



Strengthening Community Responses
to HIV Treatment & Prevention



INTERNATIONAL TREATMENT PREPAREDNESS COALITION
Treatment Monitoring & Advocacy Project

MISSING THE TARGET

9

The Long Walk: *Ensuring comprehensive care for women and families to end vertical transmission of HIV*

Community experiences of efforts to prevent vertical
transmission of HIV in India

March 2012

ABOUT ITPC

The International Treatment Preparedness Coalition (ITPC) is a worldwide network of community activists united by a vision of a longer, healthier, more productive life for people living with HIV. ITPC's mission is to enable communities in need access HIV treatment. As a grassroots movement, ITPC is the community's response to HIV and is driven, led by, and committed to the human rights of those most impacted by the pandemic. Since its inception in 2003 ITPC has formed 13 regional networks in Africa, Asia, the Caribbean, Eastern Europe, and Latin America, and has made nearly 1,000 grants totalling close to US \$10 million to community-based organizations of PLHIV in almost 100 countries.

ITPC's Treatment Monitoring & Advocacy Project (TMAP) contributes a unique perspective to global health advocacy through its *Missing the Target* series of reports. We work with civil society advocates, most often people living with HIV, across countries to build on-the-ground analyses of the barriers that communities face in accessing HIV treatment. We then partner with them to hold governments and global agencies accountable to their commitments.

All ITPC treatment monitoring reports are available online at:
www.itpcglobal.org

Four4Women campaign website:
www.four4women.org

ABOUT ICW Asia Pacific

ICW Asia Pacific (ICW-AP) is a regional network based in New Delhi, India that is affiliated with the International Community of Women Living with HIV/AIDS (ICW) international network and shares the same mission and values. ICW-AP's key themes and issues include researching and advocating for HIV-positive women's participation in decision-making; sexual and reproductive health rights; access to care, treatment and support services; freedom from violence, stigma and discrimination; and economic justice, self-determination and empowerment.

www.icwap.org

Executive Summary

A PARADIGM SHIFT GLOBALLY

In mid-2009, when ITPC issued its first report on vertical transmission of HIV,¹ the picture was bleak at both global and country levels. While vertical transmission had been virtually eliminated in rich countries, pregnant women living with HIV in poorer countries did not have access to the same quality of counselling and treatment.

The report – *Missing the Target 7 (MTT7)*² – identified several global and national challenges. Prevention of vertical transmission programmes were focused too narrowly on a single intervention of providing antiretroviral drugs (ARVs) to HIV-positive pregnant women and their infants as a way to prevent vertical transmission rather than a more comprehensive approach along the four pillars as was intended.

Moreover, lack of integrated services, the high cost of antenatal care, sparse rural coverage and widespread stigma and discrimination in health care settings meant that these programmes – limited though they were – still failed to reach the majority of women and children in need. Worse, in country after country, women were being given sub-optimal drugs for ARV prophylaxis and also receiving confusing messages and dangerous misinformation about infant feeding choices.

Two years later, as ITPC and its partners once again assess programmes to prevent vertical transmission in *Missing the Target 9 (MTT9)*, the global policy environment on vertical transmission of HIV has dramatically changed.

The crucial link between maternal health and infant survival^{3,4} is now broadly recognized, and keeping mothers alive and healthy is now an explicit goal of global programming to address vertical transmission. UN agencies and most governments openly acknowledge the failings of their past efforts and agree that women living with HIV need to be at the centre of the response if prevention of vertical transmission programmes are to succeed.

Great strides have been made in science and policy. Incontrovertible evidence now exists as to the prevention benefits of treatment in general as well as the benefits of early initiation of treatment for pregnant women. For the first time, evidence⁵ underpins new WHO recommendations regarding the provision of ARV prophylaxis to either the mother or infant during breastfeeding as well as new infant feeding guidelines.

The new World Health Organization (WHO) guidelines issued in 2010 (see chart on p8) reflect these advances and “propose earlier initiation of ART (lifelong treatment) for a larger group of HIV-infected pregnant women, with the goal of directly benefiting the health of the mothers and maximally

UN Framework to Prevent Vertical Transmission of HIV

PILLAR 1:
Preventing HIV among women of reproductive age



PILLAR 2:
Meeting the unmet family planning needs for women living with HIV



PILLAR 3:
Preventing HIV transmission to infants during pregnancy, delivery and breastfeeding



PILLAR 4:
HIV treatment and care for women living with HIV and their families



1 Activists around the world are campaigning for the programme to be known as prevention of vertical transmission rather than prevention of mother to child transmission or “PMTCT” as it adds to the stigma a woman faces by placing the blame on her for HIV transmission to her child. Some governments, including the Indian government, call the programme “PPTCT” or “prevention of parent-to-child transmission” to encourage greater male involvement.

2 ITPC. *Missing the Target 7: Failing Women, Failing Children: HIV, Vertical Transmission, and Women's Health*. May 2009. Available at: www.four4women.org/sites/default/files/resources/file/mtt7_final.pdf

3 Hogan MC, Foreman KJ, Naghavi M, et al. “Maternal mortality for 181 countries, 1980–2008: a systematic analysis of progress towards Millennium Development Goal 5.” *Lancet*. 2010.

4 Abdool-Karim Q, Abouzahr C, Dehne K, et al. “HIV and maternal mortality: turning the tide.” *Lancet*. 2010.

5 De Vincenzi, I. and Kesho Bora Study Group. Triple-antiretroviral (ARV) prophylaxis during pregnancy and breastfeeding compared to short-ARV prophylaxis to prevent mother-to-child transmission of HIV-1 (MTCT): The Kesho Bora randomized controlled clinical trial in five sites in Burkina Faso, Kenya and South Africa. Abstract LBPEC01 in The 5th IAS Conference on HIV Pathogenesis and Treatment. 2009.

EACH DAY OVER 1,000 CHILDREN BECOME NEWLY INFECTED WITH HIV.(2010)⁸

IN 2009, AN ESTIMATED 42,000–60,000 PREGNANT WOMEN DIED BECAUSE OF HIV.⁹

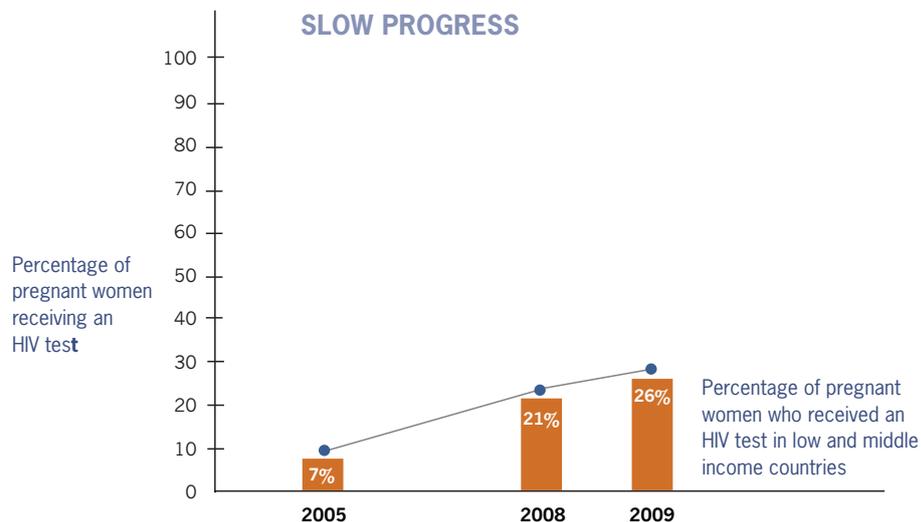
reducing HIV transmission to their children.”⁶ They are based on a clear understanding that these women are at highest risk of transmitting the virus to their children as well as at the highest risk of HIV-related mortality and morbidity. Revised infant feeding guidelines recognize that, in light of the effectiveness of ARV interventions, continued breastfeeding by HIV-infected mothers until the infant is 12 months of age capitalizes on the maximum benefit of breastfeeding to improve the infant’s chances of survival while reducing the risk of HIV transmission.

The international community realized that virtual elimination of vertical transmission of HIV was an achievable goal even in a tough economic climate. A multi-sectoral global task team deliberated and developed a global plan of action⁷ with two specific global targets for governments to achieve by 2015:

- Reduce the number of new HIV infections among children by 90%
- Reduce the number of AIDS-related maternal deaths by 50%

In 2011, world leaders gathered at the UN committed to scale up their efforts, and governments are currently in the process of developing revised national plans to achieve the above targets. There is recognition of the imperative of funding these achievable goals even in an era of funding cutbacks. Major donors, including the Global Fund and PEPFAR, have revised their strategic plans, placing high priority on funding programmes to prevent vertical transmission.

We have new science, backing of donor funding and even the political will. However, there is a long way to go to translate this into real outcomes such as lives saved and new HIV infections averted. The need at community level remains massive.



Source: UNAIDS. *Global Plan Towards the Elimination of New HIV Infections Among Children by 2015 and Keeping Their Mothers Alive, 2011-2015*. 2011.

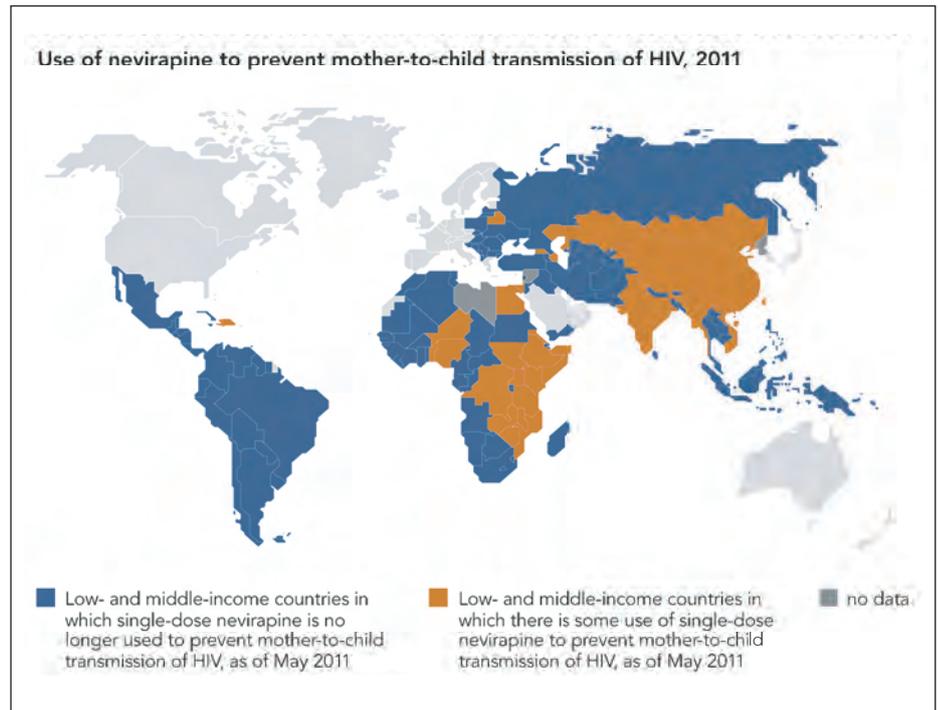
6 World Health Organization. *Antiretroviral drugs for treating pregnant women and preventing HIV infection in infants: recommendations for a public health approach*. 2010. Available at: http://whqlibdoc.who.int/publications/2010/9789241599818_eng.pdf

7 UNAIDS. *Countdown to Zero. Global Plan Towards the Elimination of New HIV Infections Among Children by 2015 and Keeping their Mothers Alive*. 2011. Available at: www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/20110609_JC2137_Global-Plan-Elimination-HIV-Children_en.pdf

8 UNAIDS. *World AIDS Day Report*. 2011.

9 UNAIDS. *Countdown to Zero. Global Plan Towards the Elimination of New HIV Infections Among Children by 2015 and Keeping their Mothers Alive*. 2011.

