based on their health care needs rather than their ability to pay.

Nearly 75 experienced physicians and leading specialists offer their time and expertise in an honorary capacity to manage 23 departments of VHS. Pioneered the model of Mini Health Centres with the aim of providing primary health care services to the poor through the trained health workers.

VHS has been at the forefront of managing comprehensive community health and STI/HIV prevention programs for marginalized population, sexual minorities and deprived groups. Backed by nearly 20 years of wide ranging experiences in implementing HIV/AIDS prevention, care and support programs, building the capacity of Civil Society Organizations (CSOs) and training health care providers, VHS has built a reputation for understanding and addressing the needs of disadvantaged communities.

About CDC

The Centers for Disease Control and Prevention (CDC), US collaborates with the Government of India and other health organizations to strengthen India's health system and address a wide range of infectious and non-communicable diseases. CDC opened the first India office in 2001 to support the Life Initiative for HIV/ AIDS prevention and control.

In support of India's National AIDS Control Organization, CDC has focused its efforts on preventing new infections, increasing access to services for people living with HIV and tuberculosis (TB), and establishing a single monitoring and evaluation system. CDC provides technical assistance on a broad range of issues, including prevention of parent to child transmission of HIV, the prevention and treatment needs of people who inject drugs, care and treatment of key affected populations, addressing the comorbidities of TB and HIV, strengthening laboratory systems, and improving district-level capacity to address HIV and TB.

About MDACS

Mumbai Districts AIDS Control Society (MDACS) is an autonomous body registered under Charitable Trust Act, established on 27th July 1998 by Municipal Corporation of Greater Mumbai (MCGM) for control & prevention of HIV/AIDS in Mumbai. MDACS serves as a nodal agency, using multi-sectoral approach collaborating with General Health System, NGOs/CBOs and people living with HIV/AIDS.

MDACS implements National AIDS Control Program (NACP) under the guiding principles of National AIDS Control Organization (NACO), Ministry of Health and Family Welfare, Government of India. MDACS serves as a nodal agency, using multi-sectoral approach collaborating with general Health System, other Government departments, NGOs/CBOs, private sector and People living with HIV/AIDS. MDACS provides services through its various divisions viz. Basic Services, Blood Safety, Targeted Intervention, STI, Care Support & Treatment, Information Education & Communication and Mainstreaming.

Abbreviations

AD	Additional Director					
AIDS	Acquired Immune Deficiency Syndrome					
ANC	Ante Natal Care					
AP	Andhra Pradesh					
APD	Additional Project Director					
ART	Antiretroviral therapy					
ARV	Anti-Retro Viral					
BCC	Behaviour Change Communication					
BF	Breast Feed					
BPs	Bridge Populations					
BSD	Basic Services Division					
СВС	Complete Blood Count					
СВО	Community Based Organization					
CD4	Cluster of Differentiation 4					
CDC	Centers for Disease Control and Prevention, US					
CMIS	Computerized Management Information System					
СРТ	Co-Trimoxazole Preventive Therapy					
CSOs	Civil Society Organizations					
CSR	Corporate Social Responsibility					
DBS	Dried Blood Spot					
DNA-PCR	Deoxyribonucleic acid -Polymerase Chain Reaction					
EID	Early Infant Diagnosis					
F-ICTCs	Facility based ICTC					
FSW	Female sex workers					
FY	Financial Year					
HIV	Human immunodeficiency virus					
HRGs	High Risk Groups					
ICTC	Integrated Counselling and Testing Centre					
IDUs	Injecting Drug Users					
IEC	Information Education & Communication					
KEM	King Edward Memorial Hospital					
LFT	Liver Function Test					

M&E	Monitoring & Evaluation			
MB	Mother Baby			
MDACS	Mumbai Districts AIDS Control Society			
MSM	Men having Sex with Men			
MTP	Medical Termination of Pregnancy			
NACO	National AIDS Control Organization			
NACP	National AIDS Control Program			
NGO	Non-Governmental Organization			
NVP	Nevirapine			
Ols	Opportunistic infections			
ORWs	Out Reach Worker			
PEP	Post-exposure prophylaxis			
PEPFAR	The President's Emergency Plan For AIDS Relief			
PNCs	Post Natal Care			
PPT	Power Point Presentation			
PPTCT	Prevention of Parent to Child Transmission			
RFT	Renal Function Tests			
S&D	Stigma and Discrimination			
SA-ICTC	Stand Alone ICTC			
SD-NVP	Single Dose Nevirapine			
STI	Sexually Transmitted Infection			
TA	Technical Assistance			
ТВ	Tuberculosis			
TG	Transgender			
TN	Tamil Nadu			
ТО	Technical Officer			
ТоТ	Training of Trainers			
TS	Telangana State			
UP	Uttar Pradesh			
VHS	Voluntary Health Services			
WHO	World Health Organization			
ZC	Zonal Coordinator			

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Acknowledgements



Dr. Joseph WilliamsDirector of Projects,
Voluntary Health Services,
Chennai

The journey of the last two years has been much rewarding. The support extended through VHS Project to successfully implement the PPTCT project in Mumbai districts was not only challenging but also a humbling experience. I would like to thank all people associated with the project, who had made it as such wonderful.

Foremost, I would like to thank the Project Director Dr. Padmaja S. Keskar IAS, for her support in allowing this project to fructify in short time. I would like to specially mention the efforts of the Additional Project Director Dr. Shrikala Acharya in understanding our needs and providing us guidance and direction at every stage of designing and implementing the PPTCT Project in Mumbai. Dr. Vidya Mane, Joint Director BSD, MDACS had ensured that the continuum of the services to the community are not hampered owing to shift in the project management leadership. Without the support from these senior officials in MDACS, the project would not have seen the speed and successful implementation.

I would also like to thank PEPFAR CDC to have bestowed VHS with the additional responsibility of managing projects in Mumbai and trusting us to set up the project in shortest time possible without any distress to the existing staff members. It was this trust that led us to fast track our processes to ensure the flawless continuum of care to the community members.

I would also like to express my sincere gratitude to the PPTCT team at Mumbai. The technical officer led the field level zonal coordinators and outreach workers, who with their immense knowledge built inroads into the community and various facilities. These staff members are asset to the project. The zonal coordinators had well mentored the team and had their hands on experience in planning and leading the PPTCT Outreach team in Mumbai is well recognized and appreciated. The fulcrum of this team has been Dr. Shubhangi Gaekwad. Her immense experience of both the subject of HIV, PPTCT project coupled with the local knowledge of Mumbai city, its culture and the community had immensely benefitted the program. VHS recognizes her leadership skills and would like to acknowledge her support and leadership in day to day administration of the project. I also would like to specially acknowledge the contribution and support of Ms. Srilatha Sivalenka from CDC India who has been instrumental throughout the project period. Her inputs to the project are highly valuable.

I would also like to take this opportunity to thank the technical and finance teams at VHS, Chennai who have meticulously worked under constricted timelines to ensure that the Mumbai PPTCT project is on track. VHS had experienced some challenging times last year and but for the support from the team, the smooth continuation of the project would have been tough. I thank the entire team that stood by us to sail through the challenging times.

VHS-CDC Project places on record the hard work and initiative of Mr Suneel Kumar Chevvu, Monitoring & Evaluation officer, without whom this process document could not have taken place.

Executive Summary

Most children who acquire HIV infection through mother-to-child transmission do so during pregnancy, labour and delivery, or breastfeeding. With no intervention addressing the risk of HIV, its transmission from mother to child is 15-30%. The NACO Technical Estimate Report (2015) estimated that out of 29 million annual pregnancies in India, 35,255 occur in HIV positive pregnant women. In the absence of any intervention, an estimated (2015) cohort of 10,361 infected babies will be born annually. The MDACS' PPTCT programme aims to prevent the perinatal transmission of HIV from an HIV infected pregnant mother to her newborn baby.

The MDACS data indicates that 505 HIV positive pregnant women were identified in the FY 2015-16, of which, 498 (98.6%) of them were initiated on ART. The number of HIV positive deliveries were reported 450 and 442 of them were live births. The number of babies initiated on ARV prophylaxis was 424 of which EID testing during the first visit was 380. The number of EID testing to live births reported was reported to be 86% and VHS program in Mumbai was initiated to address this gap in the PPTCT cascade.

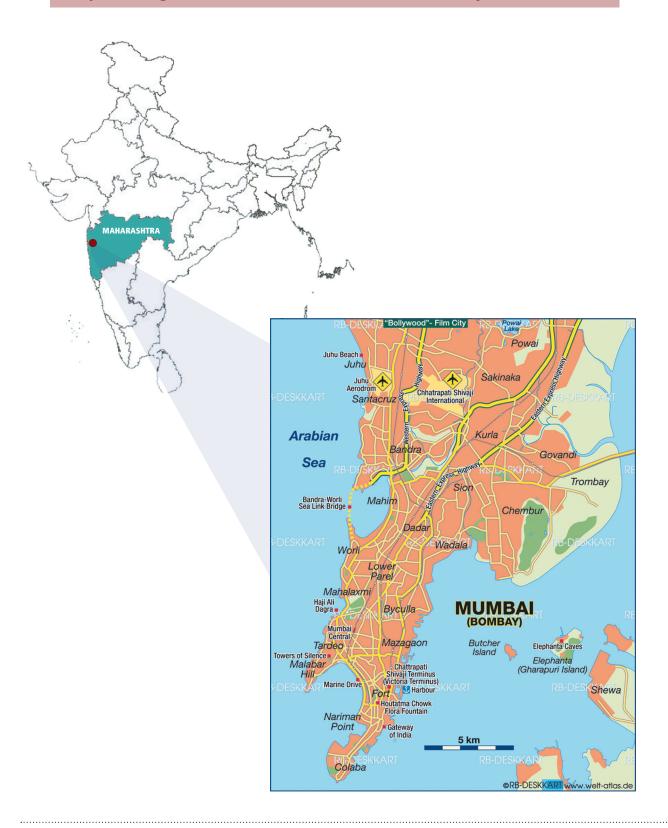
Since, April 2015-16 VHS has agreed to continue technical assistance to MDACS' Prevention of Parent to Child Transmission of HIV (PPTCT) program primarily focusing on enhancing the program response in the areas of PPTCT and partner testing. HIV interventions in Mumbai has many inherent challenges of rapid urbanization, population growth, in-migration, changing socio-economic and behavioral patterns, etc. Reaching out to the pregnant women & breast feeding mothers and their family members to deliver required PPTCT services is complex.

