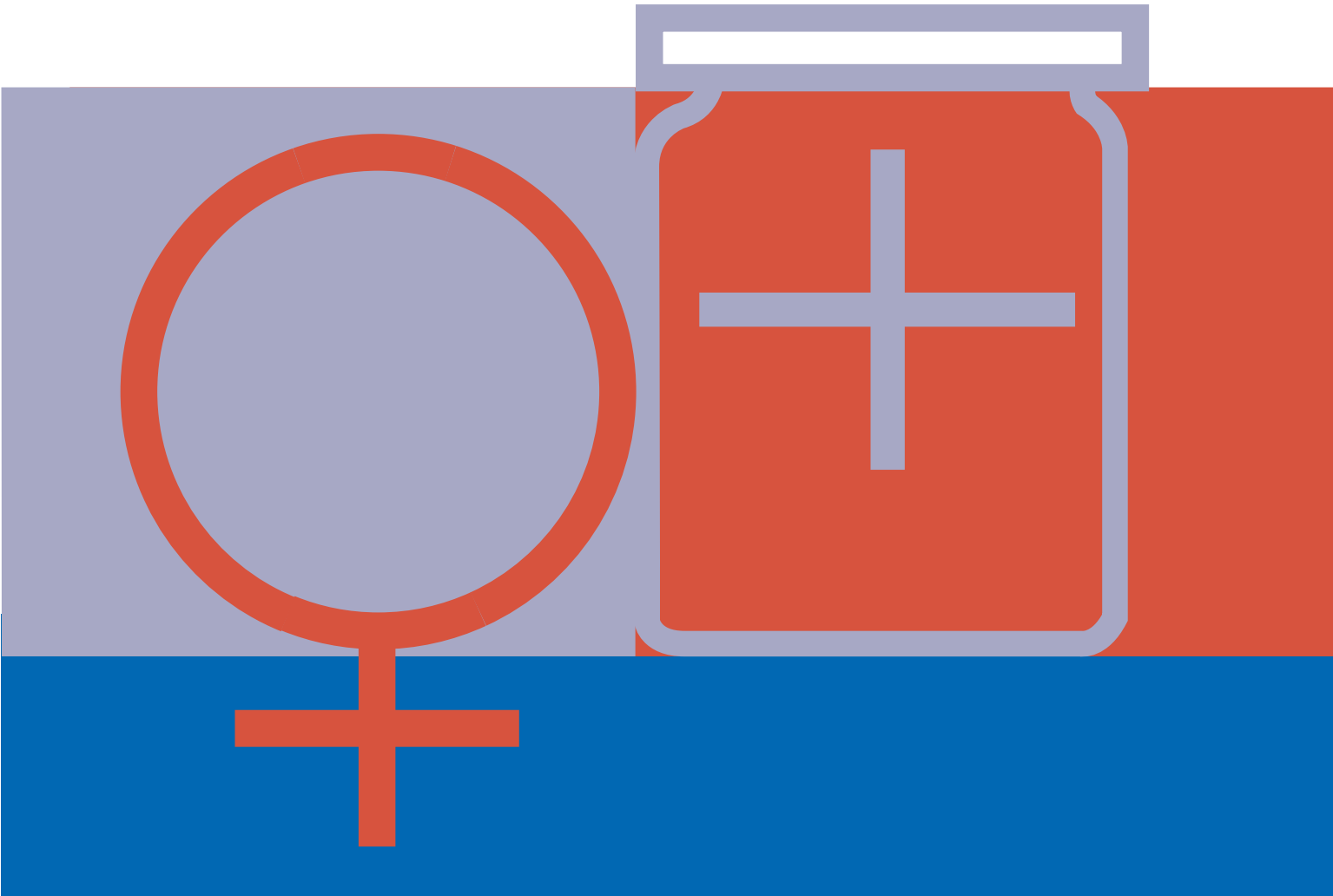
Women's Empowerment, HIV and the MDGs: Hearing the Voices of HIV Positive Women

Assessment of India's Progress on
MDG 3 and MDG 6, December 2010



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Foreword

Gender equality is the key driver in the Millennium Development Goals (MDGs) and is recognised both as an important goal in itself and central to achieving all the MDGs. However, a major challenge today is turning this understanding of gender equality into commitment and desired action.