Most programmes are still not following a comprehensive approach around the four pillars as recommended by the UN strategy. Across the world, there is not enough focus on pillars one and two despite the evidence on how critical interventions such as improving access to family planning and HIV prevention knowledge and tools support the goal of ending vertical transmission of HIV. Many women in the developing world continue to receive sub-optimal drugs and confusing messages about infant feeding, undermining even the slow ‘progress’ made on pillar three. And far too many women and infants in need of treatment are leaving prevention of vertical transmission programmes without any follow-up treatment, care and support.



Source: UNAIDS. *Global Plan Towards the Elimination of New HIV Infections Among Children by 2015 and Keeping Their Mothers Alive, 2011–2015*. 2011.

A SLOW CRAWL NATIONALLY

New research conducted in four countries and updates from five countries show that these global shifts are not yet being mirrored at country or community level. There is growing political commitment to reach the goals of preventing new HIV infections and saving the lives of mothers and babies, but this is not matched by action plans, up-to-date policies and adequate budgets. And even when governments have plans in place to meet these goals, the targets are far from being met and the policies are simply not being implemented on the ground.

KEY FINDINGS FROM FOCUS COUNTRIES

Community advocates in Cameroon, Côte d’Ivoire, Ethiopia, Nigeria and India have identified multiple barriers that women face in accessing comprehensive vertical transmission services in their countries. ITPC chose these five countries as they are among the world’s nations where gaps between need and access to prevention of vertical transmission services are the largest.

These countries also rank low on contraceptive use and have high fertility rates. The numbers of women using antenatal care (ANC) services, especially rural-dwelling and low-income women, are also low compared to other countries. In addition, young women in these countries are often several times more vulnerable to HIV than men, but lack access to knowledge and tools to prevent HIV. These related factors impact the effectiveness of vertical transmission services for women.

Several barriers emerged as common themes in the interviews conducted with affected women and health care workers in each of the five countries, including:

- Male partners are not involved in prevention of vertical transmission services, missing an opportunity to be tested and treated, mainly due to an absence of policies and strategies to engage them.
- WHO guidelines on prevention of vertical transmission and infant feeding are not being rolled out fully: single-dose nevirapine (sdNVP) is still used in three of the countries (Ethiopia, India and Nigeria), guidance on infant feeding is not clear and health care workers are not always supportive of exclusive breastfeeding (as recommended).
- Often ARVs are free, but costs of ANC, delivery, diagnostic tests, OI and STI treatment, and transportation to distant clinics are barriers for low-income women. In addition, drug stock-outs, especially for OI medicines, are common.
- Stigma which is widely encountered in health care facilities, combined with a shortage of trained health care workers, long waiting times and lack of integrated services under one roof, discourage women from accessing ANC services thus missing the opportunity for testing and treatment.

RECOMMENDATIONS

ITPC welcomes the renewed global commitment and focus on maternal health, including in programmes to prevent vertical transmission of HIV. We urge governments, donors and UN agencies to act in concert based on the community experiences to ensure more effective programmes to prevent vertical transmission of HIV.

Below are our key recommendations to governments and the international community to ensure that the renewed efforts to end vertical transmission of HIV deliver results for women and their families this time around:

Build the programme along the four pillars:

- Ensure a more comprehensive response based on the four pillars in all scale-up efforts. Each pillar represents an opportunity to stop a cycle of HIV and other health problems, for the woman and her family.

Measure real outcomes, such as infections averted not just drugs delivered:

- Track and report on resulting outcomes of the programme, such as on improving maternal and child health, on preventing HIV in young women and infants, and on increased reproductive choices for HIV-positive women.

Set the bar based on the latest science not declining budgets:

- Fully implement WHO guidelines on earlier initiation of treatment for pregnant women and the use of more effective regimens. End the use of single-dose nevirapine as the ARV prophylaxis to prevent vertical transmission of HIV.
- Provide women with the most up to date information about infant feeding choices including through proper guidance and training to health care workers and others who advise and support mothers living with HIV.

Take the services to the community:

- Fully integrate HIV prevention with sexual and reproductive and maternal and child health services. Decentralize services to ensure better coverage in rural areas.
- Initiate programmes and policies to increase male partner engagement.
- Implement innovative testing programmes and stigma-reduction strategies to increase uptake of voluntary testing and counselling services.

Ensure the programme is fully funded and fully stocked:

- Increase investment in health and allocate adequate domestic budgets and donor funds to support the scale-up of vertical transmission services.
- End drug stock-outs and shortages of other essential commodities (such as HIV testing kits).

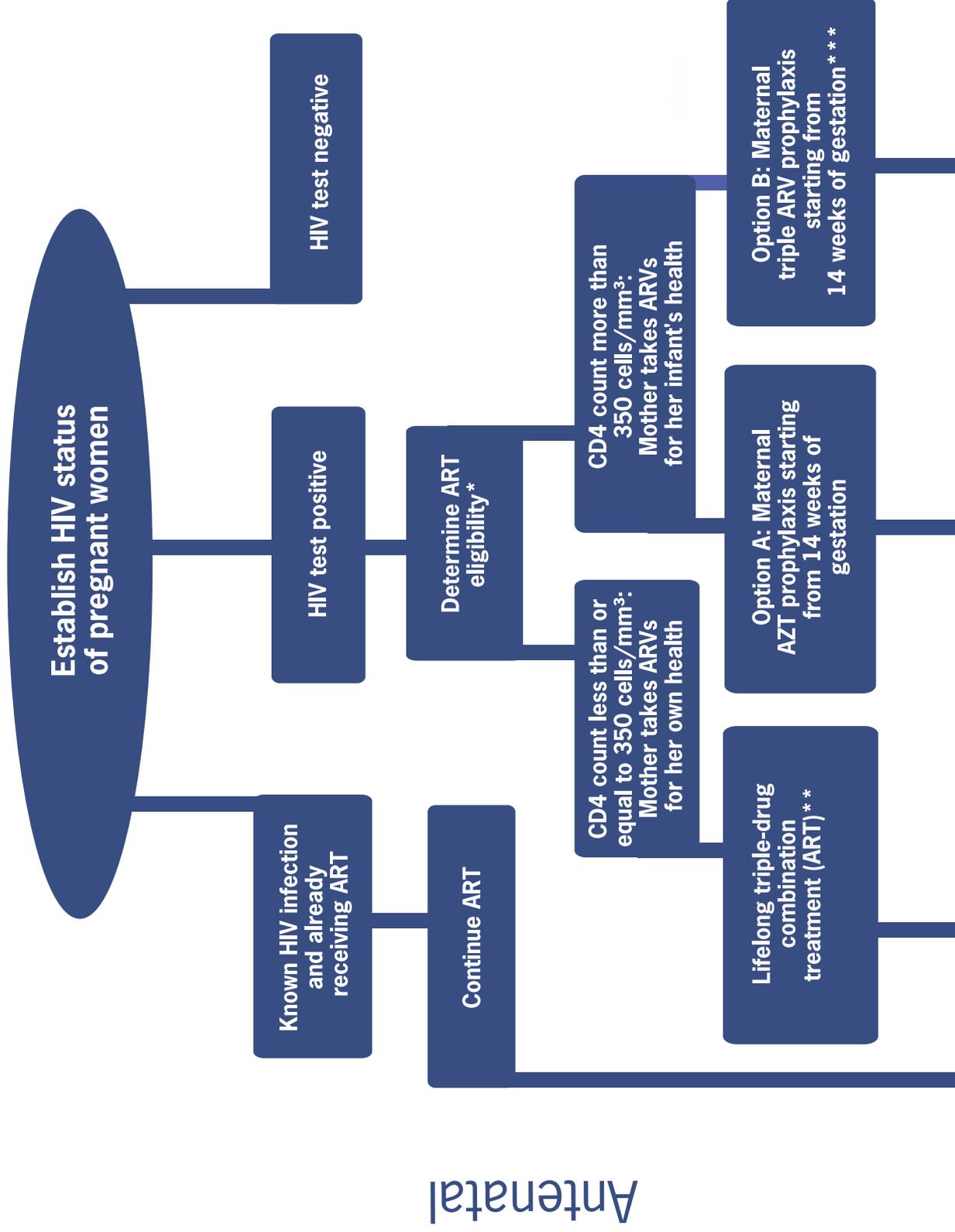
Universal access to treatment for women, children and their families:

- Ensure that women entering prevention of vertical transmission programmes are assessed on their need for treatment and those in need are enrolled, in long-term HIV treatment and care. There is also an urgent need to improve the follow-up, treatment and care for infants infected with HIV.

Comprehensive efforts to end vertical transmission of HIV provide an invaluable gateway to help meet other health goals on maternal health, child health and indeed the ultimate “health for all”. Can we afford to miss the target again?

2010 WHO PMTCT Guidelines:

ARVs for Treating Pregnant Women and Preventing HIV Infection in Infants



Labour and delivery

Continue ART

Mother:
Continue ART

Infant:
Daily NVP or twice-daily AZT from birth until 4 to 6 weeks of age

sd-NVP at the start of labour and AZT + 3TC twice daily‡

Mother:
Continue AZT + 3TC until 1 week after delivery

Infant:
Daily NVP from birth for a minimum of 4-6 weeks following birth and until 1 week after all exposure to breast milk has ended (if replacement feeding, daily NVP or sdNVP + twice-daily AZT from birth until 4-6 weeks of age)

Continue triple ARV prophylaxis

Mother:
Continue triple ARV prophylaxis until 1 week after complete cessation of breastfeeding**** (if replacement feeding, no postpartum treatment necessary)

Infant:
Daily NVP or twice-daily AZT from birth until 4 to 6 weeks of age

Postpartum

* Start ARV prophylaxis while waiting to determine ART eligibility.

** AZT + 3TC + NVP or TDF + 3TC (or FTC) + NVP or AZT + 3TC + EFV or TDF + 3TC (or FTC) + EFV. Avoid use of EFV in first trimester; use NVP instead.

*** AZT + 3TC + LPV/r, AZT + 3TC + ABC, AZT + 3TC + EFV or TDF + 3TC (or FTC) + EFV.

**** When stopping any NNRTI-based regimen, stop the NNRTI first and continue the two NRTIs for 7 days and then stop them to reduce the chance of NNRTI resistance

‡ If AZT was taken for at least the last 4 weeks before delivery, omission of the maternal sd-NVP and accompanying tail (AZT + 3TC) can be considered. In this case, continue maternal AZT twice daily during labour and stop at delivery.

Introducing the Country Report

ABOUT MISSING THE TARGET

It is widely acknowledged that community-level monitoring and advocacy are essential to ensuring that governments meet their obligation to deliver quality health care for their citizens. The *Missing the Target* series of reports, and related advocacy and capacity building activities, aim to support civil society advocates to monitor the delivery of AIDS services in their countries, and hold national governments and global agencies accountable to their commitment to ensure access for all in need.

Civil society advocates (most often people living with HIV) in each selected country analyze the barriers that communities face in accessing HIV treatment and other services. ITPC provides small research and advocacy grants, ongoing guidance, advocacy training, and support to country teams to write a national report. ITPC then collates these in one global report to help ensure that the findings and recommendations from a community perspective reach the corridors of power in their national capitals, as well as Geneva and Washington.

Over the past six years, civil society and community teams in over 20 countries have collected evidence, published their findings and advocated on the basis of the *Missing the Target* reports.

ABOUT THIS REPORT

The chapter that follows assesses the quality and accessibility of services to prevent vertical transmission of HIV in India from a community perspective (particularly, women living with HIV). India is one of the countries identified by UNAIDS with the highest numbers of pregnant women still in need of services to prevent vertical transmission of HIV. Community advocates undertook interviews, focus group discussions (with women living with HIV and others), and secondary research to identify the barriers women and their families face in accessing these services.