VHS had retained the erstwhile outreach staff consisting of Zonal Coordinators and outreach workers who were well versed with the geography of the metropolitan city and also the socio-cultural fabric of the community. The Technical officer was recruited to manage the outreach team and liaison with MDACS on a daily basis. VHS team had designed structured implementation program along with MDACS officials to address some of the PPTCT program's implementation issues. The team also developed robust monitoring and reporting tools to ensure efficiency in data collection, analysis and timely submission to MDACS and NACO. The trainings conducted by the intervention on an array of topics had helped the staff at ART, ICTC and PPTCT teams. Using various participatory methodologies the trainings had used the NACO modules to ensure compliance to the national guidelines. The capacity building exercise used case studies, energizers & facilitated-discussion on various topics from daily life situations to make the learnings more interesting thereby ensuring greater retention of the new topics.

The traditional cultural values of deliveries at mother's place, intrinsic myths and misconceptions, customary beliefs regarding delivery and infant feeding practices and the deep-rooted stigma and discrimination surrounding HIV/AIDS offers a fatal concoction of complex situations. The outreach team sway through all of this daily to deliver their communication and counselling messages and encourage them to seek institutional services. The referrals components had yielded the desired results of enhancing the referrals of pregnant women, mothers and their infants to institutionalized health care settings. Similarly, some of the cases of women required other NGOs support and the team played their part in advocating with either the doctors in the hospitals or women's organizations to take up the complex cases and safeguard the rights of the woman. The success of PMTCT efforts also depends upon the ability to reach the maximum number of women at risk of an infected pregnancy.

The Mumbai's PPTCT program is equipped with effective outreach strategy, robust monitoring framework, trained personnel, developed counselling and advocacy skills to address stigma and discrimination and hence it is on its way towards achieving the country's goal of elimination of mother to child transmission of HIV.

Map indicating location of Maharashtra State and Mumbai city (inset)





SECTION

Setting the Context

Introduction

a. VHS support to PPTCT Outreach Programme in Mumbai District

Under the aegis of the National AIDS Control Organization (NACO), VHS through its Technical Assistance to NACP funded by CDC PEPFAR is supporting the PPTCT outreach programme in Mumbai district. The project primarily ensuresthe follow up and retention of PPTCT clients in the program. During the calendar year 2015, the total ANC cases tested for HIV in Mumbai district are 1,10,643 of which 231 were detected HIV positive. The program envisages retention of PPTCT clients who have detected positive for HIV need to be followed up until the infant completes 18 months and is screened for HIV using antibody tests. The follow up of the cohort is for a period of around 18-24 months.

During the period, ANCs detected positive for HIV are to be linked to the ART centre. On ART, the ANC needs to go to the ART center every month to collect her ART drugs apart from the periodic ANC visits. The client needs to be prepared for delivery and post-delivery initiation on ARV for the infant and periodic EID screening of the infant needs to be done and finally the infant is to be screened for HIV using antibody tests. The project proposes to support 40 ORWs and other supervisory structures for effective implementation of the outreach program to ensure retention of HIV positive ANC mothers in the program.



Picture 1: Outreach team members counseling the mother at home

b. The PPTCT program in Mumbai district

In India, PPTCT interventions under NACP started in 2002 using single dose Nevirapine prophylaxis for HIV positive pregnant women during labour and also for her newborn child immediately after birth. With the National AIDS Control Organization adopting "Option B+" of the World Health Organization (WHO) recommendations (2010), India has also transitioned from the single dose Nevirapine strategy to that of multi-drug ARV prophylaxis from September, 2012.

Since January 2014, providing ART (ARV drugs) for pregnant women and breastfeeding women with HIV during the motherto-child transmission risk period and then continuing life-long ART for those women eligible for treatment is an integral component of NACO'sstrategy of providing lifelong triple ARV drugs to pregnant women and breast feeding mothers infected with HIV, irrespective of CD4 count nationwide.

The Prevention of Parent to Child Transmission of HIV services (PPTCT) program comprises

- a) Detection of HIV infected pregnant women& breast feeding mothers and children
- b) Early Infant Diagnosis (EID)



Picture 2: Follow up mother and child by outrich worker

c. Detection of HIV infected pregnant women and breast feeding mothers and children

Government of India is committed to work towards achievement of the global target of "Elimination of new HIV infection among children". National AIDS Control Organization is implementing lifelong ART (triple drug regimen) for all pregnant women and breast feeding mothers living with HIV, regardless of CD4 count or WHO clinical stage or duration of pregnancy, both for their own health and to prevent vertical HIV transmission and with additional HIV prevention benefits.

Nationally, during the FY 2016-17, out of the annual target of 140 lakhs, 76.2 lakhs of pregnant women tested for HIV and 5233 were diagnosed HIV positive as new cases and out of which 4935 initiated lifelong ART, and the known HIV positive pregnant women availed ICTC service during this period is 1,172. Similarly, a total of 3,472 HIV exposed babies were initiated on CPT and 4,735 babies were tested under EID programmes using DBS DNA PCR test².

However, in FY 2015-16, in the districts of Mumbai, total of 1,12,770 people were tested for HIV³. Among the total tested, 505 (included known HIV positive) were found HIV positive. Out of that, 491 (97.2%) were initiated on lifelong ART. Regarding the EID cases in Mumbai, out of total 441 HIV exposed babies, 419 (95%) received NVP prophylaxis for a minimum period of 6 weeks.

¹Updated Guidelines for Prevention of Parent to Child Transmission (PPTCT) of HIV using Multi Drug Anti-retroviral Regimen in India, December 2013, NACO

²Annual Report 2016-17, National AIDS Control Organization

³MDACS, PPTCT M&E data, 2015-16

d. Early Infant Diagnosis (EID)

HIV exposed infants born to infected pregnant women have to undergo DNA-PCR tests using dried blood spot and whole blood specimen. Exclusive breastfeeds up to 6 months and continued breastfeeds in addition to complementary feeds after 6 months up to 1 year for EID negative babies and up to 2 years for EID positive babies who receive Pediatric ART. Postpartum ARV prophylaxis for infant for minimum 6 weeks.

The Early Infant Diagnosis (EID) at 6 weeks of age with repeat testing at 6 months, 12 months &18 months and introduction of complementary feeds from 6 months onwards along with continuation of breast feeding for at least 1 year for adequate growth & development of the child. EID also strives towards confirmation of HIV status of all babies at 18 months using all 3 Antibody (Rapid) Tests.

In Mumbai, during the FY 2015-16, total 373 HIV exposed babies were initiated on CPT and 380 babies were tested under the EID Programme and out of that, 373 (98.2%) were tested using DBS DNA PCR & 7 (1.8%) were tested using antibody at first visit. During the FY 2015-16, 17 (4.5 %) babies were found to be reactive with DBS DNA PCR test and 6 babies had undergone confirmatory PCR test and 4 were initiated on Pediatric ART⁴.

PPTCT program in Mumbaiwith a new impetus!



Picture 3: Counselling session at PPTCT Centre, KEM Hospital, Mumbai

The erstwhile program was managed by the corporate social responsibility (CSR) wing of a large infrastructure and financial solutions in the country. The Mumbai program was transitioned to VHS project.

The PPTCT program was managed ward wise earlier and therefore had about 170 staff members. The program was implemented through various partner organizations (NGOs) across the various parts of Mumbai. Through these NGOs, the focus was on ANC referrals and community meetings, support group meetings etc.

Currently, under the leadership and guidance of VHS project, the focus is on providing linkages of services to ANC mothers and infant testing. The program underwent minor modifications with approvals from MDACS. The program has limited staff of 40 members only with field level outreach workers who are supervised by the zonal coordinators and led by Technical Officer. These members are responsible for directly implementing the project.

This lean structure is responsible to cover all the 6 zones of the Mumbai district.

Many monitoring formats have also been considerably condensed. With many partners managing various aspects of the program, number of formats were required to capture the required data. With this direct implementation, the ORWs and ZCs have minimum formats to capture the essential data as required by MDACS to monitor the program and ensure effective service delivery.

2. Goal and Objectives of the Project

VHS has entered into a cooperative agreement with the U.S.Centers for Disease Control and Prevention, US (CDC), PEPFAR Department of Health and Human Services, United States Government to provide technical support to the National AIDS Control Organization (NACO) in carrying out national level reviews and policy revisions on prevention, care and treatment programs including cross cutting issues such as capacity building, integration, planning and financial systems.

The project supports strategies to maximize resource utilization by addressing gaps identified during program reviews and scaling up high impact practices. The project functions at the cluster level, in line with the revised PEPFAR approach of pivoting to six high burden districts (three districts each in Andhra Pradesh and Maharashtra clusters), and at the national level.

The Prevention of Parent to Child Transmission of HIV (PPTCT) program in the six zones of Mumbai is being strengthened to address gaps found in HIV testing of pregnant women, coverage of Early Infant Diagnosis (EID) and initiation of Anti Retro-viral Therapy (ART) among HIV positive pregnant women and breast feeding mothers.

3. Approach and Methodology

The process documentation assignment is based on literature review, observations during the filed visit to Mumbai, discussion with stakeholders like MDACS officials, VHS project staff, key informants from PPTCT, ICTC and ART centres and beneficiaries etc.

a. Discussions with VHS team

The design of the process document entailed collection of information and materials from VHS Chennai, MDACS and Staff of PPTCT project. Also, meeting some of the key stakeholders was planned including MDACS officials like APD MDACS, JD BSD, JD M&E to understand various issues like coverage of the target population, case load at facility centres, challenges of implementing PPTCT project with concentration of high migrant populations.

From the facility centres providing services to ANC positive women and their children, it was decided to meet the counselors and medical officers. Discussions with community members was also deemed imperative to understand their perspectives on the program delivery services, attitude of health service providers, referral services, correct knowledge about critical care components, challenges of home visits, child birth and nutrition etc. This would help have a 360 degree understanding of the project.