UNDP's Human Development Report (HDR) 2010 reiterates the above challenge. The new inequality-adjusted HDI, measuring inequality across 139 countries shows that India loses 30% overall on the inequality-adjusted HDI, including 41% in education and 31% in health. India ranks 122 among 138 countries for which the gender inequality measure has been calculated. Reproductive health has emerged as one of the largest contributor to the gender inequality index.

One of the adverse impacts of gender inequality is visible in the context of HIV/AIDS. Women face barriers while accessing prevention and care services due to their lack of access to and control over resources, child-care responsibilities, restricted mobility and limited decision-making power. Women also tend to assume the major share of care-giving in the family, including for those living with and affected by HIV.

A study in India indicates that as high as 90% women living with HIV were in monogamous relationship. They got the infection through their husbands and yet many, especially those living with HIV, experience stigma, lose inheritance, possessions, livelihoods and even their children when their partners die. As high as 80% HIV widows lose their marital homes.

Recent estimates of the National AIDS Control Organisation indicate a decline in overall HIV prevalence in India. The last five years have borne witness to unprecedented achievements in improving access to HIV treatment. However, according to the UNGASS 2010 India report, prevalence among most at risk groups such as intravenous drug users, female sex workers and men who have sex with men are on the rise especially in the southern states.

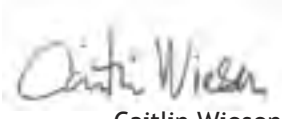
Most of HIV/AIDS-related advocacy has focused on preventing perinatal transmission and expanding access to antiretroviral drugs (ARVs). In comparison, relatively less attention has been paid to ensuring sexual and reproductive health needs and rights of the population at high risk of HIV infection and women.

UNDP recognises that critical steps toward halting and reversing the spread of HIV transmission can only begin by recognising women rights to their own body and sexuality, addressing perceptions and expressions of masculinity that undermines this right, as well as reducing sexual and gender-based violence and steering away from traditional practices that heighten their vulnerability to HIV. One of the ways to achieve the above objective is to ensure that vital voices of women expressing their needs and opinions are heard and encouraging conditions for women to participate in decision-making are created at all levels.

Towards the above objective, UNDP organised focused group discussions with women living with HIV from 12 States to listen to their voices on two critical Millennium Development Goals (MDGs) viz. Goal 3 relating to women empowerment and Goal 6 regarding HIV, Malaria and TB.

Women in the consultations reported that they experienced high levels of stigma and discrimination in various settings, including in the health care settings. Breach of confidentiality and physicians avoiding physical contact was not uncommon. Almost all women reported that though there are legal provisions safeguarding property and inheritance rights, it does not always translate into reality.

This document captures the voices of the women, on the issues and challenges, stigma and discrimination they face. It is a powerful testimony that there is still a long way to translate commitments into action.



Caitlin Wiesen
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Abbreviations

ANC	Antenatal Clinic
ART	Anti-Retroviral Treatment
ARV	Anti-retroviral
BCC	Behaviour Change Communication
BSS	Behavioural Surveillance Survey
CBO	Community-Based Organisation
CCC	Community Care Centre
CSO	Civil Society Organisation
CST	Care, Support and Treatment
DIC	Drop-in Centre
FSW	Female Sex Worker
FGD	Focus Group Discussion
GFATM	Global Fund for AIDS, TB and Malaria
HIV	Human Immunodeficiency Virus
HRG	High Risk Group
ICTC	Integrated Counselling and Testing Centre
IDU	Injecting Drug User
IEC	Information, Education and Communication
ICDS	Integrated Child Development Services
INP+	Indian Network for People Living with HIV/AIDS
INR	Indian Rupee
LAC	Link ART Centre
MTR	Mid-Term Review
MWCD	Ministry of Women and Child Development
MSM	Men who have Sex with Men
OI	Opportunistic Infection
ORW	Outreach Worker
NACO	National AIDS Control Organisation
NACP	National AIDS Control Programme
NGO	Non-Governmental Organisation
NRHM	National Rural Health Mission
OST	Oral Substitution Therapy
PLHIV	People Living with HIV
PPTCT	Prevention of Parent-to-Child Transmission
PWN	Positive Women Network
RRE	Red Ribbon Express
S&D	Stigma and Discrimination
SACS	State AIDS Control Society
STI	Sexually Transmitted Infection
TI	Targeted Intervention
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNGASS	United Nations General Assembly Special Session
WHO	World Health Organization