UN Framework to Prevent Vertical Transmission of HIV

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The MTT9 global report with summary chapters from an additional ten countries is available at the campaign website: www.four4women.org

COMMUNITY EXPERIENCES OF EFFORTS TO PREVENT VERTICAL TRANSMISSION OF HIV IN INDIA

By Paramita Kundu, ICW Asia Pacific (ICW-AP), with support from Anandi Yuvaraj (ICW-AP)

KEY FINDINGS

- The quality of HIV counselling is poor due to lack of adequate training and counsellors' work overload, and post-test counselling is rarely provided to women who test negative.
- Women reported stigma and discrimination on the part of service providers; especially around invasive procedures like delivery and surgeries, and that many service providers discourage women living with HIV from having children.
- Some public and many private service providers are unaware of the new 2010 WHO guidelines to replace the less effective single-dose nevirapine regimen with more effective regimens to prevent vertical transmission.
- Mothers living with HIV are generally advised to not breastfeed, contrary to the national infant feeding guidelines that are based on the WHO guidelines.
- The shortage of CD4 machines and therefore access to CD4 testing is a major barrier to HIV-positive mothers' ability to access treatment for their own health.
- Initiatives to address violence against HIV-positive women are missing from the PPTCT programme.

RESEARCH METHODOLOGY

Research for this report was conducted in two phases. The first phase lasted from December 2010–March 2011 and the second phase was conducted between August–December 2011 in four states of India: Karnataka, Maharashtra, Uttar Pradesh and Delhi. Research consisted of five focus group discussions conducted with women living with HIV and interviews with representatives from public and private service providers, UN agencies and State AIDS Control Societies. A total of 20 individuals were interviewed (Annex 1 provides detailed methodology information, including names of respondents and dates of interviews, and discusses the limitations of the study.)

HIV AND VERTICAL TRANSMISSION IN INDIA

The Joint United Nations Programme on HIV/AIDS (UNAIDS) estimates that about 2.4 million people were living with HIV in India in 2009, which corresponds to adult HIV prevalence of about 0.3 percent.¹ While that estimate is approximately half of earlier estimates of absolute infections, it still represents the third most infections in a country globally. Women and children account for 39 percent and 3.5 percent of total cases, respectively, and HIV prevalence among pregnant women in 2009 was estimated to be 0.48 percent.² The HIV epidemic in India has largely been concentrated among key populations including female sex workers, injecting drug users, and men who have sex with men. However, a growing share of new infections is occurring within intimate partner heterosexual relationships; for example, according to India's 2010 UNGASS Country Progress Report, more than 90 percent of women living with HIV acquired the virus from their husbands or another intimate sexual partner.³

1 As per most recent estimates from UNAIDS (for 2009) at time research was conducted. Available at www.unaids.org/en/regionscountries/countries/india/.

2 NACO Annual Report 2010-11. Available at http://aidsdatahub.org/dmdocuments/NACO_Annual_Report_2010_11.pdf.

3 UNGASS 2010 Country Progress Report, India. Available at www.unaids.org/en/dataanalysis/monitoringcountryprogress/2010progressreportsubmittedbycountries/india_2010_country_progress_report_en.pdf.

**JUST 24 PERCENT
OF THE TOTAL
ESTIMATED NUMBER
OF PREGNANT WOMEN
WERE COUNSELLED
AND TESTED FOR HIV
IN 2010–11.**

The National AIDS Control Organisation (NACO) launched its Prevention of Parent to Child Transmission (PPTCT) programme in 2001. Despite progress over the last decade in expanding access to antiretroviral treatment (ART), unmet sexual and reproductive health (SRH) and HIV prevention and treatment needs remain a huge problem in India. The country is near the top of the list of the world's countries with the highest number of women and children in need of ART who still do not have access. Ninety percent of women living with HIV who still lack access to services for preventing new HIV infections among their children⁴ are in only 22 countries worldwide – and India is the only non-African country on the list. Only 28 percent of HIV-positive pregnant women received ARV prophylaxis to prevent vertical transmission in the 2010–11 financial year.⁵

Through NACO, which works through State AIDS Control Societies, the Indian government frames national HIV/AIDS policies and provides funds and technical assistance to provide HIV-related services. Current strategies, policies and funding are provided through the National AIDS Control Programme-III (NACP-III), which runs from 2007 through 2012.⁶

SUMMARY OF RESEARCH FINDINGS: Persistent gaps in meeting the UN's comprehensive framework on vertical transmission

Research findings revealed that the PPTCT programme does not adequately cover all four prongs of the UN's comprehensive framework to reduce vertical transmission.⁷ Prongs 1 and 2 were found to be more neglected than prongs 3 and 4. According to a representative from the State AIDS Control Society in Delhi interviewed for this report,⁸ promoting institutional delivery and administering single-dose nevirapine and HIV testing of babies for HIV infection are the primary components of the PPTCT programme in India. The latest addition, he said, is ascertaining HIV-positive pregnant women's ART eligibility followed by treatment, based on their eligibility. Among the major shortcomings is the continued provision of single-dose nevirapine as prophylaxis. The World Health Organisation (WHO) have long recommended phasing out this sub-optimal regimen and recommends combination ARVs be used as the PPTCT prophylaxis.

Another major shortcoming is insufficient uptake of services. A primary concern voiced by policy makers and UN agencies⁹ is the large number of women and babies dropping out across all four prongs across the PPTCT cascade, which represents a major barrier to universal access to treatment and care of pregnant women living with HIV as well as preventing vertical transmission. They further added that despite administration of PPTCT prophylaxis being a national priority, there is a huge gap between the number of pregnant women testing positive and the number of mother-baby pairs receiving PPTCT prophylaxis.

4 UNAIDS (2011). *HIV in Asia and the Pacific: Getting to Zero*. Available at www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/20110826_APGettingToZero_en.pdf.

5 NACO. Summary from the NACP-IV Working Group (Subgroup of ICTC) on Parent to Child Transmission, June 2011. Available at: www.nacoonline.org/upload/NACP%20-%20IV/Consultation%20I%20May%202011/PPTs/NACP%20IV%20PPTCT%20May%203%20and%204%20Meeting%20Summary.pdf

6 UNGASS 2010 Country Progress Report, India. Available at: www.unaids.org/en/dataanalysis/monitoringcountryprogress/2010progressreportsubmittedbycountries/india_2010_country_progress_report_en.pdf.

7 The four prongs (also known as "pillars") of the UN's comprehensive work are as follows: 1) preventing HIV among women of reproductive age; 2) meeting the unmet family planning needs for women living with HIV; 3) preventing HIV transmission to infants during pregnancy, delivery and breastfeeding; and 4) HIV treatment and care for women living with HIV and their families.

8 As cited during an interview on 28 October 2011.

9 As cited during an interview on 22 December 2010.

Losing women in the cascade of PPTCT services in India

43,000 estimated HIV+ pregnant women



16,954 actually identified as HIV+ ... **Missing 60%**



11,962 received NVP prophylaxis to prevent vertical transmission ... **Missing 72%**



9917 pregnant women offered CD4 testing ... **Missing 77%**



17,200 estimated HIV+ pregnant women need ART for their own health*



3967 actually identified as eligible for ART ... **Missing 77%**



Only 2261 actually started ART ... **Missing 87%**



* Of the 9917 pregnant women offered CD4 testing, 3967 (40%) were identified as eligible for ART for their own health. Based on these figures, if we assume that 40% of the total estimated 43,000 HIV+ pregnant women need ART, we arrive at an estimate of 17,200 HIV+ pregnant women who need ART for their own health.

All figures are for the financial year 2010-11

Source: Summary from the NACP IV Working Group (Sub-group of ICTC) on Parent to Child Transmission 2011, NACO

One respondent noted the following:

The percentage of women accessing testing is low. Half of the pregnant women are going for home delivery and it is very hard to reach them. Out of the women who are tested and counselled, you have a big drop because women are not coming for deliveries and are missing on prophylaxis to protect their babies. Amongst those who are coming for deliveries, many of them are not referred or never come for their own ARVs to ART centres. So you are actually losing huge numbers across all prongs.

UNICEF representative, Delhi¹⁰

PREVENTING HIV AMONG WOMEN OF REPRODUCTIVE AGE



Low levels of testing among women and girls despite increased coverage of programmes

One step taken toward the goal of ending parent-to-child transmission was to prioritise the merging of disparate service facilities to form Integrated Counselling and Testing Centres (ICTCs). The number of ICTCs across India increased from 2,815 in 2005–06 to 7,538 in 2010–11. A total of 670 of these ICTCs are in the private sector.¹¹ Making collective services available at primary health care facilities (PHCs) at community levels is supposed to be another mandate of this “merge” initiative. In 2009–10, counselling and testing services have been expanded to 578 PHCs through integration with National Rural Health Missions (NRHMs) in rural areas of high prevalence districts. In addition, community-based HIV screening by auxiliary nurse midwives (ANMs) has been established to identify HIV-positive cases among pregnant women who are not accessing health facilities for antenatal care (ANC) checkups.¹² Despite many initiatives, in 2010–11, just 24 percent of the total estimated number of pregnant women were counselled and tested for HIV.¹³

Limited access to HIV testing services in rural areas, low perception of HIV risk, and HIV-related stigma were cited as reasons for low testing rates. As put forth by a focus group participant in Lucknow, “Women in rural areas don’t have access to information on testing services. They should be shown in the community on TV so that women know where to go for testing.”¹⁴ Although government-supported ICTCs have been decentralised to some extent at primary health care level in some high prevalence areas, many women must travel long distances to reach them. According to a service provider in Maharashtra, “Women are reluctant to travel long distances to get HIV testing done especially when it is meant for prevention, and moreover most of them do not perceive the risk of HIV infection.”¹⁵ Stigma is also a barrier, as told by a private service provider in Delhi:¹⁶ “Stigma associated with HIV is a major reason why women do not want to get tested. They do not want to be associated with it at all.”

10 As cited during an interview on 22 December 2010.

11 Center for Development and Population Activities (CEDPA). Maternal Health and HIV integration. Strategies for strengthening Linkages between Maternal Health and HIV services in India, Policy Brief. 2011.

12 UNGASS 2010 Country Progress Report, India.

13 Summary from the NACP-IV Working Group (Subgroup of ICTC) on Parent to Child Transmission, June 2011.

14 As cited during a focus group discussion in Lucknow on 3 October 2011.

15 As cited during an interview on 8 December 2011 with personnel from Prayas (Initiatives in Health, Energy, Learning and Parenthood) in Pune.

16 As cited during an interview on 14 December with private service provider in Delhi.

Insufficient sexuality education for girls

Under the national government's Adolescent Education programme, 16 hour-long sessions on sexuality are scheduled each year for all students in grades 9 and 11. During 2009–10, 47,000 schools imparted prevention education to their students.¹⁷ A few NGO respondents stated that sexuality and HIV prevention education is critical but that the current coverage of sexuality education is inadequate and requires scaling up.¹⁸

Although the respondents did not offer any reasons, it is likely that conservative mindsets and state-based bans hinder effective scaling up of sexuality education. In 2007, a number of state governments, including those in Maharashtra and Gujarat, introduced policies banning the Adolescent Education programme from being implemented in all state-run schools. The content, especially sections on contraception and sexually transmitted infections (STIs), were considered offensive.¹⁹

In response to this backlash, NACO and the Ministry of Human Resources and Development revised the curricula and toned down certain sections. An independent review of this revised curricula by Talking About Reproductive and Sexual Health Issues (TARSHI), a sexual and reproductive rights organisation, found that issues like conception and contraception, puberty and bodily changes, gender identity, body image, and HIV prevention (including condom use) were particularly ill-addressed by the revised curriculum. Framed within an unrealistic “abstinence only” framework, such limited knowledge on contraception and HIV prevention would then, the review concludes, put young women and girls at increased risk of unintended pregnancies and STIs, including HIV.²⁰ Some research respondents from civil society echoed this finding by saying that the current content is ineffective in equipping young women and girls with comprehensive knowledge on sexuality. There are few out-of-school education opportunities that are comprehensive, with only a handful of non-governmental organisations (NGOs) offering such programmes.²¹

“Women are reluctant to travel long distances to get HIV testing done especially when it is meant for prevention, and moreover most of them do not perceive the risk of HIV infection.”