The consultant had day long discussions with the VHS team at Chennai to understand the scope of the assignment. The VHS Project Director along with his team consisting of Technical Advisor and M&E Manager had described in detail the request from Donors and MDACS officials to continue the PPTCT project. The broad contours of the document was discussed to include the overview of the Mumbai HIV/AIDS scenario, the field level activities undertaken by the staff and the successes or challenges thereof.

It was indicated that the decision to continue the same staff members as employed by the previous project was taken by MDACS and Donor organization. The retention of the staff would only safeguard the smooth continuation of the project without losing the knowledge accumulated by the field team.

Post the discussions with the central team at VHS, the consultant had drafted a Table of Contents with them to seek their inputs and agreement on the structure of the process document.

b. Literature Review

A review of the existing literature was conducted by the consultant. The consultant had requested both VHS and the PPTCT Technical Officer to share relevant data points, review presentations, etc. to collate the information. Discussions with APD MDACS, JD BSD and M&E division was also requested to share some additional information pertaining to the initiatives undertaken by MDACS as part of their PPTCT program. The consultant had organized method of locating, assembling and understanding a body of literature downloaded from internet on various aspects of PPTCT intervention and some guidelines of the national program, technical reports published by NACO, Sentinel Surveillance reports, etc. All the citations are duly mentioned as necessary to build the arguments and sources of various data points are also mentioned accordingly.

c. Key Informant discussions at Mumbai

A comprehensive list of key informants was prepared and duly shared with VHS team. It was decided that the following members are important to meet and understand the processes included in implementing a successful PPTCT intervention in MDACS areas.

- Additional Project Director, MDACS
- Joint Director, Basic Services Division, MDACS
- Program Manager, PPTCT Project, MDACS
- Zonal Coordinators, PPTCT Project
- Supervisors, MDACS
- PPTCT Counselors
- ART Medical Officer
- ICTC Counselors
- Outreach Workers, PPTCT Project
- Community Members / Beneficiaries



Picture 4: Mumbai local train - the life line of the city

The many ordeals of implementing HIV program in Mumbai



Picture 5: The Chawl neighborhood at a Mumbai Slum

Mumbai district is recognized as one of the most critical geographies since the early days of HIV/AIDS prevention programs in the country. Through many successive programs over the years, supported both by government funding and external donor agencies, the intensity of the program and outreachto the communities vulnerable to HIV has increased manifold; simultaneously the metropolitan city has also experienced increase in the burden of HIV cases, sometimes making the city compete with other cities such as Kolkata, Chennai and New Delhi in housing massive case-loads of HIV.

Mumbai's metropolitan nature, rapid urbanization and opportunity for works had earned its sobriquet of 'city of dreams'. For these reasons, the city is a great magnet for many migrants drawing people not only from neighboring districts in Maharashtra but also from far flung areas of the country - states such as Odisha, Uttar Pradesh and Bihar.

Response to HIV epidemic in Mumbai is laced with many challenges and proffers complex situations. Rapid urbanization, population growth, in-migration, changing socio-economic and behavioral patterns, coupled with rapidly changing nature of sex-work in the city have only added to the concerns of HIV program implementers.

While the increase in HIV infection rate was observed only among High Risk Groups (HRGs) and Bridge Populations (BPs), the spread of HIV among general population had caught up with speed. Efforts of government and other agencies in the last two decades have ensured that the HIV prevalence rates are declining in the southern states, while unfortunately the 'newer pockets of HIV infections' are on the rise, especially in the northern belt of the country⁵.

4. Brief Background of the PPTCT Project

The PPTCT programme involves counseling and testing of pregnant women, detection of positive pregnant women and the administration of ARV prophylaxis to HIV positive pregnant women, breast feeding mothers and their infants, to prevent the mother to child transmission of HIV.

In India, the PPTCT services were started in 2002 under the leadership and guidance of the National AIDS Control Organization. The roll out of the PPTCT services ensured greater access of HIV testing services to all pregnant women and breast feeding mothers enrolled in Ante-Natal Care (ANC). In 2012, NACP as a policy adopted the Option B+ based on recommendations from WHO and transitioned from SD-NVP strategy to that of multi drug ARV prophylaxis⁶.

During 2016-17 in Mumbai, about 1,26,435 pregnant women were counseled and tested by the MDACS, yielding detection of 162 HIV sero-positives (positivity being 0.13%).

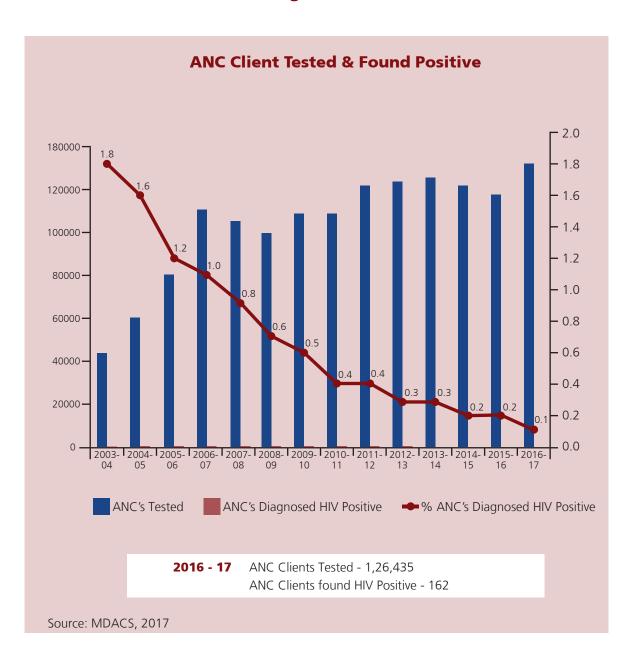
Mother Baby pair Coverage: Pregnant women found HIV positive are administered ARV prophylaxis so as to prevent mother to child transmission of HIV. Between April 2016 to March 2017, out of 433 HIV positive pregnant women detected (Including Known Positive), 288 (66.5% &out of 303 live birth 95%) Mother Baby (MB) pairs received Nevirapine (NVP) prophylaxis for prevention of transmission of HIV from mother to child in Mumbai⁷.

⁵Mid Term Assessment Report, NACP IV, NACO, 2016 ⁶NACO Annual Report, 2016-17

⁷MDACS, PPTCT M&E data, 2017

Graph 1: HIV prevalence trend among ANC (2003-16)

HIV Prevalence Trend among ANC



a. Geographical coverage of the Mumbai city

Mumbai is one of the most populous cities in the country, with a population of over 12 million people in 2011. People from many states seek employment opportunities as Mumbai is deemed to be the commercial capital of the country. This city also has road connectivity thereby facilitating the movement of truckers from and to Mumbai. Research on the growing epidemiology in Mumbai indicates that the important drivers of HIV have been the high risk groups of female sex workers (FSW), men having sex with men (MSM) & transgender (TG) and also the Injecting Drug Users (IDUs). The interplay between the HRGs and the Bridge Population of Migrants and Truckers is deemed as one of the highest in the country.

The PPTCT program covers the complete Mumbai city and the map above indicates the geographical coverage. The city of Mumbai is distributed into six zones and each zone is managed by one zonal coordinator along with outreach workers.



HIV Positive ANCs (2016-17) 35-47 47-60 60-72

Graph 2: Zone wise distribution of Mumbai city with HIV prevalence

b. Zone wise distribution of institutions in Mumbai

The six ZCs manage 33 ORWs and cover 32 stand-alone ICTCs and 12 F-ICTCs. They are responsible for 11 ART centres spread in the six zones. The table below indicates the details of each zonal coordinator and major hospitals of Mumbai in their respective zones.

Table 1: Zone wise distribution of staff and institutions in Mumbai								
	No of ORWs	No of	ICTCs	ART Centers	Major hospital in the Zone			
Zone		SA-ICTC	F-ICTCs					
Zone I	5	4	0	2	Sir JJ Hospital & BYL Nair Charitable Hospital			
Zone II	6	6	2	2	Sion Hospital & KEM Hospital			
Zone III	5	8	1	2	Cooper Hospital			
Zone IV	6	7	2	2	Ambedkar Hospital			
Zone V	6	2	3	1	Shatabdi Hospital			
Zone VI	5	5	4	2	Rajawadi Hospital			

Source: PPTCT program, MDACS, 2017

c. Zone wise distribution of case load in Mumbai

Table 2 below indicates the total number of cases being followed by the outreach team. The total ANC cases supervised by the ZCs are 204. More than 50% of the cases are from Zone II (54) and Zone V (50). These ANC cases are closely monitored by the outreach team to ensure that proper communication is provided to all of them on the importance of registering at ART centres, taking the ART medicines regularly, importance of institutional delivery, partner testing and also about EID for the baby. Preparation of them on these subjects takes weeks sometimes months. The ZCs would meet them at the various institutions where the ANC mothers are seeking services and for some cases as demanded, they also conduct the mandatory home visits.

The PNC cases that this team is responsible for is upwards of 1000 cases in a year. Here, it is observed that Zones I, II and IV have roughly



Picture 6: ORW visiting community member's house at a Mumbai slum

70% of the load. It is to be kept in mind that few ANC cases move to their state of domicile, while others prefer to shift residences, when they learn about their HIV status. The outreach team needs to closely monitor them as the important components of EID and partner testing follow up is most crucial. Exclusive breast feeding or resorting to only top-feed is an important message coupled with the patients' continuation of ART medicines. Post child birth the mothers tend to slip away from taking regular ART. Many factors contribute to pause in continuation of medicines.

Discussions with the outreach team indicated that many women would not disclose their HIV status and deliver the baby in private hospital. When the mother or the baby experience health complications, then such cases are required to be followed by PPTCT. The team ensures that couple along with their child are tested and as per their test results and CD4 count, they link them to various services.