Terms Used in the Document

Integrated Child Development Services (ICDS) Scheme - The ICDS Scheme was launched in 1975. It provides a package of services to children aged 0-6 years for early childhood development.

Anganwadi Worker - Under the ICDS, one Anganwadi worker (AWW) is allotted to a population of 1000. AWW is trained in various aspects of health, nutrition and child development.

ASHA - The National Rural Health Mission (NRHM) provides every village with a trained female community health activist – 'ASHA' or *Accredited Social Health Activist*.

Auxiliary Nurse Midwife (ANM) - The ANM holds weekly/fortnightly meeting with ASHA, and provides on-the-job training by discussing the activities undertaken during the week/fortnight.
Indian currency Rs 45 = approx US $ one

Janani Suraksha Yojana (JSY) - It is a centrally sponsored scheme aimed at reducing maternal and infant mortality rates and increasing institutional deliveries in below poverty line (BPL) families. JSY falls under NRHM and covers all pregnant women belonging to households below the poverty line, above 19 years of age and up to two live births.

Introduction

The Millennium Development Goals (MDGs) are the most broadly supported, comprehensive and specific development goals the world has ever agreed upon. These eight time-bound goals include targets for reducing poverty, hunger, maternal and child mortality, disease, inadequate shelter, gender inequality, environmental degradation and the Global Partnership for Development.

Adopted by world leaders in the year 2000 and set to be achieved by 2015, the MDGs are both global and local, tailored by each country to suit specific development needs. They provide a framework for the international community to work together towards a common end, making sure that development reaches every human being everywhere.

More than 25 years into the HIV and AIDS epidemic, gender inequality and unequal power relations between and among women and men continue to be major drivers of HIV transmission. Gender inequality and harmful gender norms are not only associated with the spread of HIV but also with its consequences which affect women especially HIV positive women, such as stigma and targeted violence.

Effectively addressing the issues related to needs and rights of women and girls in the context of HIV requires a comprehensive response that is grounded in the experience informed by evidence and based on the promotion and protection of the human rights of all women and girls. It is, therefore, clear that if we are to achieve progress against MDG 3 (Gender Equality and Empowerment of Women), it is essential that progress against MDG 6 (Combat HIV/AIDS, Malaria and other Diseases), be also achieved. HIV and gender-related vulnerabilities of women and girls need to be addressed as a central element of HIV and AIDS programmes and is an urgent priority for national governments.

This report aims to capture progress achieved towards meeting MDG 3 and MDG 6 in special context and in relation to community perspectives. A desk review of India's MDG Report 2010 and UNGASS Report 2010 was undertaken to compare data and get insight into issues related to women living with HIV in India. In addition, UNDP India undertook six focus group discussions (FGDs) in different parts of the country to obtain perspective of women living with HIV.

It was envisaged that this work will contribute to the discussions held at the 2010 UN Millennium Development Goals Summit, in September this year. In addition, this report is expected to serve as an important guide to identification of focus areas to accelerate progress towards meeting MDGs 3 and 6 by their target date of 2015.