**Service provider,
Maharashtra**

Lack of comprehensive HIV-related counselling

Interviews with civil society groups revealed that women (especially those who are not members of key affected populations, as key affected populations can benefit from targeted interventions) rarely access HIV counselling and testing services voluntarily owing to fear and stigma surrounding HIV. Most women get screened for HIV when they are pregnant and are encouraged to access antenatal care.²² During site visits in Maharashtra and Karnataka, researchers observed that at public hospitals offering PPTCT services, pre-test counselling involves group counselling with almost negligible post-test counselling for negative women, an omission that greatly misses a vital opportunity to assist them in remaining negative.^{23,24} Moreover, this runs counter to NACO's ICTC operational guidelines clearly outlining the importance of conducting post-test counselling for negative women.²⁵

17 UNGASS 2010 Country Progress Report, India.

18 As cited in an interview on 1 November 2011 at MAMTA Health Institute for Mother and Child, Delhi.

19 As cited in “Between tradition and modernity: Controversy in India about the sex education programme in state-run schools” by Renuka Motihar, an independent consultant. Available at www.kit.nl/net/KIT_Publicities_output/ShowFile2.aspx?e=1421.

20 See “A review of the revised sexuality education curriculum in India”, published by TARSHI. Available at www.tarshi.net/downloads/review_of_sexuality_education_curriculum.pdf.

21 As cited during an interview on 8 December 2011 with personnel from Prayas (Initiatives in Health, Energy, Learning and Parenthood) in Pune.

22 As cited during an interview on 8 December 2011 with personnel from Prayas (Initiatives in Health, Energy, Learning and Parenthood) in Pune.

23 As cited during an interview on 9 November 2011 in Nagpur.

24 As cited during an interview at Ramaiya Hospital in Bangalore on 20 October 2011.

25 Operational Guidelines for Integrated Counselling and Testing Centers, NACO, July 2007.

HIV-positive women who receive post-test counselling report the content to be insufficient.

One service provider in Maharashtra agreed, acknowledging the following:

There are doubts about the quality of counselling services being provided. Sometimes the counsellor has work overload especially if the facility is such that counsellor has many other responsibilities besides counselling. Five to seven days training, the normal provided now for the counsellors, is not enough and there are doubts on how much information they retain.²⁶

Research further indicates that the situation is even worse in the private sector, as most facilities do not provide any pre- or post-test counselling, regardless of test result.²⁷ In general, therefore, pregnant women receive insufficient information and support regarding HIV, which in turn means that they are often unaware of the full range of options and services to safeguard their own health and that of their infants.

Lack of routine gynaecological care including cervical cancer screening and treatment

Although cervical cancer ranks as the most commonly diagnosed cancer among women in India, the national health programme does not currently cover screening for it.²⁸ None of the focus group participants reported accessing routine cervical cancer screening or, for that matter, routine gynaecological care unless they had symptoms. On the supply side, the health system was found to not support provision of routine gynaecological care to women living with HIV. Some of the public health care workers (doctors) interviewed said although all women above 30 years of age should be routinely screened for cervical cancer, there is no guideline recommending such routine screening to any woman within the public health system.²⁹ A gynaecologist in a public hospital in Uttar Pradesh said the following: “We don’t provide routine screening for cervical cancer to women here. We refer the women to medical college if they report with symptoms.”³⁰

Few doctors interviewed were aware of additional risks of cervical cancer in women living with HIV. In Maharashtra one government hospital was found to encourage HIV-positive women to undergo cervical cancer screening but provided no treatment facilities. If found reactive, treatment options are discussed and patients are referred to private clinics for treatment that is costly.³¹ Even within the private sector screening for cervical cancer is not encouraged, according to an NGO service provider in Maharashtra.³² Most service providers interviewed said that they followed a syndromic approach in managing reproductive tract infections (RTIs) and STIs in HIV-positive women. This is in line with NACO’s STI guidelines that outline syndromic case management as the cornerstone of this service. Out of NACO’s annual STI treatment target of 15 million (calculated as 50% of the national estimated episodes), only 8.49 million STI episodes were treated during

26 As cited during an interview on 8 December 2011 with personnel from Prayas (Initiatives in Health, Energy, Learning and Parenthood) in Pune.

27 As cited during interviews on 3 and 4 October 2011 in Lucknow.

28 World Health Organization (WHO) and Institut Català d’Ontologia (ICO), September 2010. *Human Papillomavirus and Related Cancers Summary Report Update*. Available at http://apps.who.int/hpvcentre/statistics/dynamic/ico/country_pdf/IND.pdf.

29 As cited during an interview at Vani Vilas Maternity Government Hospital in Mysore on 12 December 2011.

30 As cited during an interview with a doctor at a leading public hospital in Lucknow, 4 October 2011.

31 As cited during an interview at Indira Gandhi Medical College in Nagpur, 9 November 2011.

32 As cited during an interview on 8 December, 2011 with personnel from Prayas (Initiatives in Health, Energy, Learning and Parenthood) in Pune.

2010–11. Sex disaggregated data is however not available.^{33,34} One of the challenges for treating STIs as pointed out by health care providers in Maharashtra is a shortage of syndromic management kits for genital warts. They also said that women feel hesitant to access STI services from a male doctor (STI specialists are mostly men) and because of the long waits and huge demand, they do not get adequate one-to-one consultation time with a doctor.³⁵

With India having adopted the framework on elimination of new paediatric HIV infections and congenital syphilis in Asia Pacific, the importance of ANC syphilis screening is increasingly being recognised within the national health system though it is yet to be scaled up.³⁶

“If a positive woman wants to be pregnant, I am not sure if I would want her to go ahead with that. HIV is scary.”
A private gynaecologist in Delhi

MEETING THE UNMET FAMILY PLANNING NEEDS FOR WOMEN LIVING WITH HIV



Lack of respect for reproductive rights of women living with HIV

A majority of focus group participants reported stigma and discrimination on the part of service providers. They said that many service providers discourage women living with HIV from having children, especially if they already have one child.^{37,38} For example, one focus group participant, a new mother living with HIV, reported that the counsellor at a leading public hospital in Delhi scolded her and strongly advised her not to have her baby, stressing particularly that proceeding would be inappropriate. The woman ignored the strongly worded advice, but indicated that it was unpleasant to hear and caused a lot of stress.³⁹ Focus group participants in Mysore emphasized the additional pressure that HIV-positive sex workers face to not have children.⁴⁰ The following two quotes from doctors illustrate the problem:

Positive women should not be allowed to have more children. Who will look after the child? Someone should take responsibility. Who will adopt positive children?

A gynaecologist at a public hospital in Uttar Pradesh⁴¹

If a positive woman wants to be pregnant, I am not sure if I would want her to go ahead with that. HIV is scary.

A private gynaecologist in Delhi⁴²

According to focus group participants, some pregnant women living with HIV are advised to undergo sterilisation after their first delivery, an option supported generally by service providers on the pretext of further limiting the possibility of future HIV transmission. It was not clear from research the extent to which consent for sterilisation is sought and obtained

33 UNGASS 2010 Country Progress Report, India.

34 NACO Annual Report 2010-11. Available at http://aidsdatahub.org/dmddocuments/NACO_Annual_Report_2010_11.pdf.

35 As cited during an interview at Indira Gandhi Medical College in Nagpur, 9 November, 2011.

36 As cited during the Consultation on Integration of Maternal Health and HIV Initiatives in India, 17 January 2012 in New Delhi.

37 As cited during a focus group discussion in Lucknow on 3 October 2011.

38 As cited during focus group discussions in Delhi on 19 August 2011 and 11 November 2011.

39 As cited during focus group discussions in Delhi on 19 August 2011 and 11 November 2011.

40 As cited during a focus group discussion in Mysore on 20 October 2011.

41 As cited during an interview at a government hospital in Lucknow on 4 October 2011.

42 As cited during an interview with a private doctor in Delhi on 14 December 2011.

before proceeding. As per comments from focus group participants and representatives of HIV-positive women's networks who participated in focus groups, informed consent processes are not followed and HIV-positive women are not asked to sign any consent form prior to the procedure.^{43, 44}

Research indicates that most of the time HIV-positive women do not feel empowered enough to challenge the provider's narrow advice on sterilisation, knowing well the ridicule and accusations they would have to face if they dare to challenge it. In the absence of comprehensive information on a range of family planning methods, this attitude from service providers creates pressure for women to comply, even if they may not be comfortable doing so.

Most focus group participants mentioned abortion as another option advised to HIV-positive women by counsellors in public hospitals, especially if they already have one child. They said that many HIV-positive women report confusion and pressure to comply, especially in the absence of full information on the risks of pregnancy to their own health; the risks of transmission of HIV to their infant; the effectiveness and the availability and cost of ARVs for treating HIV and for preventing transmission of HIV among infants; the potential toxicity of such drugs; and the specific risks of abortion procedures.^{45, 46}

Focus group participants from Maharashtra also said that information and counselling on abortion is never provided within health care settings. One noted the following:

Information and counselling about abortion is not given in government hospitals, and post-abortion care is not adequate. When I went for an abortion in a government hospital, I was asked to buy universal precaution kits and medicines from outside. I felt I was being singled out because I am positive; I did not feel like going back.

Focus group participant from Maharashtra⁴⁷

Such reported gaps are validated by earlier research indicating that women living with HIV have reported that concerns about the assumed negative effects of pregnancy and childbearing on their own health and about HIV transmission to their infant influenced their decision to terminate a pregnancy.⁴⁸ It is worth noting as well that WHO guidelines say that it is essential that women seeking abortion undergo comprehensive counselling.⁴⁹

Limited choices on contraception and family planning

Proper and comprehensive counselling on family planning methods is difficult to obtain in India, including at public health facilities, and neither ART nor PPTCT centres offer adequate information or resources on family planning. Focus group participants in Delhi and Uttar Pradesh stated that contraceptive methods primarily advised to women living with HIV are male

43 As cited during a focus group discussion in Lucknow on 3 October 2011.

44 As cited during focus group discussions in Delhi on 19 August 2011 and 11 November 2011.

45 As cited during a focus group discussion in Lucknow on 3 October 2011.

46 As cited during focus group discussions in Delhi on 19 August 2011 and 11 November 2011.

47 As cited during a focus group discussion in Nagpur on 22 October 2011.

48 deBruyn, M. "Safe abortion for HIV-positive women with unwanted pregnancy: a reproductive right." *Reproductive Health Matters*. 2003. 11:152–161.

49 WHO and United Nations Population Fund. *Sexual and reproductive health of women living with HIV/AIDS: Guidelines for care, treatment and support for women living with HIV/AIDS and their children in resource-constrained settings*. 2006. Available at: www.who.int/hiv/pub/guidelines/sexualreproductivehealth.pdf.

condoms and sterilisation; information on other family planning methods such as intrauterine devices (IUDs) is rarely provided.^{50, 51}

We endorse that there has to be a basket of choices in various types of methods. There is an overemphasis on certain methods (say, sterilisation) not only for positive but for all women. This needs to be done away with.

Representative of NGO working on women's issues, Delhi⁵²

Positive Women Network representatives who participated in a focus group discussion in Delhi stated that few HIV-positive women who had used the Copper T IUD had obtained it from a private-sector source without disclosing their status. They further stated that although abortion services are available in the government sector, due to stigma and discrimination within public health settings, most sought abortion in the private sector without disclosing their status. However, that option is not always helpful because many women reported being turned away or charged more when their HIV status became known.^{53, 54}

A private-sector gynaecologist from Uttar Pradesh stated that some women on denial of services approach quack doctors and end up having unsafe abortions.⁵⁵ This is a serious problem as unsafe abortion is the cause of 13 percent of all maternal deaths in India.⁵⁶ Evidence also shows that women living with HIV are at an increased risk of infection and may be particularly at risk of complications, a situation that clearly points to the need to have safer abortion services for women living with HIV.⁵⁷

As per the NACO 2011 report and interviews conducted with service providers, female condoms are not available in the public health system. Some pilot projects to expand access to female condoms have been undertaken with sex workers, but they have not been expanded to reach the general population. Most women and service providers interviewed said the main limiting factors were affordability and availability. Some NGO representatives interviewed suggested using a social marketing approach as a way to increase access to female-initiated contraceptive methods such as female condoms.⁵⁸

50 As cited during a focus group discussion in Lucknow on 3 October 2011.

51 As cited during focus group discussions in Delhi on 19 August 2011 and 11 November 2011.

52 As cited during an interview with representative of women's group in Delhi in January, 2011

53 As cited during a focus group discussion in Lucknow on 3 October 2011.

54 As cited during focus group discussions in Delhi on 19 August 2011 and 11 November 2011.

55 As cited during an interview with a private-sector doctor in Lucknow on 4 October 2011.

56 Kounteya Sinha, "Despite abortion laws, 66% of Indians use unsafe route". *Times of India*. 19 January 2012.

57 WHO and United Nations Population Fund. *Sexual and reproductive health of women living with HIV/AIDS: Guidelines for care, treatment and support for women living with HIV/AIDS and their children in resource-constrained settings*. 2006. Available at www.who.int/hiv/pub/guidelines/sexualreproductivehealth.pdf.