Table 2: Distribution of zone-wise PPTCT case data in Mumbai

Total number of cases

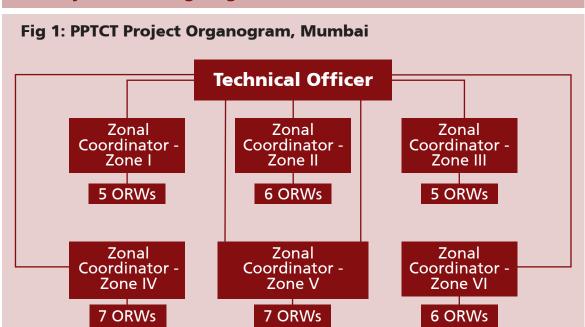
No of ORWs ANCs* PNCs# Live births Infants positive expires

Lone	ORWs	ANCs*	PNCs#	Live births	Infants	positive	expired
Zone I	5	37	276	285	285	9	2
Zone II	6	54	211	209	209	9	3
Zone III	5	23	159	158	158	4	4
Zone IV	6	17	191	197	197	5	2
Zone V	6	50	72	73	73	3	0
Zone VI	5	23	100	93	93	8	4

Source: PPTCT Project Outreach data, as on November 2017

^{*} Ante Natal Care, Post Natal Care





e. The Outreach Team - its key responsibilities

This team lead by the ZCs and ORWs is termed as the outreach team who are responsible for the following activities:

Outreach Workers' key responsibilities

- Mobilize pregnant women & breast feeding mothers for ANC registration at the Health Care facilities especially from the hard-to-reach pockets
- Mobilize pregnant women screened positive with WBFPT.
- Follow up pregnant women and the mother baby (MB) pair up to 18 months of the age of the baby ensuring uptake of PPTCT services
- Facilitate linkage of pregnant women detected HIV positive at ICTC/PPTCT facilities to ART centre or STI clinic and ensure maturity of referrals.
- Facilitate institutional delivery
- Home visit to monitor compliance with ART medication and EID visits
- Provide information to the pregnant women & breast feeding mothers and their family on PPTCT services and prevention methods including feeding practices

Key Responsibilities of Zonal Coordinators

- Supervise the outreach component of the PPTCT program implementation.
- Develop work plans for ORWs and out-reach micro plan in coordination with the ORWs. Update micro plans with special emphasis on "hard to reach" areas.
- Develop relevant tools for assessment or effectiveness of district team. Identify training needs to
 ensure quality work.
- Monitoring and supervision of ORWs. Make supervisory field visits and review activities at district level
- Support the Project Manager in organizing and conducting project review meetings and to maintain up to date programme date/ records/ registers and submit as appropriate.

Case Study 1: The mystic Mumbai: The Maximum City - 'Max problems with Max solutions' too!

Mumbai has earned the title of 'Maximum City'. It is maximum because everything is stretched to its maximum levels. Be it the local railway tracks, or slums or sometimes even the lives of people living in this city.

Meena, (name changed) the Zone III Coordinator received a call from Dr. Varsha, the Paediatrician of Suchak Hospital in Malad to request her to help an HIV positive woman who had delivered baby boy and is seeking help to arrange for Nevirapine (NVP). As she underwent C-section she and her husband were not in a position to leave the hospital and get the NVP from the nearby ICTC.

The ZC requested the AD-ICTC at MDACS and informed her about the situation and requested her to call up MW Desai Hospital ICTC and allow her to register the patient and get NVP. AD-ICTC made the necessary calls and informed her that she can get NVP syrup by completing the necessary formalities. Meena travelled from Santa Cruz to Malad a distance of about 15 kms in the Mumbai local, appraised the ICTC staff about the situation and bought the syrup. She met the Paediatrician and delivered the syrup to be administered to the new born baby.

Meena had met the husband waiting outside the delivery room and learnt that his HIV test result was negative. The husband was in a predicament regarding the HIV status of the child. Fear of HIV and confusion was writ large on his face. Not missing the opportunity to counsel, she took him for a cup of tea at the canteen outside the hospital and spoke to him.

He had many doubts in his mind. He had doubts on the HIV test results and he himself was not sure about the discordant status. Meena told him about many instances during her career wherein due to timely administration of NVP, the new born babies have far less chances of being



Picture 7: ORW counselling the family during her home visits

HIV positive. She spoke about safe sex practices that the discordant couple can adopt.

She also learnt that his wife who had initiated ART had discontinued it, as the ART centre was located far from her residence. He was worried about the additional expenses of the second line drugs. She informed him that to begin with they need to work towards internal transfer of cases and then after some tests the doctor would suggest if the patient has to be put on second line of ART. From L&T Health Centre at Andheri her case can be transferred to Dr. Ambedkar General Hospital Kandivali(W), which is located close to their residence.

Next day she met him and they travelled together to Ambedkar hospital. She met the ART Medical Officer and Counselor and apprised them of the family's concern. After necessary paperwork, their case was transferred from far off location to a nearby centre.

With the timely intervention of the program staff, the baby is lucky to be negative.

This news was like music to their ears and they had maximum relief!





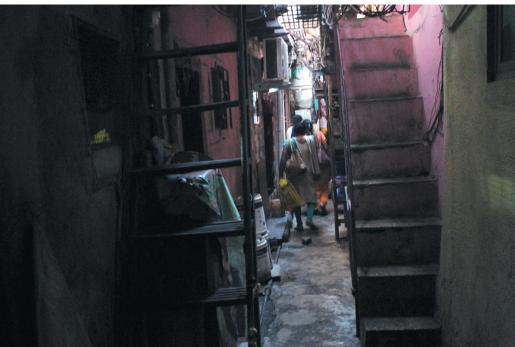
Details of components of the program strategies

5. Outreach initiatives

The outreach activities are the backbone of the PPTCT project. With committed and well trained outreach workers (ORWs) the program was able to sustain the efforts of enhancing the effective service delivery to all ANC mothers and their children. The outreach activity is led by the six Zonal Coordinators (ZCs). Mumbai city has been sub-divided into six zones and each ZC would be in-charge of the geographical area who are helped by the outreach workers. The ZC and the ORW would therefore can be easily termed as the outreach team who are responsible for host of field level activities - both at the facility level and also at the community level.

As part of the program design, the Zonal Coordinators get the list of all HIV positive ANC cases from ICTC counselor. This then is added to the line listing of each ORW. During the discussions with the ZCs, it is learnt that each ZC would get about 6-8 'new' positive ANC cases every month. While meeting them personally to build personal rapport is important, the ZCs are also responsible to follow up with the existing ANC cases.

The outreach activities are mainly focused on the services provisions to ANC during her tenure of pregnancy.



Picture 8: The ORW and Zonal Coordinators during their field visits

a. The First Trimester

ORW's role starts immediately after post-test of a HIV positive ANC. She is taken to ART for ART registration. She is put on ART immediately and is provided with 15 days of medicines. Meanwhile, the patient is asked to undergo some investigations like CBC, LFT, RFT, SGOT, SGPT, Sr Creatinine & CD4. ORW also accompanies the ANC case to lab to give blood sample. This helps in developing rapport with the positive ANC. Her verbal consent is taken for home visits for further follow ups. Subsequently, ORW also visits ANC's home the same day (or as early as possible) to verify the address.

At home again with the consent of the woman, her husband & previous children (if any) are also tested for HIV if their status is unknown. Monthly home visits plan is prepared and shared with the supervisors with a brief on the test results and the interactions the ORW had with ANC mother. Along with the ZC, the ORW would propose frequency of visits depending upon the complications like low haemoglobin, non-acceptance by the client/family, need of emotional support, etc.

During monthly visits, the outreach worker would request the ANC to provide her alternate address (if any). This is deemed important in the case of the first pregnancies. Culturally, most of the Indian women seek to be at their parents' place during the first delivery. In such cases, the ORW counsels the woman to share her address and also provides information on the facilities available at the destination place. While the numbers are low, there have been instances when the outreach team in Mumbai had followed up with the case in other cities and town of Maharashtra and sometimes outside the state too.

The outreach team also regularly follows up with the ANC mothers on their ART medicines and provides required information on nutritious diet. Many women during this period experience nausea which is common among most pregnant women. The discordant couples also need counselling on safe sex practices.

Lastly, the follow up also includes if any woman decides to go for MTP, they accompany the ANC mothers to the facility centres and seek professional medical advice. The mushrooming informal health services providers do conduct cheap abortions and could result in many dangers. Therefore, the outreach team insists on seeking the professional medical help from Government hospital doctors and act upon it.

b. The Second Trimester

As part of the monthly visit plan, the 2ndtrimester ANC cases need different doses of communication and assistance. The visits to ANC mothers in 2nd trimester are focused on 'cases with complications'. During this period, efforts are reinforcing the key messages as shared with them during the previous trimester period. Introduction of new topics like – benefits of breastfeeding, the follow up of repeat test of spouses if they were found negative during their last tests, importance of institutional delivery, etc.

Programmatically, it is the duty of the outreach team to ensure through the regular follow up visits, if ANC women are planning to shift from the current address. Many social reasons are attributed to their shift in the houses after they discover their HIV status. If the couple are planning to shift from current address to another locality in Mumbai city, the PPTCT team ensures that their new address is known to them. This would help in the internal transfer of ANC case and would help in avoiding duplication of registering the same case in other centre. Additionally, an internal transfer from one outreach team to another should also be planned. The outreach team follows up over the phone if all PPTCT services are continued. It needs to be noted that despite many efforts by the outreach team, in a city like Mumbai, women would not like to share the details of their residence shift. Such cases lead to Loss to follow up cases.



Picture 9: Group counselling session during peak hours at PPTCT centre

c. The Third Trimester

All messages in first & second trimester especially about breastfeeding & institutional delivery are reinforced during this period. Breastfeeding technique is taught, with the nearing of 17th week of pregnancy, two visits per month during 7th & 8th months and weekly visits in 9th month is planned with the women. ORWs also disseminate information on symptoms of labour.

Her records and files are kept ready with all the required reports, ART medicines & a bag with cotton clothes. The ORWs also informs her to let them know if the family members are taking her to the hospital for delivery. They then would duly inform the hospital staff regarding the details of the case.

d. Immediately after delivery (in the hospital)

The outreach team also follow up with the case post-delivery. At the time of delivery they ensure zero discrimination and proper treatment.

The medical staff administer Nevirapine to the baby. Breastfeeding is promoted by both the medical and the outreach team, but in case if there are any complications or the mother and family members have decided for top feeding, the parents' decision is respected and they inform her about the correct procedures. Maintaining hygiene (proper boiling of utensils, no use of bottles, giving top feed in proper dose & making fresh feed every time) are important messages that are disseminated.