Millennium Development Goals with Special Reference to Goals 3 and 6

In 2000, the Millennium Declaration was adopted by 191 member states of the United Nations. To make the commitments more manageable, eight MDGs were identified, and a time frame set for reaching these goals by 2015, underlining urgency of the commitments. The Goals are:

- Goal 1: Eradicate extreme poverty and hunger
- Goal 2: Achieve universal primary education
- Goal 3: Promote gender equality and empower women
- Goal 4: Reduce child mortality
- Goal 5: Improve maternal health
- Goal 6: Combat HIV/AIDS, malaria and other diseases
- Goal 7: Ensure environmental sustainability
- Goal 8: Develop a global partnership for development

To map and assess progress on gender equality, women's and girls' human rights and achievements on HIV, two MDGs are of significance – MDG 3 and MDG 6. While all the MDGs are important for gender equality and women's empowerment, the third Goal focuses specifically on achieving these outcomes. MDG 3 is to promote gender equality and empower women. MDG 6 is to combat HIV, Malaria and other diseases. There are three specific target areas for this Goal, the first two of which relate directly to HIV. These are:
Target 6a: Halt and begin to reverse the spread of HIV/AIDS
Target 6b: Achieve, by 2010, universal access to treatment for HIV/AIDS for all those who need it

Gender inequality and harmful gender norms are not only associated with the spread of HIV but also with its consequences, such as violence targeted toward HIV positive women. Intimate partner violence, challenges in negotiating safer sex, unequal access to primary and secondary education, unequal access to income and control over household assets and other manifestations of gender inequality are closely associated with the risk of women becoming infected with HIV. While a variety of initiatives for women to reduce inequality have been implemented by national and state led governments, there is, however, much to be done in terms of coverage, intensity, impact and quality.

HIV and AIDS contribute to the perpetuation of gender inequality. Experience world wide confirms that women tend to suffer more than men from HIV-related stigma, in terms of loss of respect, employment, protection and property rights that places women at a greater disadvantage in communities.

The last five years have witnessed unprecedented achievements in improving access to HIV treatment. According to the latest UNAIDS global epidemic update, anti-retroviral treatment (ART) coverage in 2008 was 42%, up from only 7% just five years earlier. Furthermore, the annual number of new HIV infections globally has declined. The total number of people living with HIV (PLHIV) in 2008 reached an estimated 33.4 million. Of these, around half were women and girls. Thus, while much has been achieved globally, nationally and locally against AIDS, much remains to be done if this MDG is to be reached in the foreseeable future.

India's Progress in Women Empowerment and Combating HIV

India's response to the changing nature of the HIV epidemic and status of women is reflected, both in the India's MDG Report 2010 as well as the UNGASS Report 2010.

India's national development plan for 2007-12 has reaffirmed its commitment to attain the MDGs. The national targets as stated in the five-year plan are dovetailed to that of the MDG targets. However, to a certain degree, these envisage faster results when compared to what the MDGs are defined to attain.

India is poised to make a quick turnaround in the elimination of gender disparity at the primary and secondary education levels, an arena where India has not made much progress until now. Gender Parity Index (GPI) 10 ratios in primary and secondary education are 0.94 and 0.82 respectively in 2006-07, up from 0.76 and 0.60 respectively in 1990-91 which is significant to achieving gender parity in enrolment by 2015. The ratio of literate women to men in the age group 15-24 years tends to exceed 1 by 2015, implying attainment of gender parity in literacy by 2015.These can be major gains for women in acquiring access to learning and development of skills, economic independence, authority of decision making and self-determination.

Empowerment of women is still a major concern and requires urgent attention. Employment of women and their participation in the process of decision making remains far less than that of men and the disparity is not likely to be eliminated by 2015. The GPI in tertiary education however, remains sluggish, moving from 0.61 in 1990-91 to 0.69 in 2006-07. On the other hand, the degree to which the labour market in the country is opening up to women in industry and service sectors, as measured by the share of women in wage employment in the non-agricultural sector, has increased by only six percentage points between 1990-91 and 2004-05, from 13% to 18%.

India is geographically large and culturally diverse as a country. The prevalence of the HIV epidemic is low and primary drivers of HIV are unprotected paid sex/commercial sex work, unprotected anal sex between men and sharing of injecting equipment among injecting drung users (IDUs). Another section of individuals considered at high risk of HIV are truck drivers and single migrant men.