58 As cited during an interview on 8 December 2011 with personnel from Prayas (Initiatives in Health, Energy, Learning and Parenthood) in Pune.

PREVENTING HIV TRANSMISSION TO INFANTS DURING PREGNANCY, DELIVERY AND BREASTFEEDING



Mandatory nature of antenatal HIV testing

The section on provider-initiated testing for pregnant women in the ICTC operational guidelines clearly spells out an opt-out option.⁵⁹ However, in practice, women rarely get a chance to make informed choices about testing using this option. Most service providers interviewed said that although pregnant women are routinely screened for HIV, they rarely have the option to opt-out of the test. Some said that women who refuse tests despite counselling already know their status and counsellors therefore try their best to urge them to consent to a test as it is a part of the ANC mandate and practiced under provider initiated testing and counselling (PITC) based on WHO guidelines.⁶⁰ Moreover, most women are ignorant of their right to say no to providers when they recommend testing. Therefore many reportedly relent in the face of counsellors' pressure.⁶¹

HIV testing is routinely done as part of ANC care in our hospital. They cannot not get it done. We seek to persuade all women to undergo HIV tests. We tell them they should do this to protect their babies. Most agree when we stress that point.

Gynaecologist at a private hospital in Bangalore⁶²

A private practitioner in Uttar Pradesh said that in most private-sector facilities, no counselling services are offered to pregnant women prior to HIV testing. HIV detection is one of the several routine tests prescribed by the doctor and most times the woman is just handed the list without being told that she is being tested for HIV.⁶³

In an environment characterised by stigma and discrimination against people living with HIV, pregnant women living with HIV are hesitant to refuse a test even if given the option to do so. Although not explicitly told by service providers, they are scared that services might be withdrawn or that they would not receive the health care systems' cooperation and support during pregnancy if they refuse the test.

Insufficient follow-up after initial antenatal HIV test

Interviews with service providers revealed that most pregnant women are offered HIV testing only once during the course of their pregnancy, regardless of which trimester they are in when they first access antenatal services. As a result, women who seroconvert later in their pregnancy may continue to assume they are HIV-negative. This risk is heightened by substandard post-test counselling provided to women who test negative, thus further increasing the vulnerability of pregnant women to HIV throughout the course of their pregnancy.^{64, 65}

Continuation of single-dose nevirapine as PPTCT prophylaxis

Interviews with service providers revealed that for pregnant women with CD4 counts above 350 cells/mm³, single-dose nevirapine is still being administered

59 NACO. Operational Guidelines for Integrated Counselling and Testing Centres. July 2007.

60 Ibid.

61 As cited during an interview at St John's Hospital in Bangalore on 20 October 2011.

62 As cited during an interview at St John's Hospital in Bangalore on 20 October 2011.

63 As cited during an interview with a private-sector doctor in Lucknow on 4 October 2011.

64 As cited during an interview at Indira Gandhi Medical College in Nagpur on 9 November 2011.

65 As cited during an interview at a government hospital in Lucknow on 4 October 2011

in public health facilities as the PPTCT prophylaxis. This situation persists in much of the country despite the government's plan to fully implement 2010 WHO guidelines that strongly recommend phasing out the use of single-dose nevirapine.⁶⁶ As a matter of fact, India does not even fully follow the 2006 WHO guidelines, which noted that a combination of AZT and single-dose nevirapine is significantly more effective than single-dose nevirapine alone, and is less likely to lead to drug resistance in HIV-positive women. It is now well known that besides being less effective as a prophylaxis, single-dose nevirapine can compromise HIV-positive women's own treatment options because of its potential to cause resistance. However, official Indian guidelines have yet to be changed and single-dose nevirapine is still the main regimen being prescribed in the country.

Some public service providers interviewed for this report were unaware of the new 2010 WHO guidelines and very few private sector providers contacted were aware of the current regimen being used except those ones partnering with State AIDS Control Societies under the public-private partnership model. In the words of one private sector gynaecologist in Lucknow, "The government I think is providing antiretrovirals. I am not aware of the regimen being given. Private doctors are not provided regular trainings on ARVs."⁶⁷

According to a representative from the Delhi State AIDS Control Society, stock-outs of single-dose nevirapine sometimes occur (as has happened in several states, including Delhi), which means that women in need sometimes cannot obtain affordable prophylaxis medications from public facilities despite national policies guaranteeing access. The same representative reported that "plans are underway [by NACO] to phase out single-dose nevirapine and replace it with combination ARV regimens as recommended in the 2010 WHO guidelines starting with the high prevalence districts. Training guidelines on the updated regimen should be rolled out soon. But I am worried about the delay."⁶⁸

"I am not aware of the regimen being given. Private doctors are not provided regular trainings on ARVs."

Private sector gynaecologist, Lucknow

Low coverage in providing PPTCT prophylaxis

Recent national statistics indicate that only 27.8 percent of the estimated HIV-positive pregnant women received PPTCT prophylaxis.⁶⁹ Service providers, policy makers and representatives of UN agencies interviewed for this report expressed concern at this huge gap and attributed it to low rates of HIV testing and significant loss to follow up. Several noted that the number of women who are tested and counselled is already low, and that there is a further drop off as many do not return to facilities for their deliveries and thus do not receive prophylaxis to protect their babies.⁷⁰ The proportion of institutional deliveries remains low, posing missed opportunities to prevent new infections among infants. Although the number of institutional deliveries rose from 700,000 to 10 million between 2006 and 2010, the most recent numbers represent only 40 percent of all deliveries in India. Of the total, 37 percent are in government hospitals.⁷¹

66 World Health Organization. *Antiretroviral drugs for treating pregnant women and preventing HIV infection in infants: recommendations for a public health approach. 2010 version.* Available at: whqlibdoc.who.int/publications/2010/9789241599818_eng.pdf

67 As cited during an interview with a private-sector doctor in Lucknow on 4 October 2011.

68 As cited during an interview at the Delhi State AIDS Control Society on 28 October 2011.

69 Center for Development and Population Activities (CEDPA). *Maternal Health and HIV integration, Strategies for strengthening Linkages between Maternal Health and HIV services in India, Policy Brief.* 2011.

70 As cited during an interview with representatives from UNICEF in Delhi on 22 December 2010.

71 UNGASS 2010 Country Progress Report, India.

ALTHOUGH THE NUMBER OF INSTITUTIONAL DELIVERIES ROSE FROM 700,000 TO 10 MILLION BETWEEN 2006 AND 2010, THE MOST RECENT NUMBERS REPRESENT ONLY 40 PERCENT OF ALL DELIVERIES IN INDIA.

Most research respondents cited two main reasons that HIV-positive women do not return for institutional deliveries: i) stigma and discrimination in health care settings, and ii) the occasional need for women to buy delivery kits from outside. Focus group participants in Uttar Pradesh and Delhi said that although delivery kits are supposed to be provided in public hospitals for free by State AIDS Control Societies, sometimes, owing to stock-outs, hospital authorities ask women to buy them from outside. Most of the times these women do not return, and thus miss out on receiving critical PPTCT prophylaxis.^{72, 73, 74} As the bulk of deliveries in India take place at home, it is therefore necessary that appropriate strategies are developed for home deliveries to prevent new infections in infants and to keep mothers healthy and alive.⁷⁵

On a more hopeful note, a counsellor interviewed at a public-private partnership in Karnataka spoke about the Yashaswini Cooperative scheme that has been introduced by the Karnataka State AIDS Prevention Society. He said that the public-private scheme guarantees financial incentives to private sector facilities for conducting deliveries of women living with HIV. The scheme reportedly pays 8,000 rupees (\$165) for a Caesarean section and 3,000 rupees for normal deliveries.⁷⁶

Policy makers interviewed added that strategies to reach out to women delivering at home are few and sporadic.⁷⁷ Respondents from Maharashtra, however, cited an NGO project that uses outreach to follow up with women delivering at home and provides them with single-dose nevirapine prophylaxis at home.⁷⁸

Unclear infant feeding advice

The Indian government's latest Infant and Young Child Feeding Guidelines (from 2010)⁷⁹ are based on the revised WHO recommendations.⁸⁰ The guidelines on infant feeding recommend that the national health authorities promote a single infant feeding practice as the standard of care to improve HIV-free survival of HIV exposed infants. According to the recommendations, all mothers irrespective of their HIV status should exclusively breastfeed their infants for the first six months of life and then introduce complementary foods while continuing breastfeeding for 12 to 24 months. For mothers who might wish or need to use alternative feeding methods, the recommendations state that the choice/selection should be based on the principle of AFASS (acceptable, feasible, affordable, sustainable and safe).

However, widespread rolling out of these guidelines has yet to happen, and a representative of an HIV-positive women's network in Maharashtra noted in January 2011 that trainings continued to be conducted for counsellors.⁸¹ Almost all counsellors and government and private sector doctors interviewed said that they currently recommend HIV-positive mothers to formula-feed the infant. They further said that although they are told about

72 As cited during focus group discussions in Delhi on 19 August 2011 and 11 November 2011.

73 As cited during a focus group discussion in Lucknow on 3 October 2011.

74 As cited during an interview at a government hospital in Lucknow on 4 October 2011.

75 UNGASS 2010 Country Progress Report, India.

76 As cited during an interview at Ramaiya Hospital in Bangalore on 20 October 2011.

77 As cited during an interview with DSACS official. October, 2011.

78 As cited in an interview with personnel from the NGO Saathi in Nagpur on 9 November 2011.

79 Infant and Young Child Feeding Guidelines (2010). Available at <http://indianpediatrics.net/dec2010/dec-995-1004.htm>.

80 World Health Organization. *Guidelines on HIV and infant feeding, 2010*. Available at: http://whqlibdoc.who.int/publications/2010/9789241599535_eng.pdf

81 As cited during a conversation with the president of Maharashtra branch of the Positive Women Network on 23 January 2011.

“Positive women don’t want to stay in hospital post-delivery because of fear of stigma. They are scared that others would know their status if they stay beyond the bare minimum required. Sometimes they want to leave before that.”

Doctor at a government hospital in Uttar Pradesh

exclusive breastfeeding for six months as an option in their trainings, they are afraid to advise the same strongly to HIV-positive women. They fear that breastfeeding might aggravate the risk of HIV transmission. The result is that counsellors often leave women confused because they are hesitant with their recommendations. Many focus group participants noted their confusion, some said that service providers had advised them to artificially feed but were unsure about the value or risks of breastfeeding.