Most importantly, they confirm that the ART doses are not missed. They also encourage the couple for family planning methods.

After 6 weeks of delivery, it is important that mother to bring the baby for DBS testing at ICTC. The outreach teams facilitate the visit and counsel the mother and family members on all the required immunizations required for the baby. The baby is tested at 6 months, 12 months & 18 months. If she tests positive, the baby is put on ART. Then follow ups are done to ensure that mother & baby are consuming ART regularly as per the result baby is finally declared positive or negative.

6. Prevalent myths and misconceptions, Stigma & Discrimination

The prevalent cultural beliefs among pregnant women & breast feeding mothers in Mumbai city are varied and one can see the complete spectrum of all cultures in the country. Some of the common beliefs that are predominant irrespective of the state the women hail from are as follows:

- **Visit their mother's place for the delivery:** This is almost religiously followed by most women for their first delivery. They would return to Mumbai only after 45 days post-delivery. The visit to the quacks or traditional therapists would start during this period and it would continue till child birth.
- **Restricted food intake for pregnant women:** It is observed that some of the women especially in a joint family setting are not given proper food during the first few months, also some cultures ban the consumption of coconut, milk or other such food items. Many myths are associated with food items and impose restrictions on food consumption by pregnant women & breast feeding mothers.
- **Myths surrounding colostrum and early initiation of breast feeding:** The beliefs among post-natal mothers are quite astonishing. Many family members view that breast feeding the child during the first six-months should not be encouraged. Instead of feeding the new born baby the mother's precious colostrum.

10% of HIV infected mothers do not choose exclusive breast feeding, which may put the baby's health at risk. ⁸The care and advice to give HIV-positive women who decide to breastfeed is the same as to other breastfeeding women: Breastfeed within the first hour of birth, so that the baby gets the full benefit of colostrum will all its anti-infective properties. Instead, the mothers feed Guti or honey to keep baby healthy. Moreover, in the families where the PNC mother opts for top-feeding the mother is made to answereveryone explaining why she is not breastfeeding the child.

- **Stepping out of the house would invite bad omens:** In India, lactating mother & baby is not supposed to go out of home at least for 45 days. So they tend to ignore minor illnesses & avoid going to hospital during first 45 days. Such traditions facilitate the need for seeking informal healthcare providers or round-the-corner traditional healers / guacks.
- **Religious beliefs:** Also the religious beliefs especially of Muslims prohibit them from taking any medicines / ART during the holy month of Ramadan. These staunch practices hamper the intervention deliverables.
- **Social status of women:** Apart from all of these, it needs to be understood that the status of women in the country is lower than their male counterparts. The women are not the decision makers too. It creates hurdles in HIV testing, ART adherence, institutional delivery, baby testing, nutrition etc. More so, if husband is non-cooperative in providing proper health care to the woman.

The outreach team through their experiences had gathered about such cultural nuances and comprehend the importance of belief systems associated with pregnancy and child birth practices. These practices are reckoned to hinder the smooth intervention and the behaviour change the outreach team is attempting to bring about.

This is not to indicate that all ANC women would be categorized as fitting into anyone or more cases. Some women may not subscribe to any of the myths and misconceptions mentioned above. During the interactions with outreach team, it was learnt that strong cultural beliefs do cause unintended harm to the intervention and either through trainings, counselling and communication these issues need to be addressed. Through regular home visits and counselling to ANC women help project staff would track the intake of ART medicines, nutritious food, treatment of opportunistic infections and women migrating to native villages.



Picture 10: Health camp at Mumbai slum

a. Stigma and Discrimination

Stigma and discrimination towards the HIV positive ANC cases affect the expected outcomes of not only the service uptake at the facilities but also results in hampering the life in families, communities and workplaces and schools, etc.

The outreach team in Mumbai, encounters cases of stigma and discrimination towards the ANC mothers. It is learnt that most of them suffer from 'anticipated self-stigma'. Many mothers indicated they were afraid to disclose their status because they feared others would start gossiping about them.

Stigmatization and discrimination may arise when an individual identified as HIV-positive is seen as a source of infection to others. There have been instances in Mumbai of sero-discordant couple and the husband had either ill-treated, abused and resorted to violence on the women and in some extreme cases they even sought divorce. They feared losing a husband and believed that a woman's infection and pregnancy would spark off a chain of deaths after delivery with the baby, herself and then her husband's dying. The outreach team does provide them family counselling but larger advocacy is required to address the problem.

Their status is also kept hidden from other family members, leading to 'act-normal' and therefore avoid medicines and other necessary care to maintain their health. Women also feared the response of their families, believing that they will be ignored, isolated, and openly disgraced and blamed.

The second setting where S&D is experienced by ANC mothers are at the health care facilities. Perhaps it is the most conspicuous context for HIV/AIDS-related discrimination, stigmatization, and denial. Negative attitudes from health care staff generate anxiety and fear among PLHA.

Consequently, many keep their sero-status secret, fearing still worse treatment from others. It is not surprising that among a majority of HIV-positive people, AIDS-related fear and anxiety, and at times denial of their HIV status, can be traced to traumatic experiences in health care settings.

The women if they are employed, would not like to reveal their HIV status fearing loss of employment. Such women need additional support from other agencies specialized to provide necessary support. While, the government of India and also the state government had announced certain social benefit schemes for the HIV positive persons, availing the same is also limited. Unless the ANC mothers discloses her HIV status, she would not be eligible to seek such social benefit schemes. Anticipated stigma would prevent her from both disclosure and claiming the benefits.

7. Trainings

Building capacity of health care providers and other associated personnel in PPTCT program is crucial to the success of the programme. The VHS project developed training curriculum and materials, built a pool of master trainers, conducted refresher training and strengthened the outreach team in order to improve the quality of PPTCT program. All the trainings provided by VHS Project was in accordance to NACO guidelines. The trainings planned by the project staff have been revised to suit the requirements of the local staff. While some of the training programmes mentioned in the guidelines are planned for 8 days, the same trainings were conducted in 6 days as most of the participants had have been trained already and these were more of refresher trainings in nature. The agenda and training curriculum were drafted in consultation with MDACS to update the knowledge and skills of the service providers, incorporating essential components, to facilitative the delivery of quality services. Facilitators carrying expertise and experience in subject matter and training skills were identified and invited to facilitate the training.



Picture 11: Training session of the Counsellors

In 2016, MDACS had recruited 22 ICTC, STI and ART counselors in Mumbai. The counselors in ICTC work closely with other department counsellors as the services offered in a facility are inter related. Therefore, it is imperative for all counselors to have similar knowledge levels of other components of the program too. For e.g. counselor working at STI department also needs to have adequate knowledge on ART, PPTCT and ICTC counseling.

Case Study 2: The balance of personal 'touch' during professional work

The Post Test Counselling and the declaration of her HIV status for any ANC woman is a traumatic experience. It becomes all the more challenging if it is her first pregnancy. Often the PPTCT counselor informs the ZCs to be at the counseling centre if there are positive ANC cases. This is important for ZCs to initiate the discussion with the ANC women at the centre and then offer to accompany them to their homes. It helps build confidence with them and also they can verify the address as provided at the centre.

During the initial few days they provide basic information and motivate them by sharing stories of other such positive women.

The zonal coordinator would meet her on a regular intervals with her consent and impart relevant education on Health and Hygiene, Nutritious food, importance of continuous ART medicine emphasizing on life-long intake of the medicines, periodic ante-natal check-ups and registration at facility for institutional delivery, management of Opportunistic infections (Ols) especially TB-HIV cases, etc. She also accompanies her to some of the the facilities centres (Hospital and ART centre, etc.).

The outreach team members follow up with the ANC mother to counsel her on the regularity of ART medicines. The pregnant women when experience nausea during pregnancy period often get discouraged to continue the medicines.

Stigma and Discrimination is an important component that the outreach team helps the community members to deal with. Many community members have self-stigma and also discrimination arising from family, friends and service providers, spouse etc.



Picture 12: Counseling session at home by ORW

The follow up by the outreach team is from the post-test counseling of the ANC case till 18 months of the child. Throughout this period they plan to keep in touch with the ANC cases often being invited for their cultural events such as "Godbharai" (a cultural practice in India when other women bless her during this ceremony). Not doing such cultural events would only raise eyebrows and often ANC cases are pestered by neighbors, family and other community members.

With the consent from ANC women, sometimes the ZCs and ORWs also meet their family members to prepare them and disclose the HIV status. The outreach teams role is also sought extensively when there is case of discordant couple (ANC woman is positive but her husband test reveals his negative status). Often many husbands would react angrily and resort to violence and even seek divorce.

The all women ZC team indicated that they would have tread this road carefully as the woman seek their support but family members view them as external members and hence would like to keep them out. Some cases have also been reported where the woman would like to sell the new born and migrate to other places. The ZCs have many instances when they swung into action and through the support of counselors and other NGOs, they helped the women to settle the domestic cases and new born infants were admitted to child care centres.

Handling such complicated cases require both experience and skills. While they are tough on ANC cases when the ART adherence is stopped they also are soft in approaching the complex social fabrics of family and treat them with gentleness.

For the efficient and optimal management of human resources, MDACS has suggested to utilize the service of the counselors across the program components/facilities. Hence, all these counselors ought to be well equipped to provide correct and consistent information and guidance on HIV/AIDS to the client, across the cascade, at any service delivery point (facility). This was the driving thought for 'integrated induction training of counselors'. Such trainings will help counselors understand broader perspective of HIV/AIDS program and will help them to counsel their clients effectively.

The key objectives of the training program are:

- Provide an overview of the HIV/AIDS epidemic and efforts to contain it
- Enhance skills of health care personnel in comprehensive diagnosis and management of HIV infection and associated diseases including opportunistic infections
- Provide detailed background information on the need for ART, rationale for use of ART and adherence
- Orient the counselors on the basics of the key program components (such as ART, STI/RTI, HIV/ TB, PPTCT, EID, PEP, M&E etc.)
- To build capacities of counselors for counseling skills which would help counselors to support and counsel clients more effectively.
- To orient them on the linkages between STI, ICTC, TB and ART and emphasize on optimal referral and linkages to facilitate early diagnosis and treatment.
- To impart knowledge in regards to M & E tools.

a. Training Methodology

The trainings conducted had used various participatory training methodologies including case studies, demonstrations, energizers & facilitated-discussion on the M&E tools. Interactive audio-visual presentations were used. The participants were given NACO's learner's manual to reinforce the learning and also to serve as desk reference.