More than 90 percent of women acquire HIV from their husbands or their sexual partners, not due to their own sexual behaviour, but because they are partners of men who belong to the high risk group (HRG). The wider implication of this situation is that in almost six percent of cases in 2008, the route of transmission of infection was from mother to child. Therefore, one of the most important indicators depicting the spread of HIV among the general population in India is the HIV prevalence among pregnant women between the age group of 15-24 years, which has seen a decline from 0.86% in 2004 to 0.49% in 2007. As per the DLHS 52.2% of married women had heard of HIV and in 2007-08, the number had gone up to 58.6%. Condom use and correct HIV awareness was higher among urban women than rural women.

The estimated adult HIV prevalence has come down to 0.34% in 2007 from about 0.45% in 2002. Percentage incidence of HIV cases among all types of high risk people observed at the sentinel sites across the country has showed a discernible declining trend in the last five years. India is witnessing mini-epidemics where HIV prevalence is declining in certain and increasing in others, both geographically and demographically. For example, there is a decline in the epidemic among female sex workers (FSWs) in the South Indian states, but rising trends are evident in the North-East. HIV prevalence among Men who have sex with men (MSM) nationally has seen an upward trend.

Methodology for Data Collection and Compilation of the Report

UNDP's regional office conducted a situation analysis to identify critical issues related to women's vulnerability to HIV in the region. This was used to develop a list of the critical HIV-related indicators (see below) for achieving MDG 3 and MDG 6. Based on this list, the consultant formulated key questions around how these indicators have contributed to progress in the two MDG areas, and what country-specific responses have been. UNDP India identified state networks from Indian Network for People Living with HIV (INP+) and Positive Women's Network (PWN) to seek experiences for FGDs in which the "country picture" was presented and discussed by participants and the key questions were raised and discussed.

1. Reduce sexual transmission of HIV
2. Prevention of parent-to-child transmission of HIV
3. Assured access to treatment
4. Access to harm reduction technologies
5. Removal of punitive laws, policies, practices, stigma and discrimination
6. Eradicate violence against women
7. Empower young people to prevent HIV
8. Enhanced social protections for people affected by HIV
9. Guarantee sexual and reproductive rights
10. Ensure women's property and inheritance rights
11. Increase girls' enrolment in secondary education
12. Improve women's access to income and control over household assets
13. Promote social norms that support the changes identified above.

A desk review of India's MDG Report 2009 and UNGASS Report 2010 was undertaken to compare data and receive insight into issues related to women living with HIV in India. Women living with and affected by HIV are uniquely placed to assess and analyse their region's response to gender inequality and HIV, therefore, UNDP India hired a consultant who with UNDP staff undertook six Focused Group Discussions in the cities of Ahmedabad, Pune, Chennai, and Guwahati to obtain perspective of women living with HIV from the state networks of INP+ and PWN. The team conducted FGDs using a semi-structured interview guide to get a deeper understanding of the full range of issues at play. Inputs sought from women living with HIV gave a first-hand experience of gender inequality's impact on HIV vulnerability, and vice versa.

Analysis of the FGD Data together with Other Available National Data

Empower young people to prevent HIV

Information related to sexuality and sexually transmitted infections (STIs) is not widespread among girls and boys while those living in rural areas have even lower access to it. FGDs highlighted that topics of "sexuality" and "HIV" are still treated like a taboo among Indian families. The parents are not comfortable speaking on sex related issues, hence, do not provide adequate sex education.

According to India's UNGASS progress report, under the Adolescence Education Programme (AEP), 288,000 teachers were trained in counselling for HIV and 47,000 schools have been covered to impart the knowledge and skills to their students during 2009-10. A majority of the participants observed that in most states, the sex education programme which catered to grade eighth to tenth students was discontinued three years ago. None of the FDG participants, their relatives or children had received life skills education in schools. Participants from North-East unanimously stated that schools in their region did not provide sex education.