Financial consequences are also notable. Artificial feeding is not only a sub-optimal approach as per international standards, but it is comparatively expensive as well. One focus group participant in noted the following: “I have to spend 1,800 rupees [about \$34] per month to buy artificial food for my daughter. Having to spend so much sometimes seems a pressure on me and my family.”⁸²

Stigma and discrimination in health care settings

In 2010, a pregnant woman living in Andhra Pradesh reportedly was thrown out of the hospital for being HIV-positive and was forced to give birth on the streets.⁸³ Unfortunately, such instances are not rare and indicate the profound and persistent HIV-related stigma and discrimination women living with HIV, fear and experience within health care settings in India. These include refusal of treatment, breach of confidentiality, and degrading practices by health care workers.⁸⁴

Focus group participants in Delhi noted that pregnant women living with HIV face stigma and discrimination at the hands of gynaecologists and other health care workers like nurses and ward boys, particularly for invasive procedures like delivery and surgeries.⁸⁵ A woman in Maharashtra provided the following story: “I suffered from excessive bleeding for the last two years. A gynaecologist in a government hospital examined me and diagnosed me with fibroids (in my uterus). She advised hysterectomy (removal of uterus) but because of my HIV status all doctors in the government hospital kept refusing and postponing my surgery. My health condition worsened. Ultimately with support from the state positive women’s network, a kind-hearted gynaecologist conducted my surgery.”⁸⁶

Breach of confidentiality was another example of discrimination cited by focus group participants in Uttar Pradesh:

The other day I accompanied a woman in labour to a government hospital and they were reluctant to admit her. One of the nurses remarked, “You keep bringing HIV-positive women to us.” They said they didn’t have any vacant beds. I took her to the labour room. The staff there shouted that she is HIV-positive. Her family members were nearby, and this was the first time they had heard about her status. So I think the hospital staff’s actions were unethical.

Focus group participant from the Uttar Pradesh Network of People Living with HIV⁸⁷

82 As cited during focus group discussions in Delhi on 19 August 2011 and 11 November 2011.

83 Chew, Clarence. “Discrimination against women, the stigma of HIV.” 17 October 2010. See <http://vitalwaveblog.com/2010/10/discrimination-against-women-the-stigma-of-hiv/>.

84 Coursen-Neff, Z. “Future forsaken: Abuses against children affected by HIV/AIDS in India.” *Hum Rights Watch*. 2004; pp. 39–57.

85 As cited during focus group discussions in Delhi on 19 August 2011 and 11 November 2011.

86 As cited during a focus group discussion in Nagpur on 22 October 2011.

87 As cited during a focus group discussion in Lucknow on 3 October 2011.

Personnel from many private-sector facilities interviewed cited a lack of universal precautions as an excuse to not attend to deliveries of women living with HIV. Most service providers interviewed said that extra caution is prudent, adding that HIV-positive people have a moral responsibility to disclose their status to minimise risk of transmission. Interviews with private sector doctors in Maharashtra revealed that private hospitals charge more for conducting deliveries for HIV-positive women – about 25,000 rupees for normal deliveries and 50,000 rupees for a Caesarean section as opposed to normal (5–10,000 rupees) and caesarean deliveries (30–40,000 rupees) for non HIV-positive women and justified such additional charges to meet expenses for extra precautions.^{88, 89} Private service providers from Karnataka also reported increased charges for conducting deliveries of women living with HIV.⁹⁰

According to a doctor at a government hospital in Uttar Pradesh, stigma and discrimination are the main barriers preventing HIV-positive women from accessing health care. Their health suffers as a result. She said, “Positive women don’t want to stay in hospital post-delivery because of fear of stigma. They are scared that others would know their status if they stay beyond the bare minimum required. Sometimes they want to leave before that.”⁹¹ A focus group participant from Maharashtra reported that although she wants to undergo sterilisation, she is not willing to go to a government hospital for fear of stigma and discrimination.⁹² Many women thus accept this discriminatory treatment as their fate and decide not to visit facilities for future pregnancies or other reproductive health problems, which can compromise their own health and that of their future children.

The critical need for peer support groups

Some focus group participants spoke about the supportive role that networks of HIV-positive women have played in confronting such attitudes and securing non-stigmatising and comprehensive access to delivery services. Focus group participants in Maharashtra strongly recommended supporting HIV-positive women’s networks as pressure groups to promote the reproductive and sexual rights of women living with HIV.

When doctors in a government hospital refused to do my uterine surgery, I went to HRLN [Human Rights Law Network] and the Positive Women Network. After they did advocacy in the hospital, one gynaecologist conducted my surgery. This shows that NGOs and networks play an important role.

Focus group participant from Maharashtra⁹³

Similarly, a focus group participant from Delhi stated, “In PPTCT centres, doctors are sometimes reluctant to conduct deliveries. Now when the woman goes through the positive network, she gets services.”⁹⁴

Lack of regulation and training of staff in the private sector

Many private service providers interviewed stated that because of extensive demand, insufficient numbers of staff (including doctors) and poor quality of services in public hospitals, many pregnant women prefer accessing care in the private sector. Most private sector gynaecologists interviewed said that they have not been trained to work with HIV-positive cases and are not

88 As cited during an interview in Nagpur on 9 November 2011.

89 As cited during an interview with a private-sector doctor in Lucknow on 4 October 2011.

90 As cited during an interview at St John’s Hospital in Bangalore on 20 October 2011.

91 As cited during an interview with a gynecologist at a leading public hospital in Lucknow in October 2011

92 As cited during a focus group discussion in Nagpur on 22 October 2011.

93 As cited during a focus group discussion in Nagpur on 22 October 2011.

94 As cited during focus group discussions in Delhi on 19 August 2011 and 11 November 2011.

aware of policies or procedures regarding antiretroviral regimens. As a result, private practitioners often refuse to serve HIV-positive pregnant women, thus forcing them into the public sector. One private sector gynaecologist in Delhi said the following: “I don’t see positive cases. I refer them to the government hospital. I don’t know how to handle them.”

It also emerged from the interviews that the private health sector is highly unregulated, with no provisions and mechanisms for accountability and addressing complaints.^{95, 96}

Most private clinics do not take up HIV cases. It is very difficult for a positive woman to get delivery done in private services. Gynaecologists are often reluctant to offer services as they are not told how to handle HIV-positive cases in their curriculum. They have to convince their whole staff that the staff has to attend to a positive woman. Private doctors are not updated on current ARV guidelines.

Private-sector doctor from Uttar Pradesh⁹⁷

HIV TREATMENT AND CARE FOR WOMEN LIVING WITH HIV AND THEIR FAMILIES



Limited focus on HIV-positive mothers' own health needs

According to most focus group participants and service providers interviewed, post-natal care and follow-up of pregnant women and mothers living with HIV for their own health needs is poor. Focus group participants in Uttar Pradesh said that the emphasis of the programme is on the health of the infants.⁹⁸ Most service providers and policy makers interviewed stated whether at the policy level or at the service delivery level, the health and follow-up of HIV-positive mothers are often neglected and less valued.

Follow up of positive mothers is a challenge. Adequate attention is not given as the baby is the main focus. We have started getting data of CD4 testing of mothers. We now know their CD4 counts. But we don't have data on how many are on ART and how many are not on ART. Focus is lacking from doctors, ART centres, policy makers. There has to be refocusing on women.”

Representative of Delhi State AIDS Control Society⁹⁹

Inadequate linkages to treatment and care

Although new national guidelines recommend initiation of ART for all HIV-positive pregnant women with CD4 counts below 350 cells/mm³, this standard has yet to be recognised or achieved in all parts of the country.¹⁰⁰ In 2010, a total of 9,917 HIV-positive pregnant women were offered CD4 testing; of them, 40 percent were deemed eligible for ART and 57 percent of those eligible were started on treatment.¹⁰¹ Service providers and policy makers

95 As cited during an interview with a private-sector doctor in Lucknow on 4 October 2011.

96 As cited during an interview with a private-sector doctor in Delhi on 14 December 2011.

97 As cited during an interview with a private-sector doctor in Lucknow on 4 October 2011.

98 As cited during a focus group discussion in Lucknow on 3 October 2011.

99 As cited during an interview at the Delhi State AIDS Control Society on 28 October 2011.

100 National AIDS Control Organization (Care, Support and Treatment division). Revised Guidelines on Initiation of ART in Adults and Adolescents, Office memorandum, November 2011. Available at: www.nacoonline.org/upload/Divisions/CST/Revised%20guidelines%20on%20initiation%20of%20ART%20in%20adults%20and%20adolescents.pdf

101 Center for Development and Population Activities (CEDPA). Maternal Health and HIV integration, Strategies for strengthening Linkages between Maternal Health and HIV services in India, Policy Brief. 2011.

IN 2010, A TOTAL OF 9,917 HIV-POSITIVE PREGNANT WOMEN WERE OFFERED CD4 TESTING; OF THEM, 40 PERCENT WERE DEEMED ELIGIBLE FOR ART AND 57 PERCENT OF THOSE ELIGIBLE WERE STARTED ON TREATMENT.

interviewed said that among those who present for deliveries, many do not come back to ART centres for their own treatment needs or never follow through with referrals.^{102, 103, 104} Focus group participants in Delhi cited the following reasons for why most women do not follow through: lack of proper support, counselling and guidance throughout the pregnancy term and the critical months after birth, including in regards to referrals and linkages to treatment and care.

Lack of effective counselling and referrals was also cited by policy makers and representatives of UN agencies as a primary reason HIV-positive mothers do not access treatment. As a UNICEF representative from Delhi noted: "Because they did not receive comprehensive counselling, women are not likely to understand the implications of not coming back for their own health or their babies' health. That is one area that needs to be prioritised."¹⁰⁵

Limited availability of CD4 machines

This was mentioned as a key challenge, by service providers and policy makers interviewed, to HIV-positive mothers' ability to access treatment for their own health. They said that although regular CD4 testing is a part of the PPTCT cascade, many pregnant HIV-positive women are unable to access such tests because CD4 machines are not available at link ART centres (those providing decentralised services at the community level). According to a focus group participant in Uttar Pradesh, women are often reluctant or unable to travel long distances to district-level ART centres for CD4 tests.¹⁰⁶ A representative of the Delhi State AIDS Control Society agreed, noting: "Pregnant women find it difficult to go to ART centre for CD4 testing. Thus many cases are lost and ART cannot be started."¹⁰⁷

Inadequate nutritional support for new mothers

Focus participants in Uttar Pradesh and Delhi mentioned that within the counselling component limited attention is given to nutritional issues that is of great importance to HIV-positive mothers. As far as nutritional supplements are concerned, they said, food is provided until the time the mother stays in the hospital. Once she goes back home, there is negligible nutritional guidance or support provided. An HIV-positive network representative participating in a focus group discussion in Delhi questioned whether without any nutritional supplement it is feasible for an economically disadvantaged HIV-positive woman to exclusively breastfeed and produce enough milk to feed her baby. She demands that the government provide such supplements.¹⁰⁸ Other focus group participants in Maharashtra emphasised the need for counsellors to link pregnant HIV-positive women to various nutrition-related government schemes.¹⁰⁹

Lack of follow-up of babies

According to 2009-10 NACO estimates, some 57,000 children are infected at birth in India every year. As of January 2010, a total of 63,889 children were registered as living with HIV; of them, a total of 18,763 were receiving ART. In the past couple of years, an early infant diagnosis programme through DNA-PCR tests to closely monitor HIV-exposed infants and identify HIV status has been rolled out through 766 ICTCs and 181 ART centres; by January

102 As cited during an interview at the Delhi State AIDS Control Society on 28 October 2011.

103 As cited during an interview at UNICEF in Delhi on 22 December 2010.

104 As cited during interview at Vani Vilas Maternity Government Hospital in Mysore on 12 December 2011.

105 As cited during an interview at UNICEF in Delhi on 22 December 2010.

106 As cited during a focus group discussion in Lucknow on 3 October 2011.

107 As cited during an interview at the Delhi State AIDS Control Society on 28 October 2011.

108 As cited during focus group discussions in Delhi on 19 August 2011 and 11 November 2011.

109 As cited during a focus group discussion in Nagpur on 22 October 2011.

2011, a total of 9,016 infants and children under 18 months of age had been tested under this programme.¹¹⁰ This new programme that recommends that newborns of HIV-positive mothers be tested regularly through 18 months to confirm serostatus may help address limited follow-ups and facilitate provisions to detect infants early. According to policy makers and representatives of UN agencies interviewed, the first tests are taken from six weeks after birth. The first sample includes a dry blood sample and the second confirmatory test requires a whole blood sample to be taken.