Care was taken to ensure to impart technical information with new guidelines, and if any specific counseling skills were required on common problems faced by clients like discordant couple, client with STI complaints, ANC mother etc. such topics were also dealt with at length.

- The pretest tool was prepared to assess knowledge of counselors and posttest tool to asses gain in knowledge after the training.
- Each session was taken with help of PPT, questionnaires, case studies, role plays, group discussion exercises as per requirement.
- Wherever required samples were displayed and explained like Syndromic management kit in STI, ART drugs in ART session, Family planning methods.
- Flip charts and body basic chart were used in body basics and sexuality session.
- Feedback from participants on 4 main points was collected through feedback form; main points are content of subject, methodology used, duration for session and facilitator of session.
- Facilitated discussion on the M&E tools

All the facility level staff consisting of specialist doctors, medical officers, nurses, lab technicians and counselors have been developed. The intensive training programmes included an extensive hands-on component, to address ART and HIV care, treatment and support.

Where necessary the technical sessions, experienced trainers from medical colleges in Mumbai were invited for conducting the training session. Specialized trainers were invited for skill building sessions, who have been working in the HIV field from several years & have built capacities of field workers.



Picture 13: Technical Officer reviewing the progress of Zonal Coordinators

Table 3: Details of trainings conducted by VHS-CDC project in Mumbai

Sr. No	Name of the Training	Cadre	No of participants	No of Days	Major topics covered
1	Training of Trainers (ToT) of Labour Room Nurses in their roles and responsibilities for PPTCT of HIV	Labour room nurses & PPTCT medical officers	25	3 days	Practice of whole blood finger prick test for HIV screening, Roles and responsibilities of Labour room nurses in PPTCT Programme, ART and ARV prophylaxis for prevention of vertical transmission of HIV
2	Sensitization Workshop on PPTCT, EID and Syndromic Management of STI/RTI	orkshop on TCT, EID d Syndromic anagement of		4 days	updated PPTCT and EID guidelines, STI/RTI management guidelines, documentation of the F-ICTC and M&E tools, to ensure coverage of clients across the entire PPTCT cascade
3	Integrated Training of Counsellors	ICTC, ART, STI counsellors	130	4 days	Basics of HIV/AIDS and HIV Diagnosis & NACP Updates, Basics of STI/RTI
4	Induction Training of Counsellors	ICTC, ART, STI counsellors	22	6 days	& Syndromic management, Syndromic management counselling, Counsellor self-awareness, Enhancing counsellors competency, Pre-Post Counselling, Basics of HIV-TB, Body Basics & sexuality, Understanding marginalization, Vulnerability, stigma & discrimination, Basics of PPTCT & EID, Basics of ART, Family Planning, M&E, USP & PEP, BCC
5	Orientation of Project Coordinators	Project Coordinators	6	1	Technical officer explained PPTCT indicators, the technical officer explained review indicators
6	Continuous handholding of ORWs	ORWs	36		Explaining of formats, reinforcement of communication skills, communication of changed guidelines, right messages to be shared & no wrong information to be shared, due list is shared with them monthly, rapport building with clients, full forms, dosages of various medicines

8. Referrals

PPTCT project in Mumbai ensure sustainable continuum of care and referral system for pregnant women, breast feeding mothers, infants, children and family members infected and affected by HIV. The referrals in this project are mainly two pronged approach - the clinical referrals and community referrals.

The clinical referrals refer all HIV exposed and infected Infants identified with a medical conditions for specialized care.



Picture 14: Health Camp at Mumbai Slum

These may include the following:

- STI Clinic (if the case so demands)
- Paediatric clinic (for care of the new born and children living with HIV)
- Feeding Programs (Nutritional Rehabilitation Unit, supplementary feeding)
- TB Clinic (if the patient suffers from TB)

Community referrals facilitate a connection with community-based initiatives by networking with supportive community agencies, identifying key partners and preferred methods of contact and communication:

- PLHIV networks, to seek solace and support from other women dealing with similar situations,
- Issues of stigma and discrimination: Mumbai is a cultural pot with people drawn from all states in the country. The pregnancy related issues are also laced with community level norms, beliefs, values, myths and sanctions. Communities may associate HIV/AIDS with immorality and ill-treat those who become infected with HIV. It is important to address these issues so that people living with HIV can freely access services without feeling threatened.

9. Communication initiatives

The HIV/AIDS epidemic is driven by a complex set of factors in India including social, economic & gender related factors. The complexity of this disease renders communication approaches that are based on the assumption of a rational individual who makes choices in a social vacuum both redundant and ineffective. Therefore, it is imperative that strategic communication consider the social context in which PLHIVs negotiate their lives and recognizes the need for long-term and sustained efforts with relevant and appropriate responses. Such an approach promotes collective discussion and promotes self-awareness, and simultaneously attempts to address the social, economic and gender related factors in an attempt to create health enabling contexts.

Case Study 3: Going beyond the Call of Duty: Working together with referral agencies

Lakshmi (name changed) has been attending the pregnant women meeting when organized by the outreach workers in the slum areas of Zone I. While she did not reveal her occupational details during the meetings, but the trained zonal coordinators could establish that she was under distress. She used to be passive listener of all the stories shared by the outreach team and the list of do's and don'ts during the pregnancy. The ZCs had an eye on her as she was mostly quiet and used to leave soon after the meetings. It seems she had many queries in her mind but could garner courage to seek solutions.

Regular interaction and personal counseling helped them to establish rapport with Lakshmi. It took many months for the team to establish that personal connect with her. During her 3rd trimester, she had personal discussions with the ZC. She mustered strength and shared her life story. A story filled with grief, burden of the family, lonely battle of the woman in metropolitan city. Her story was filled with instances of abuse, exploitation and harassment.

Lakshmi hailed from Karnataka and was sold into the brothels of Mumbai. Here, she met the same treatment that is bestowed upon many of her workmates. She also revealed that she had to undergo MTP many times in the last few years. She had decided that even this baby, if alive, she would sell. She was forced to have the baby this time as doctors refused MTP procedure on her. She was confused and was unable to decide her future.

The PPTCT outreach team had referred her case to the NGO working on human trafficking and introduced Lakshmi to them. The NGO staff had provided shelter to Lakshmi and counseled her to undergo delivery at Mumbai as she could not have traveled to her native village in the condition she was in.



Picture 15: Follow up of community member at PPTCT centres

Lakshmi decided to chalk a new future for her. The new born baby is growing up in an orphanage in Mumbai. Fortunately, the baby has tested negative. With counseling and support, Lakshmi has been regular in taking the medicines and undergo periodic tests.

The NGO team helped Lakshmi to reach her mother's place in Karnataka and she owes this new future a new life to the PPTCT Team at Mumbai.

The PPTCT project in Mumbai has limited but effective communication material. Much of the communication materials were used by the project as developed and shared by NACO. Additionally, translation of communication materials like posters, ready reckoners and pamphlets in the local Marathi languages is also undertaken by the project to ensure greater utilization of the material by the community. At the PPTCT centres, relevant communication material addressing the issues faced by ANC mothers and discordant couples are addressed. A ready reckoner showing dosages of CPT, Nevirapine & Zidovudine is available. Some hand-outs focused on family planning methods and other information pertaining to child care were available. The Mother and Child Card printed by the state government talks about the importance of breast feeding and immunization.

The discussion with the PPTCT counselors and outreach team indicated that a comprehensive communication strategy along with relevant materials would have definitely strengthened the elements of the intervention. The communication specifically designed for PPTCT should include all the key components of ANC check-ups, the importance of institutional delivery, regularity of ART medicines, and advantages of Nevirapine-etc,.

10. Monitoring and Review

Monitoring of HIV infected pregnant women & breast feeding mothers is an essential component of quality patient care in PPTCT programme. It involves documenting all ANC women, spouses of the patient and their family members by maintaining regular and filled-in records of key aspects of the services provided to the PPTCT beneficiaries and her baby.

A set of M&E tools have been devised by NACO to ensure that continuum of care from detection of HIV infection among pregnant women to their linkage to ART centre and for EID after delivery is well maintained. In addition to regular CMIS format of monthly reporting a PPTCT beneficiary Line-list has been designed, which shall be updated on an event basis by ICTCs and ART centres to ensure delivery of the complete package of PPTCT services to all pregnant women & breast feeding mothers viz. Anti-Retroviral Therapy, Delivery; Feeding history; Early Infant Diagnosis along with final confirmation at 18 months.

Monitoring of PPTCT Project in Mumbai comprised of the Technical Officer, Zonal Coordinators and Out Reach Workers who work hand in hand with program staff from PPTCT, ART and ICTC centres and other key stakeholders to

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Picture 16: Counsellors filling up the details of all patients

ensure that there was timely and meaningful progress and measurement of project objectives.

Effective monitoring mechanisms facilitates the assessment of the performance of an individual (Efficacy of an ORW, Project Coordinator) as well as the performance of the overall PPTCT programme, which forms the basis of decision making, policy planning and resource allocation and mid-term corrections, if required.

The Monitoring and reporting mechanism is conducted in 3 layers in the VHS PPTCT Project in Mumbai:

- Level 1: ORW --> Project Coordinators
- Level 2: Project Coordinators --> Technical Officer
- Level 3: Technical Officer --> MDACS officials

Level 1

The PPTCT project in Mumbai has devised robust monitoring plan. The field activities are carried out by the outreach workers who are responsible to prepare the detailed monthly 'micro-plan'. Micro plans of all outreach workers are submitted to the zonal coordinators who checks and approves the same. Any deviations or sudden changes in the micro plans should be communicated to ZCs and post their approval the ORWs would follow. Weekly updates and review meetings are held by the ZCs to ensure the ORWs are meeting the required ANC cases, follow up of EID cases, home visits, etc. Surprise visits to facilities like ICTC, ART, PPTCT centres are conducted by ZCs who would also check the meetings conducted by ORWs and number of patients met and followed up.