About 80% participants were of the opinion that schools and colleges have recognised the need for educating and informing their students because of which they call upon positive networks to conduct awareness sessions on HIV and sexuality. Positive speaking is also a part of the National Service Scheme (NSS) programme for the youth. While the initiative is good, there are fixed parameters attached to it, for example the school authorities insist on not demonstrating condom use while colleges seem to have no objections to such demonstrations. A woman from the Tamil Nadu Network shared her experience:

"We find that young men have several misconceptions. They often consume alcohol during village festivals and engage in unprotected sex with eunuchs. They think they can get HIV only from women."

Initiatives like red ribbon clubs (RRCs) for youth in colleges and schools, blood donation camps, street plays and music bands educate youth on HIV transmission. Responses showed that non-governmental organisations (NGOs) and networks collaborate with youth clubs mainly in cities and occasionally in villages. About 60%

Last year in the Alleppey district, three girl students committed suicide due to the circulation of their photographs in compromising positions.

In Kozhikode, a 13 year old son of negative parents was infected after sexual abuse by a teacher.

respondents said that participation in the red ribbon express (RRE) which carries HIV related messages is mainly limited to the organising NGOs and network staff.

There was a mixed response to the mass media messages and TV programmes on sex education. While the participants agreed that a lot of information and messages are relayed by media but they were not satisfied with the quality of information. Moreover, a common consensus was that most of the messages are general and very few are youth focused like "jawan hoon, nadan nahin" (I am young but not naive).

It was also noted that boys have greater access to information via different mediums such as the internet. Girls mainly get information through TV, magazines and peer groups. About 20 % of participants said that since they had been affected or infected by HIV, so they provide sex education to their children. A few examples where communities take the initiative in providing information are:

- Christian communities in Kerala conduct three-day classes for girls just before their marriage.
- Self-help groups (SHGs), anganwadi workers (AWWs), Mahila Samiti societies and NGOs provide information to girls on HIV, drugs, anaemia, reproductive health and nutrition.

Availability and use of condoms

In Palghat district, a positive man refused to use condoms and hence, his wife got pregnant several times. She also underwent several abortions before the childbirth.

Almost all the participants were aware of condoms and their availability in NGOs, government clinics, shops, pharmacies, integrated counselling and testing centres (ICTCs), ART centre, prevention of parent-to-child transmission (PPTCT) centre, Family Planning Association, positive networks and boxes placed in public toilets and village structures such as gram panchayats. The accredited social health activists (ASHAs) give out condoms in rural areas. However, accessibility to and understanding of condoms in rural areas is poor. UNGASS report notes that during 2009-10, the condom social marketing programme was scaled up to cater to 294 districts; 4.64 lakh condom outlets serviced by the programme distributed 23.4 crore pieces of condoms till January 2010.

The fact that no woman in the group had ever picked or procured a condom proves that women are shy to publicly access condoms and married women consider condoms "dirty' and feel that condoms are a man's prerogative. Generally condoms are seen as instruments which are used by women in the field of sex work. A woman from the Kerala Network shared, 'If women insist on condom usage, they are accused of carrying some virus or disease".

Participants shared that HIV positive couples have the tendency to not use condoms in order to have children.

The National AIDS Control Organisation (NACO) runs a female condom programme in: Andhra Pradesh, Tamil Nadu, West Bengal and Maharashtra. The United Nations Population Fund (UNFPA) supports the Population Services International (PSI) in implementing female condom scale up programme in Rajasthan, Bihar, Jharkhand and Orissa. Till January 2010, approximately 600,000 female condoms were reported sold. However, FGDs showed that few participants were aware of female condoms underlining that limited information is available on female condoms. Female condoms are expensive, and are not easily available. Another testimony is: "I have heard that they are very painful to use". Another reason for the lack of widespread usage of female condoms mentioned by a few participants was that women lack the negotiating skills needed to convince men, who generally do not wish to give up their position of control in a sexual encounter.

In Ahmedabad, a HIV negative wife knew the HIV status of her husband and was being pressurised by the unaware parents to have a baby, so much so that the wife was ready to be infected by HIV as long as they could have a child. They went for a counselling session at GSNP+ where they were referred to PPTCT. Here they were advised for IVF.