They noted, however, that loss to follow-up still remains a challenge as many mothers do not do not return with their babies for the second sample.¹¹¹ According to one respondent, only half return for the second sample.¹¹² One reason cited is the lengthy delays for the results of the confirmatory test; another is that service providers often fail to inform mothers of the importance of follow-up.¹¹³

CROSS-CUTTING ISSUES ACROSS THE FOUR PRONGS

Lack of services to address violence against women, including those living with HIV

Although there is now a growing evidence base to establish that partner violence is linked to HIV, violence has mostly been understood in the context of HIV prevention. It stands to reason that if partner violence was part of the backdrop to HIV acquisition, it is likely to remain so even after the diagnosis. Yet this and the range of other types of violence which HIV-positive women experience remain a hidden phenomenon. Often the violence experienced by HIV-positive women mirrors that experienced by women generally, but HIV also acts as one more “determinant” pushing women further down the hierarchy of power and thus intensifying violence. Studies conducted in India revealed that HIV-positive women are usually blamed for their husband’s death. Many are often evicted from their houses, with one study putting the numbers of women experiencing that fate as high as 91 percent.¹¹⁴ Such experiences were reiterated by focus group participants in Uttar Pradesh who cited instances where women living with HIV have been pushed out of their matrimonial homes and denied custody of their children (who were HIV-negative) after being diagnosed HIV-positive.¹¹⁵

Representatives of women’s groups interviewed in Delhi said that gender-based violence is one of the major barriers for women, including for those who are HIV-positive, in accessing maternal health and treatment-related services. However, until now, little has been done to address it.

Talking about family planning and maternal health without talking about gender-based violence has a negative impact on access to maternal health. It has remained a separate women’s issue unless somebody brings it up as a negative influence on access to maternal health.

Women’s group representative, Delhi¹¹⁶

110 NACO Annual Report 2010–11. Available at http://aidsdatahub.org/dmdocuments/NACO_Annual_Report_2010_11.pdf.

111 As cited during an interview at the Delhi State AIDS Control Society on 28 October 2011.

112 As cited during an interview at UNICEF in Delhi on 22 December 2010.

113 As cited in an interview with personnel from the NGO Saathi in Nagpur on 9 November 2011.

114 Hale Fiona and Vazquez Marijo (2011). “Violence against women living with HIV/AIDS: a background paper”. Prepared by Development Connections and the International Community of Women Living with HIV/AIDS (ICW) with the support of UN Women. Available at: www.dvcn.org/uploads/client_70/files/VAPositiveWBkgrdPaper2011.pdf.

115 As cited during a focus group discussion in Lucknow on 3 October 2011.

116 As cited during an interview with Center for Development and Population Activities (CEDPA) personnel in Delhi on 4 January 2011.

In their interviews with service providers and policy makers, researchers for this report found that components to address violence against HIV-positive women are completely missing from the PPTCT programme, both in terms of content and monitoring. This gap is a major shortcoming as HIV prevalence in India has been found to be four times higher among married women who experienced both physical and sexual violence by their intimate partners than women who were not abused.¹¹⁷ However, no service provider or policymaker interviewed for this report acknowledged violence as a serious issue that HIV-positive women face, or one that increases the risk of HIV transmission generally in women. The following comments illustrate that perception: “Violence is an occasional case. This is not a serious problem.”¹¹⁸

Most service providers interviewed acknowledged the existence of stigma and discrimination like denial of delivery services within the health care sector but fell short of accepting those as instances of violence against HIV-positive women. Recent literature review by ICW Global suggests that often occurrences of violence within the health care sector are framed as ‘stigma and discrimination’, or lack of respect for human rights, and only rarely are they referred to as violence against HIV-positive women. It is concerning, the review says, that while the visibility gained for women’s experiences through work on ‘stigma and discrimination’ has been a big step forward, and has placed them firmly on the agenda of the HIV community, the identification of women’s experiences as ‘stigma and discrimination’ has meant that HIV-positive women’s experiences have not been taken up as examples of violence against women.¹¹⁹

“During my first ANC visit to the government hospital, my husband accompanied me. The counsellor talked to us jointly. But during the subsequent visits they did not counsel him.”

A focus group participant from Delhi

Lack of male partner involvement

Research for this report identified lack of male partner involvement as an impediment to expanded and comprehensive services for HIV-positive pregnant women and their families. Thus in India and many other contexts, involving male partners is increasingly being promoted as a key element in the prevention of parent to-child transmission of HIV. However studies have reported that women’s experiences upon disclosing their status to their male partners were often “complicated” because of concerns about resulting violence. Some studies reported violence levels of up to 14 percent following disclosure, while others stated that about half of HIV-positive women said their partners reacted supportively to the disclosure.¹²⁰

Service providers in Maharashtra interviewed for this report noted that if couples visit ANC and ART centres together, the male partners are tested only if their pregnant spouses test positive for HIV. Male partners rarely receive additional counselling throughout the course of pregnancy and delivery as that aspect is not mandated within the health care system.¹²¹ A focus group participant from Delhi gave the following account: “During my first ANC visit to the government hospital, my husband accompanied me. The counsellor talked to us jointly. But during the subsequent visits they did not counsel him.”¹²²

117 Silverman et al. “Intimate partner violence and HIV infection among married Indian women”. *Journal of the American Medical Association*. 2008.

118 As cited during an interview at the Delhi State AIDS Control Society on 28 October 2011.

119 Hale Fiona and Vazquez Marijo. “Violence against women living with HIV/AIDS: a background paper.” Prepared by Development Connections and the International Community of Women Living with HIV/AIDS (ICW) with the IV/AIDS (ICW Global) and the support of UN Women. 2011. Available at www.dvcn.org/uploads/client_70/files/VAPositiveWBkgrdPaper2011.pdf.

120 See for example: PlusNews. “KENYA: The downside of male involvement in PMTCT.” 15 January 2012. Available at: www.plusnews.org/report.aspx?reportid=94652.

121 As cited during an interview on 8 December 2011 with personnel from Prayas (Initiatives in Health, Energy, Learning and Parenthood) in Pune.

122 As cited during focus group discussions in Delhi on 19 August 2011 and 11 November 2011.

Most NGO service providers, policy makers and representatives from UN agencies interviewed emphasised the importance of couples counselling as a way to tackle gender-based violence. However, women's group representatives interviewed for this research cautioned that couples counselling should be contingent on the consent of the woman and should ultimately protect the rights of women. Otherwise, she said, there could be increased violence.¹²³ Such caution was underscored by the following observation from a focus group participant in Delhi: "I did not want my husband to know that I was suffering from an STI. He would have suspected me. The counsellor was kind enough to speak to me alone."¹²⁴

CONCLUSION AND RECOMMENDATIONS

The Indian Government has committed to the targets set in the "*Global Plan towards the Elimination of New HIV Infections among Children by 2015 and Keeping their Mothers Alive*," and is in the process of revising the national plan and budget accordingly. As India's health minister declared his country's commitment, addressing the UN General Assembly in June 2011 to "convert the 27 million annual pregnancies into institutional deliveries for efficacious preventive interventions through better detection of HIV positivity amongst pregnant women."¹²⁵ However, there seems no sense of urgency to meet the stated targets.

If India is to meet the targets set by the Global Plan, urgent acceleration of efforts is needed to ensure and scale up a comprehensive PPTCT programme based on the UN-recommended four prongs. The latest policy directions have repeatedly highlighted the need to integrate vertical HIV-specific programmes within the broader health system and develop cross-sectoral linkages across ministries including the Ministry of Health and Family Welfare and the Ministry of Women and Child Development resulting in an improved PPTCT programme with strong linkages with reproductive and sexual health services for women living with HIV. India has also committed to increase spending on health care to 2.5 percent of its gross domestic product (GDP) during the 12th Five-Year Plan (which starts on 1 April 2012) from the present level of around 1 percent.¹²⁶

The latest consultations for the fourth phase of the National AIDS Control Programme (NACP-IV) have also prioritised areas such as access to family planning services to all pregnant women living with HIV and ensuring 100 percent ANC coverage by integrating NACP with national rural health missions; guaranteeing treatment and care for pregnant women and new mothers living with HIV; preventing loss to follow-up; and reducing stigma.¹²⁷

High-level political will and commitment is needed to ensure that these pledges are implemented quickly and effectively, especially at the community level. Otherwise HIV-positive pregnant women and mothers will continue to face major challenges in obtaining comprehensive treatment, care and support. The iteration and implementation of NACP-IV, due to be

123 As cited during an interview with Center for Development and Population Activities (CEDPA) personnel in Delhi on 4 January 2011.

124 As cited during focus group discussions in Delhi on 19 August 2011 and 11 November 2011.

125 UNAIDS. *HIV in Asia and the Pacific: Getting to Zero*. 2011. Available at: www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/20110826_APGettingToZero_en.pdf.

126 Keshri, Gyanendra Kumar. "Healthcare spending to be upped to 2.5 percent of GDP: Azad." 7 January 2012. Available at: http://twocircles.net/2012jan07/healthcare_spending_be_upped_25_percent_gdp_azad.html

127 Summary from the NACP-IV Working Group (Subgroup of ICTC) on Parent to Child Transmission, June 2011.

launched in 2012, offers an ideal opportunity to address the following set of recommendations stemming from research conducted for this report.

MINISTRY OF HEALTH AND FAMILY WELFARE AND NACO:

- **Improve quality of counselling services:** The scope and quality of counselling services for pregnant women and mothers living with HIV should be enhanced to include issues of sexual and reproductive rights. All should have access to information about such issues and the various family planning options and resources aimed at responding to gender-based violence. Counsellors should receive more intensive and regular training on issues of sexual and reproductive health and rights in the context of women living with HIV. Peer support and counselling should be introduced in the context of PPTCT services to enable women living with HIV to comfortably discuss all such issues.

NATIONAL AIDS CONTROL ORGANISATION:

- **Replace single-dose nevirapine prophylaxis with triple-combination ART prophylaxis:** Use of single-dose nevirapine to prevent transmission to newborns must be immediately phased out and replaced with more effective, evidence-informed triple drug combination ARV regimens as per the 2010 WHO guidelines. All public and private service providers must comply with this policy change, and caregivers at all facilities must be adequately trained on how to administer the new regimen and why it is preferable.
- **Call for treatment for women in need and their children and families:** Appropriate strategies must be designed and implemented to lower the persistently high rates of loss to follow-up for HIV-positive mothers and babies throughout the continuum of care. The goal should be 100 percent engagement and access from first presentation at ANC facilities through birth and beyond. Referrals and linkages to treatment and care should be strengthened for women living with HIV who are pregnant or who are mothers.
- **Accelerate universal implementation of infant feeding guidelines:** There must be accelerated implementation of the 2010 version of the national Infant and Young Child Feeding Guidelines based on the latest WHO guidelines, including new efforts and attention to inform health care providers and pregnant women. Such awareness-raising should take place across facilities at both ANC and ART centres.
- **Address stigma and discrimination in health care settings:** The training guidelines for all health care staff, and especially nurses and counsellors, should be reviewed and modified to address stigma and discrimination issues against people living with HIV. In addition, HIV management (including in regards to stigma issues) should be made a mandatory part of curricula at medical schools. NACO should establish and enforce regulatory and accountability mechanisms at both public and private health settings to monitor compliance with new regulations forbidding HIV-related stigma and discrimination. It should also create a mechanism for confidential complaints, and then ensure that these are addressed.

DONOR AGENCIES:

- **Ensure sustainability of HIV-positive women's groups:** Networks of HIV-positive women and support groups not only help many women living with HIV understand and navigate difficult and often painful

service-access routes, but also serve as sources of critical monitoring and advocacy efforts on behalf of HIV-positive women. Most of these networks face consistent human resource and financial constraints. Donors including UN agencies should provide direct funding support to strengthen and sustain such networks and groups. Donor support must also be provided to build capacities of communities to put forth their concerns and issues.