Project Coordinators monitor ORWs' work on the basis of following documents:

a) Micro plans:

- ORWs prepare their respective micro plans and submit the same by the 3rd of every month.
- The ORWs routinely follow the number of individuals enrolled, percentage of eligible individuals receiving ART or prophylaxis, program discontinuation (death, loss to follow up, and patient withdrawal), determination of infant HIV-1 status, and CD4 cell count
- Part I of the micro plan depicts the details of the hospital where the PPTCT cases are being followed, number of clients tested and detected, number of ANC cases due for various services in the new month and lastly number of EID cases to be followed up.
- The Part II of the Micro plan depicts the various actions undertaken by the team. Each action points are duly mentioned with the details of day wise visits, purpose & place of every visit is also mentioned in the action plan.

b) Daily diaries:

- ORWs maintain their day to day work in their daily diaries. The document the details of names of clients, hospitals they visited everyday.
- The daily diaries also depict the details of various meetings with PCs, counsellors, etc.
- These daily diaries are also shared with the project coordinators to ensure that they could supervise the work of ORW effectively. Not to mention these daily diaries would be helpful in compiling the weekly and monthly formats. Lastly, any pending cases and the reasons thereof can be easily tracked at a later date.

c) Time Sheets:

- ORWs prepare their respective time sheets in which they mention their day wise work actually done as against the micro plans.
- These filled in time sheets are then submitted by the ORWs submit to their supervisors on 25th of every month.

d) Line Listing:

• ORWs update their PPTCT line list on daily basis post their daily visits to meet the ANC clients as per the line listing.

In order to ensure effective monitoring steps the Project Coordinators verify all the above mentioned documents submitted by ORWs & cross check with the actual work done by the ORWs on daily basis. PCs check the ORWs daily diaries, randomly visits ICTCs & also some meet certain ANC women in the field (The PCs ensure that prior consent has been obtained by ANC women for their visit). Lastly, PCs analyse the sheets and share monthly due list with ORWs at the end of every month, check if all those cases are attended to by ORWs and if the line list is updated periodically. These filled in documents are them submitted to the Technical Officer.

Level 2

At level 2, Technical Officer monitors the Project Coordinators' work on the basis of following documents, as prepared by PCs.

1. Time Sheet:

- PCs maintain their daily work in the time sheets.
- PCs submit their time sheets to Technical Officer on 25th of every month.

2. Daily diaries:

- PCs maintain their daily work in their daily diaries. The daily diaries include details of clients, hospitals visit roster, etc.
- The daily diaries also include key points from the meetings conducted during the month.

3. Line Listing:

• PCs update their PPTCT line list on weekly basis.

Technical officer makes visits to ICTCs to verify presence&coordination of ORWs & Project Coordinators with ICTC counsellors. The TO also checks on regular basis if all the cases in PPTCT line list are updated, preparation of monthly due list for PCs.

The TO also conducts preliminary analysis and shares the key findings during her quarterly review meetings. The review points include number of cases attended to by ORWs and frequency of updating the line list, etc. The quarterly review meeting is conducted on 25th of every month.

Level 3

The MDACS officials conduct the monthly review meetings of all departments. The Technical Officer is responsible from the project to appraise the MDACS officials of the progress of the project and the challenges thereof. Issues of shortage of medicines, institutional deliveries, partner testing, reverse testing of spouses of pregnant women (where the ANC woman is non-reactive and her partner is reactive), number of EID cases, migration of clients and other such challenges are presented to government through analytical data sets and presentations.

The Technical Officer is also responsible to check the veracity of data, avoid duplication and analyse the same. The TO works closely with the M&E division which is responsible for data management and analysis. The PPTCT team fill in all the necessary formats as prescribed by the national program to submit periodic CMIS data to NACO.

Interesting case studies are documented by ZCs and Technical Officer to highlight the situations of the program. The case studies documentation include both success stories and challenges of the program to reflect the true situation on ground. Lastly, the team provides necessary inputs to MDACS in publication of periodic reports. Quarterly newsletters and Annual reports comprising developments from all departments are published by MDACS and PPTCT team provides necessary data sets and stories, experiences from various personnel working in the program and case studies of the community members.

The PPTCT project does not proffer any "magic bullet" to improve program performance rapidly; but instead, they ensure careful monitoring and quality improvement initiatives, tailored to the specific challenges of each zone in Mumbai.

11. Advocacy

Advocacy is important in HIV prevention, treatment, and care. It enables things to be done by raising awareness about HIV/AIDS. It promotes the knowledge about how HIV spreads thereby reducing the stigma of people living with HIV. The complex socio-cultural fabric in India is precarious in nature and it is observed, that any attempt to categorize the purposes of HIV/AIDS advocacy is likely to provoke debate.

The PPTCT project needs assistance of many agencies who can support their efforts to enhance the response of the communities confronting the menace of HIV/AIDS. It is observed in the paragraphs above of the various challenges a HIV positive pregnant woman & breast feeding mothers faces. With the prevalent social position of the woman in the society especially drawn from the particular socioeconomic background they hail from and immersed in the traditional, cultural belief systems they subscribe to, her fight against the systems becomes one-sided.

Support from NGOs, health care facilities, religious leaders and political establishment is unreachable to her. It is through the efforts of the PPTCT team and the linkages developed thereof; the woman would be able to raise her voice. The society at large needs to be made aware of the disease and its pattern in spreading through various routes. While both the Government of India and the state government in Maharashtra since last two decades had undertaken this daunting effort to 'educate' the society on the routes of transmission, perils of HIV, and most importantly the need to provide secure environment to the HIV positive person, it appears that much efforts are still required to improve their awareness of important social and cultural dimensions behind HIV/AIDS.

The PPTCT team did initiate efforts of advocacy in the hospital settings, at community level, family and also to the woman / partner.



Picture 17: Counselor at PPTCT centre in Mumbai

Table 4: Advocacy efforts by PPTCT team at Mumbai				
Hospital	Community	Family	Self	
Training & sensitization at various levels & all cadres	HIV awareness	HIV awareness especially how it is spread & how it is not spread.	Try to develop positive thinking & attitude	
Importance of maintaining confidentiality (e.g. 'HIV positive' should not be written on case papers)	Rights of HIV positive people are communicated	Encouragement to participate in support group meetings (sharing of experiences & emotions)	Suggested to join support group meeting, HIV positive peoples' groups, and network people for emotional needs.	
		Peer counsellors can are used.	Everyone has some health issues. Diabetics also have to consume medicines for lifelong.	
		ORWs are appointed as per family's background (e.g. if family is from UP, ORW from the same state is		

The PPTCT team had initiated addressing stigma at workplace/schools with the help of officials. They briefed the zonal education officers for school advocacy on the prevailing situations at school and requested him to use the laws in favour of HIV positive people. Awareness sessions for other staff members in the same office is conducted to raise their knowledge levels on the legal provisions and the rights of the HIV positive school children.



Picture 18: Outreach team help clarify many doubts of community members





Challenges, Way Forward & Conclusion

12. Challenges

Challenges in implementing PPTCT project in Mumbai are mentioned below:

- The foremost challenge lies in reaching to all pregnant women & breast feeding mothers accessing ANC services at registered health service delivery points and to reach early in pregnancy to those reached. Mumbai city is vast and to cover all the ANC women with focused approach is a daunting task. After the first visit to one ANC women, the time taken for the outreach team to pay the second visit as per their roster is sometimes too long.
- Continuing from the above point, the other challenge is the incorrect address which is shared by ICTC. Finding the correct address in Mumbai is overwhelming for the outreach team, especially when one is expected to cover vast geographies.
- Challenges with ANC women were reported by PPTCT team by some of the women who were identified as HIV-positive refused antiretroviral prophylaxis. This problem especially appeared particularly when women were tested late in the pregnancy, without time to cope with their HIV status. The intensity of the challenge is enhanced when any discordant couples' case is referred to PPTCT team.



- The follow-up of HIV-positive women is a major challenge. Some women attended the antenatal clinic once and then go missing from the radar of the program. Others did not deliver in the PPTCT hospitals and so missed antiviral prophylaxis. It is known that most women either go to their mother's place for delivery or shift houses and choose not to share the details with the PPTCT team.
- The follow-up of women and their babies after delivery is difficult. The mother tends to forget her medicines as she gets busy with her new born baby. Enhanced monitoring visits are required at least for few months till the behavior change among PNC women is observed.
- The outreach team considered ANC women disclosing their HIV status to their partners as being particularly difficult. They saw this as compounded by a lack of male partner involvement in PPTCT counselling. They also reported non-disclosure of the HIV status to the partner / other family members as creating serious problems in family planning. Some women, for example, had returned with second and third pregnancies after initial diagnosis of HIV.
- Loss to follow up cases are more observed in the cases where the ANC women had not disclosed her HIV status to her spouse / other family members. The most common reason cited is that they prefer not to be traced into their community. Most women stay in Chawls in Mumbai and the proximity of houses are only divided by thin walls. Generally, the neighbors know about the routine of the members in the community. When things are not shared, suspicion increases. Sudden increase in visits to their homes by project staff are also not liked by many women.

Case Study 4: Moving the mountains of ignorance

Rajani's (name changed) case is not complicated but also bolstered with dogmas people associate HIV with. On one hand it raises questions on the immense efforts put in by government machinery supported by army of HIV activists to fight stigma and discrimination, while on the other hand it mirrors the deep-rooted fear of hatred towards what the society believes as the 'fallen-guys'.

Rajani knew about her HIV status, discovered during her routine ANC tests and she was bewildered to learn about the dreaded disease. After much persuasion by the counsellor for partner testing, she got her husband for HIV tests and his test result turned negative. It was another 'bolt out of the blue' experience for her.

The couple delivered the baby at KEM hospital, as private facilities refused to conduct her delivery. The couple along with the baby went home only to find that the in-laws refused to let her in and threw her things out of their shack and asked her to leave. The baby was born during the monsoon season in Mumbai. It was raining incessantly and the roads in the city were swollen, reflecting her own swollen eyes and continuous stream of tears. Her clothes and other belongings were soaking in the rain water outside her chawl, and she felt lonely in a city brimming with million people.