HIV testing and STI management

NACO has strengthened convergence with the National Rural Health Mission (NRHM) for STI treatment. According to UNGASS 2010 report, during 2009-10, approximately 6.8 million people with STI were managed by NACO across the country. The number of ICTCs was expanded from 2815 in 2005-06 to 5135 in 2009-10. This increase was possible as barriers such as timing of ICTC, staff attitudes towards HRG, inconvenient location of testing facilities were addressed.

Most FGD participants were aware that STI treatment, ART and ICTC are available through government, NGOs and private health providers.

Fear of disclosure of status seemed to be the main barrier to access testing and treatment. About 80% of them felt that confidentiality is usually maintained in government hospitals. However, because one needs to go to an ART centre for registration and possible treatment, there may be a breach of confidentiality. North-Eastern participants felt that the government health institutions often do not maintain confidentiality.

While about 20% of the participants did raise a question on the quality of counselling in Government ICTCs but about half of the participants were happy with group counselling provided at ICTCs. The private facilities apart from being expensive, lack counselling services and provide little respect to confidentiality.

All groups observed that counselling on STIs was a rarity in both government and private hospitals and in cases requiring partner notification, the management had not followed up. Eighty percent of the participants said that they would prefer to go to a private clinic for STI treatment than visit government clinics due to lack of privacy, unavailability of female doctors as well as fear of breach of confidentiality. Other constraints faced by women for being tested are: limited access to testing centres, lack of information, time, childcare, resources, transportation, and fear of discrimination.

Prevention of parent-to-child transmission of HIV

In Trivandrum Medical College, a HIV positive woman who had delivered a baby was asked to breastfeed the child. Fortunately, a woman from the network, who was present in the ward at that time, was able to convince the hospital authorities not to feed the baby. She also bought alternative feeding material using her personal money.

UNGASS report notes an overall decline in HIV prevalence among antenatal care (ANC) clinic attendees in high prevalence states; however, there is an increase in some low and moderate prevalence states. PPTCT services are provided at 5,135 ICTCs to pregnant women who access hospital/health facilities where these centres are located. Whilst in 2007 approximately three million women were counselled and tested, it increased to approximately 5.5 million in 2009. Despite the scaling up of the programme, only 20% out of the estimated 27 million annual pregnancies were counselled and tested for HIV in 2009.

Most FGD participants had a good understanding of PPTCT and were aware that in PPTCT centres, pregnant mothers are tested for HIV. They were also able to mention other sources of information on PPTCT – positive networks, NGOs, AWWs, ASHAs and village health nurses. In the groups from high prevalence states, most mothers had been to ANC clinics, while those from low prevalence states like Kerala and Meghalya lamented the lack of information and availability of PPTCT services.

Almost all participants said that there is no pre-test counselling though post-test counselling is done if needed. Information given to pregnant women is limited to nevirapine prophylaxis and breastfeeding. Also, follow up with the spouses does not happen. The lack of PPTCT follow up has suffered a setback with the end of Global Fund for AIDS, TB and Malaria (GFTAM) Round 2 project which provided outreach workers (ORWs) with resources needed for following up. However, sometimes the network staffers follow up on their own accord and without any support. The hospitals and the networks are sometimes unable to work together because the hospital authorities feel that the networks are a nuisance as they protest against stigma and encourage hospital delivery.

Women who are economically stable generally prefer private hospitals for their deliveries. However, here the pregnant women are tested for HIV irrespective of their consent or lack of it. If detected positive, they are referred to government hospitals for delivery. In other cases, a caesarean section is done even if a normal delivery was possible.

According to the UNGASS report, 40% of the deliveries in India are institutional. Rural areas account for 31% of this percentage whereas urban areas account for the remaining 69%. Participants in the group discussion were of the opinion that women do not want to avail government hospital facilities because of the rude behaviour of the staff. In many cases, pregnant women who are tested HIV positive, often deliver babies in a different facility from where they were tested. If delivery takes place in a different geographical region from the place of residence then the patient loses out on PPTCT services. A point which came up strongly was that in both government and private hospitals, positive women are advised to abort the pregnancy even if the pregnancy is in the second trimester.