SOURCES

LIMITATIONS

- The research team struggled to collect district and state level data for the report. A big challenge was the lack of updated data on the State AIDS Control Society websites.
- Interviewing public health service providers was a challenge in itself as all asked for formal authorisation from NACO before agreeing to be interviewed. Staff from NACO also refused to be interviewed for the study as their engagement had not been formally approved by policy makers at the organisation. This delayed the interviews by months and proved to be a major barrier for a time-bound project. The challenge was enlightening, though, in that the requirement to seek permission from a national agency for participation in a community-led study implies a major lack of trust in communities and the value of community-led research.

LIST OF INTERVIEWS:

Service providers

Dr. P.K Goswami, Senior Advisor, Mamta Health Institute of Mother and Child (NGO); New Delhi, November 2011

Dr. Sonia Sharma, Private practitioner (gynaecologist); New Delhi, December 2011

Dr. Alok Bannerjee, Technical advisor (formerly ran Marie Stopes Clinic), ParivarSewaSansthan (NGO); New Delhi, December 2011

Dr. Vinay Kulkarni, Founder and director, PRAYAS; Pune, Maharashtra, December 2011

Dr. Kshama Kedar, PPTCT director, Indira Gandhi Medical College; Nagpur, Maharashtra, November 2011

Ms. Bhavna Mendhe, STI Counsellor, Indira Gandhi Medical College; Nagpur, Maharashtra, November 2011

Mr. Manish Soosai Mudaliar, Associate Director (Programme development), SAATHI; Nagpur, Maharashtra, November 2011

Dr. Annamma Thomas, Head of Obstetrics and Gynecology department, St John's Hospital Bangalore (public-private partnership); Bangalore, Karnataka, October 2011

Mr. Rakesh Kumar, PPTCT counsellor, Ramaiya Hospital; Bangalore, Karnataka, October 2011

Dr. Suresh Kankananner, Asst. Professor, Bangalore Medical Collage Research Institute and Hospital, OBGYN, Vani Vilas Maternity Govt. Hospital; Bangalore, Karnataka, December 2011

Dr. Neelam Singh, Private practitioner (gynaecologist); Lucknow, Uttar Pradesh, October 2011

Anonymous, Leading public hospital in Lucknow, Uttar Pradesh, October 2011

Anonymous, Chief pathologist, Satyam Diagnostics Center; Lucknow, Uttar Pradesh, October 2011

Maternal health and women's groups

Ms. Sudeepta Mukherjee, Advisor, CEDPA, India; New Delhi, January 2011

Dr. Abhijit Das, Executive Director, Center for Health and Social Justice; New Delhi, January 2011

Policymakers

Dr. A.K. Gupta, Additional Project Director, Delhi State AIDS Control Society; New Delhi, October 2011

Anonymous, Government agency; Lucknow, Uttar Pradesh, October 2011

Multilaterals

Ms. Ivonne Cameroni, Chief HIV Department, UNICEF India Country Office; New Delhi, December 2010

Dr. Charles Gilks, UNAIDS Country Coordinator, UNAIDS India; New Delhi, February 2011

Dr. Polin Chan, Country Officer (HIV), World Health Organization-India; New Delhi, January 2011

FOCUS GROUP DISCUSSIONS

CATEGORY	PLACE	DATE
Four representatives from Delhi Positive Women Network, ages 27–35 years	New Delhi	August 2011
Five women living with HIV, ages 25–35 years. One of them was pregnant and accessing PPTCT service at a public hospital and one was a new mother with a 10-month-old girl.	New Delhi	November 2011
Eleven women living with HIV, ages 21–35 years. Five of them were pregnant and two had children less than three years of age.	Nagpur, Maharashtra state	October 2011
Fourteen sex workers living with HIV from Ashraya (network of HIV-positive sex workers), ages 25–50. All but one were married; eight had children. Most had undergone primary education but few had continued to 10th grade.	Mysore, Karnataka state	October 2011
Four women living with HIV, ages 24–30. Two were pregnant and accessing ANC care in government hospitals in Lucknow. One had just delivered a child, and one had a five-year-old child.	Lucknow, Uttar Pradesh	October 2011

ANNEX 1

CHARTER OF DEMANDS

The Charter of Demands was initiated by the MTT9 team during a training and advocacy strategy meeting with partners in November 2011 where the initial findings of the research was shared.

MY HEALTH, MY CHOICE, MY CHILD, MY LIFE!

Women demand the roll out of a comprehensive national action plan to end vertical transmission of HIV in India

Globally, momentum has been built to reinvigorate efforts to reduce maternal and infant mortality and improve maternal health including for women living with HIV. Nationally, women and children have been the stated priority of the government HIV programme since the beginning. The Indian Constitution guarantees the right to equality for all women and the right to life and health of all. In order to succeed in meeting these goals, civil society, especially women and mothers living with HIV, must be engaged and listened to, as we know the on-the-ground realities in the communities we live and work in.

Countries across the world are revising their national plans on preventing vertical transmission of HIV in order to meet the globally agreed goals of reducing the number of new HIV infections among children by 90% and reducing the number of AIDS-related maternal deaths by 50% by 2015. India is one of the 22 priority countries where the gap between the need for and access to vertical transmission services is amongst the largest in the world. Yet, we see no urgency or political will to try and bridge this gap.

We the undersigned,¹²⁸ put forth the charter of demands below, and call on the Indian government to act on their commitments and urgently roll out a national action plan for ending vertical transmission of HIV – that is comprehensive, that uses the best tools science has to offer, and that ensures women rights are upheld.

- **Place women at the centre of PPTCT programme:** It is the inherent right of all women, including those living with HIV, to have universal access to comprehensive health care including access to HIV prevention, treatment and care, reproductive and sexual health and maternal health services. We demand that the national PPTCT plan be reviewed and implemented along the comprehensive four-prong strategy recommended by the United Nations.¹²⁹
- **Provide quality counselling services:** Peer support and counselling should be introduced in the context of PPTCT services to enable women living with HIV to comfortably discuss their issues. We urge that the scope and quality of counselling services for women living with HIV be enhanced to include issues related to reproductive and sexual health and rights including information and processes related to various nutritional schemes and aspects.
- **Protect, promote and fulfil the right to reproductive and sexual health:** Women living with HIV are often denied the right to sexual and reproductive choices, including in healthcare settings, and strategies

¹²⁸ Signatures are currently being collected in support of the charter.

¹²⁹ UNAIDS. *HIV in Asia and the Pacific: Getting to Zero*. 2011. Available at: http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/20110826_APGettingToZero_en.pdf

to end this must be part of the PPTCT programme. A full range of reproductive and sexual health services including information, advice, services and tools for contraception, abortion, screening and early treatment of cervical cancer, STI diagnosis and treatment and assisted reproductive technologies must be made available to all women including women living with HIV.

- **Ensure voluntary and confidential HIV testing for women who are pregnant:** Voluntary and confidential HIV testing combined with quality counselling services for women who are pregnant must form the bedrock of the government programme. Since women are most likely to be tested first for HIV, clear partner notification guidelines for healthcare workers in the public and private sector should be adopted that also take into account the likelihood of violence or abandonment for the woman if her status is revealed to her partner and family. In addition, any integration planned with the National Rural Health Mission or other health programmes to broaden the provision of services must determine how the confidentiality of women and couples living with HIV will be maintained.
- **End the use of single-dose nevirapine:** Given that it is less effective and compromises future treatment options for women living with HIV, the continued use of single-dose nevirapine regimen as PPTCT prophylaxis is unacceptable. We demand that the use of single-dose nevirapine as PPTCT prophylaxis be ended immediately and replaced with more effective and less toxic, combination ARV regimens as per the 2010 WHO guidelines on prevention of vertical transmission of HIV. We insist that the government safeguard access to current and future treatment options for women living with HIV, their children and families including through continued updating of treatment guidelines and ensuring the affordability of medicines through generic production and supply.
- **Ensure correct infant feeding guidance:** The 2009 Infant Feeding Guidelines must be immediately adopted and rolled out. Roll out should be coupled with adequate training so that health care providers including counsellors provide correct and clear guidance to women living with HIV on the best infant feeding practice. Continued counselling and other support such as nutritional support must also be provided to help women practice exclusive breastfeeding.
- **Implement new ART guidelines:** We demand that the new national guidelines recommending initiation of ART for all pregnant women living with HIV and with CD4 counts below 350 cells/mm³ be implemented and rapidly scaled up with immediate effect without compromising the quality of services. Technical assistance must also be provided to the private sector to update them on the latest treatment and care and PPTCT guidelines for women living with HIV and accountability mechanisms put in place to ensure that these guidelines are adhered to.¹³⁰
- **Ensure HIV treatment for women in need and promote linkages to care:** We demand that greater focus is placed on improving the quality of PPTCT services so that referrals and linkages to treatment and care are strengthened and loss to follow up is minimized for women living with HIV who are pregnant or who are mothers in need of HIV treatment for their own health.

130 Revised guidelines for ART initiation in adults and adolescents, office memorandum, 2011

- **Meet the nutritional requirements:** Meeting the nutritional requirements of women who are pregnant and lactating is essential to reduce maternal and infant morbidity and mortality. Regular counselling on nutritional aspects and schemes and nutritional supplements must be provided to all such women and especially to pregnant women and mothers living with HIV.
- **Eliminate stigma and discrimination in the health sector:** The widespread stigma and discrimination against women living with HIV, including those belonging to marginalized groups such as sex workers and drug users, within health care settings must be eliminated. The training guidelines for paramedical staff and counsellors must be reviewed and modified urgently to address stigma and discrimination issues against people living with HIV. We urge the government to establish and enforce regulatory and accountability mechanisms to ensure stigma-free and discrimination-free services to women living with HIV at both public and private health settings and to provide avenues for grievance redress.
- **Enhance male partner involvement:** In many cases pregnant women tested for HIV, as part of antenatal services, are the first indication of HIV incidence in the family, and often, the woman's test result is the source of violence, stigma and discrimination against her within the family and the community. There is a need for innovative strategies to involve male partners throughout pregnancy, delivery and after, for the programme to be more effective as well as to help reduce stigma and violence. Couple testing and counselling is essential but must be contingent on the consent of the woman.
- **End violence against women living with HIV:** Violence against women living with HIV must be acknowledged and addressed as part of PPTCT programmes and ARV services. Health care providers must be sensitized on identifying, addressing and protecting the reproductive and sexual rights of women living with HIV. Violence within health care settings (such as coerced sterilization of positive women and advice against having children because of HIV status) must be also acknowledged and addressed through training and accountability mechanisms within the health care system as well as the legal system.
- **Create the legal and policy space for upholding the rights of women living with HIV:** We demand that the HIV/AIDS Bill which has been languishing with the government since 2006 and which addresses issues of discrimination, access to treatment, legal rights for women living with HIV, access to services for pregnant women and provides legal redress for the violation of rights of women living with HIV among other issues be finalized and presented in Parliament in an open and transparent manner at the earliest.
- **Ensure participation of stakeholders in decision making:** We demand that women living with HIV are provided opportunities to participate meaningfully within all legal and policy institutions including national, state and district level AIDS committees as well as any National Steering Committee set up to implement the 'Global Plan Towards Elimination of New Infections in Infants by 2015 and Keeping their Mothers Alive'. In addition, investments must be made towards building their technical capacities to engage meaningfully into such decision-making processes.

ACRONYMS AND ABBREVIATIONS

The following acronyms and abbreviations may be found in this report:

ANC	antenatal care
ART	antiretroviral treatment
ARV	antiretroviral
AZT	azidothymidine
ICTC	Integrated Counselling and Testing Centre
ICW	International Community of Women living with HIV/AIDS
IUD	intrauterine device
NACO	National AIDS Control Organisation (India)
NACP	National AIDS Control Programme (India)
NGO	non-governmental organization
OI	opportunistic infection
PEPFAR	U.S. President's Emergency Plan for AIDS Relief
PPTCT	prevention of parent-to-child transmission
sdNVP	single-dose nevirapine
SRH	sexual and reproductive health
STI	sexually transmitted infection
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNGASS	United Nations General Assembly Special Session
UNICEF	United Nations Children's Fund
WHO	World Health Organization

Note on text: All "\$" figures are U.S. dollar amounts, unless otherwise specified.

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Missing The Target 9, March 2012
www.itpcglobal.org



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