When PPTCT outreach team learnt about the case, they reached her home late at night and tried to persuade the family members. Her father-in-law agreed to let her stay separately in a small room for few days as it was pouring heavily outside. At home, she was denied of any domestic chores as they considered food prepared by her, would possibly infect them too. Her husband was jobless and was dependent on his father for his daily expenses. He recused himself of supporting his wife, owing to his economic condition.



Picture 19: ORW counselling community member at night

During the next few days, the outreach team enquired about Rajani's parents and other family members. They learnt that Rajani lost her parents when she was young and was raised by her relatives. Her brother expired couple of years ago and she was hesitant to seek support from her relatives as she would be forced to reveal her HIV status. Rajani had no place to go.

Much persuasion by outreach team to let her stay in the house fell on the deaf ears of her inlaws. Finally, the team took her to the relatives place for few days. But to their surprise not only the relatives' family refused to let her stay with them, they burnt the bedsheets and other linen she used for fear of contracting the disease.

When Rajani along with her new born baby realized that there was no place to go, her dependency on the outreach team only increased. Upon enquiry by team of what she would do next, quickly she replied that she trusted them and had no particular plan anyways. The team had helped her admit in an ashram in Mumbai along with her baby. Couple of week later the baby's DBS test was done and the result indicated that baby was HIV positive.

With no place to stay and her next meal not guaranteed, important subjects of ART medicines, follow up tests for the baby and her own health took backseat for Rajani. The outreach team had attempted to counsel her and help her spend rest of her days in the ashram with her baby.

It is only hoped that efforts put in for addressing issues of stigma and discrimination; and educating people on 'ways how HIV is not transmitted' could reach as many people as possible. Discourse in the society on HIV needs to increase. The efforts of PPTCT team to move the mountains seem 'just not enough'.

The success of the program is not limited to the robust development of the various moving parts of the program machinery but also requires the human element to ensure the sweetness of success is shared with all. The team at PPTCT project have put in their maximum efforts to make it successful. Outreach workers through their tireless efforts have ensured that she lived her life with dignity!

- A further challenge is in dealing with ANC women who is under family pressure, especially on the advice on breast-feeding. Government program's messages are focused in advocating importance of breast-feeding. Resorting to top-feeding is not normal practice and invites much criticism. The ANC women realize their quandary positions. The ZCs pointed out that infant feeding was not a matter for the mother alone as other family members also has a say in how infants are to be fed especially mothers-in-law or married sister-in-law. Non-disclosure of HIV status increases the risk of mixed feeding.
- Most cases are of migrant women from other districts of Maharashtra or other states. Poverty undermines the family's ability to initiate top-feeds. Some mothers do start but after few months realize that they cannot afford to continue the expensive proposition of top-feeds. The mixed feeding hence, puts them at major risks. Moreover, some women are not aware of the complete hygienic preparation required for top-feeds.
- At PPTCT centres, the counsellors provide group counseling due to load at these centres. Individual counselling is not possible though desired by all of them.
- It was noted that because women had to wait for up to 18 months before their babies' HIV status is determined, mothers are consequently very anxious whenever their babies fell ill. Repeated calls to counselors and visits are made, sometimes takes away the precious time and if overlooked the rapport built over last many months hangs by a thinthread. HIV is not only a physical disease, it is also very emotional. Patients tend to get hooked on to program team members.

13. Way Forward

The VHS supported PPTCT project in Mumbai has ensured continuation of the ANC women coverage and provision of an array of services that are sustaining the reduction of vertical transmission of HIV from mother to child. Moving forward it is imperative that all stakeholders concerned work towards elimination of pediatric HIV as envisaged by the national government.

Some of the key issues are mentioned below.

The Government of India, has scaled up the PPTCT programme using option B+ nationwide in a phased manner in order to achieve elimination of pediatric HIV. The PPTCT program in Mumbai needs to enhance the detection of HIV positive pregnant women, especially those that are seeking from private health facilities.

Awareness about the rights of the women needs to be communicated effectively to all ANC positive cases probably as part of the counselling package. Stigma and discrimination issues weaken the ANC women's endeavor to live a dignified life and also hamper the efforts of the project staff. These S&D issues need to be dealt with urgency.

Communication efforts need to be strengthened to ensure that consistency and correctness of communication initiatives are maintained across the spectrum of the PPTCT project. The counselors and the outreach workers need to have more synchronization in dealing with various issues pertaining to affected women through effective and easy-to-understand communication methods. Messages are to address the key topics of infant feeding, nutrition, family planning to ensure high testing coverage and linkage of HIV positive pregnant women & breast feeding mothers along with their baby to appropriate services. Efforts should be made to retain women on treatment for life for their own health and benefit.

Shortages of medicines ought to be addressed with the support of the supply and logistics department of NACO and MDACS. Continuous or delay in addressing the shortage of medicine might deter the HIV positive persons affecting the efficiency of the PPTCT staff too.

Partner testing and treatment is an important facet of the project and it needs much attention from the authorities to support the PPTCT team. The challenges in increasing the partner treatment numbers is well known. Better follow up and tracking tools needs to be developed supported by development of communication tools, trainings on counselling skills etc. needs to be looked into urgently. Greater involvement of male members in the family and community would help women seek better and timely medical services and better negotiate their rights, thereby altering the unequal gender dynamics.

Similarly, follow up with PNC mothers and retention and high coverage of EID at six months and 12 months is a major road block for PPTCT team. Counsellors and ORWs should emphasize the need for follow up EID testing even when the 6 weeks EID is found negative. The PPTCT cascade seems to get thinner as it progresses. Where possible, additional help from either community leaders, other supportive HIV positive mothers who can volunteer for the program and civil society partners; may also be considered to seek help improve follow up of PNC cases.

14. Conclusion

In Mumbai, the social fabric of the families severely affected by HIV and AIDS are staring at the danger of being eroded. The two decades long fight against the dreaded disease had shown signs of declining, but if elimination of parent-to-child HIV transmission is the target then the need to increase the momentum is greater than before. It is this last mile battle, which is most daunting.

The journey thus far has highlighted the urgent need to provide better communication tools with stronger messages reaching to wider audiences. The powerful combination of fear, shame and stigma feeds the culture of discrimination. The HIV positive women and their family members grieve in silence. Efforts to reduce the stigma and discrimination need to be taken up on war footing. This would safeguard not only the rights of the HIV positive womenbut also give a fillip to the efforts of the PPTCT interventions.

Capturing the correct address of the pregnant women & breast feeding mothers is prerequisite for many institutions. The chain of institutions - ICTC, ART and PPTCT benefit mutually to ensure that the package of services are proffered to the HIV positive women. It would therefore, help in mitigating the loss to follow up cases and facilitate the reduction of new HIV cases. It is an imperative to provide essential services to all the affected members and not losing even a single case. Supply Chain and Logistics management of essential drugs in yet another step to ensure that all the patients are assured of their treatment rights.

HIV is not only a health issue but more importantly it is asocial, economic and emotional disease. The seriousness and urgency of the crisis cannot be overstated. Yet despite the large numbers of women and children affected, despite the fact that many families have been shattered by HIV and AIDS, much can be done to prevent further harm and support existing responses. Swift and determined action is required. With proper care, support and protection, mustering the combined efforts of the local, regional and national programs, families affected by the pandemic can rebuild their hope for the future and lead healthy, productive and fulfilling lives.

The VHS PPTCT program implemented in Mumbai has ensured through its many endeavors – the structured outreach program, capacity building efforts, regular monitoring, addressing stigma and discrimination and robust reporting mechanism- have contributed to the the efficacy of the project. It sustained the momentum of the program and had kept up the good work. Hopefully, the successive teams would find the implementation of PPTCT project enthusing and comfortable.

The PPTCT Program implemented by MDACS and VHS in Mumbai would like to acknowledge the support of the following field team members:

Dr. Shubhangi Gaekwad Technical Officer, PPTCT Program, VHS Sakshi Ashish Vichare Zonal Coordinator Mansi Mahesh Naik Out Reach Worker Savitha Rakesh Pacharkar Out Reach Worker Sadhana Madhukar Mahadik Out Reach Worker **Guljahan Salahuddin Ansari** Out Reach Worker **Manisha Anand Panaskar** Out Reach Worker Nisha Janardhan Jadhav Zonal Coordinator Yashwanthi Khandu Lokande Out Reach Worker **Usha Bandu Ghorpade** Out Reach Worker **Chhaya Anurath Suryavanshi** Out Reach Worker Sarvesh Laxman Shigwan Out Reach Worker **Chaitali Chandrakant Rane** Out Reach Worker Suchitra Tapan Bhattacharya Out Reach Worker Meena Purushottam Maraskole Zonal Coordinator Nirmala Tukaram Kurdekar Out Reach Worker Jyotsna Jitendra Rambade Out Reach Worker **Aparna Anil Juwale** Out Reach Worker **Sunanda Shrimant Bhogan** Out Reach Worker Khwaja Sayeed Baig Out Reach Worker **Sushma Sunil Patel** Zonal Coordinator **Anita Damodar Naik** Out Reach Worker Mehrunisa Rizwan Khan Out Reach Worker **Suman Shyamshankar Mishra** Out Reach Worker Vandana Kiran Khandagle Out Reach Worker **Dolly Shatrughan Jaiswal** Out Reach Worker Suvarna Balasaheb Patil Out Reach Worker Sangita B Sohani Zonal Coordinator **Usha Raghunath Bobhate** Out Reach Worker Out Reach Worker Kanchan Kisan Garle **Nalini Rajesh Nitnawre** Out Reach Worker **Jyoti Ramesh Palkar** Out Reach Worker Ravina Ravindra Amberkar Out Reach Worker Vaishali Shasikant More Out Reach Worker **Meena Suryakant Rane** Zonal Coordinator **Sharada Lavu Tarfe** Out Reach Worker **Bharati Ashok Pagare** Out Reach Worker SangIta Chandramani Gupta Out Reach Worker Madhuri Madhukar Kijbile Out Reach Worker **Shakila Mohammed Yunus Khan**

Out Reach Worker

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