The group was of the opinion that the PPTCT services have definitely reached out and scaled up extensively. However, the impact would have been more provided the service was complemented by appropriate follow up and tracking of cases.

Nutrition supplements for women and children

Through various general schemes like ICDS, women and children are provided with supplements such as cooked food, flour, powder, chocolates but this is limited. The biggest barrier to linkages is confidentiality and disclosure of HIV status, something the link workers scheme in India is also struggling with. FGD participants unanimously felt that much more needs to be done especially in the North-East. Quality of nutrition also needs to be improved.

"I deny myself of nutritional food to feed my baby", said a woman.

Access to treatment

According to the UNGASS report, implementation of the ART Universal Access Programme has been successful and some targets under the National AIDS Control Programme (NACP-III) are likely to exceed expectations, for example, the number of ART centres and adults alive and on ART. In response to limited or

"I was not aware of ART when my husband was diagnosed with HIV in 2006. His CD4 count was 19 and I feared that he might die. I took him home, gave him a good diet and he started ART. His CD4 count is now 1024 but his one eye has lost sight making him irritable. The side-effects scare me." - A woman from Tamil Nadu Network.

poor access to ART centres, 208 Link ART Centres (LACs) have been established. Second line ART was started on a pilot basis at two centres in 2008 and as of January 2010, there are 970 patients on second line ART. There is provision of prophylaxis and treatment of opportunistic infections (OI) at tertiary and district hospitals. A total of 63,889 children living with HIV are registered at ART centres out of which, 18,763 were receiving ART as of January 2010. Ten orphanages have been set up in collaboration with the Ministry of Women and Child Development and the Ministry of Social Justice and Empowerment.

Most participants were well informed about ARV and stressed on its importance.

"*If you want to live, ART is a must. We need ARVs to be healthy, so that we can be saved from OIs and can live longer.*"

Nearly half of the positive women in the groups were on ARVs while some were delaying the start of ARV by eating nutritious diet out of the fear of side-effects and resistance to ARV.

In case of HIV positive pregnant women, information is limited to prevention of HIV transmission to the child. Women do not want to initiate ART prophylaxis or therapy in fear that they may harm their unborn child. It is not possible for working women to take leave every month, to collect ART without disclosing their status. There are several obstacles in the path of continuing ARV for women after delivery. Their relatives are not aware of their status and it is difficult to explain the need to visit the hospital for ART collection.

While ART is provided free of cost by the government since 2004, the travel involved in accessing the services proves to be a burden for the patients. FGDs revealed that ART collection centres can range from 7-100 km from the place of commencement and the expenditure is approximately US$ 2-6 per visit. This problem is compounded by the fact that the fixed timings of the facilities may force patients to stay overnight either at community care centres (CCCs) or on hospital floors. The medication for OI is often not available and the burden of purchasing medicines solely rests on the patients. Although, laboratory support and tests such as CD4, scans etc. are free for the patients but these are also subject to availability because resources such as testing kits and other equipment are very often not in stock.

Setting up of LACs in districts has reduced travel costs. However, proximity of the LACs to the place of residence may discourage patients to access LAC because it

In Gujarat, under a government initiative the to-and-fro journey of the client for getting the treatment is reimbursed. This together with the maintenance of confidentiality during the travel, because for availing to the subsidised ticket one does not need to reveal their HIV status, acts as a motivating factor. This only solves a part of the problem because issues like delay in the reimbursement process for an alternative mode of travel, other than public, have not been considered.

brings about the fear of status disclosure as well as the fact that LAC does not pay for travel.

Care and support

FGD participants noted that PLHIV get good care and support from NGOs, positive networks, CCCs, drop-in centres (DICs) and NGOs. While UNGASS report says that the care, support and treatment (CST) services have significantly improved in the country, participants were of the view that government services are limited and not satisfactory as funds for care and support are far less in comparison to those available for prevention. The closing down of some care and support programmes gives substance to this opinion of the participants.

Stigma and discrimination in healthcare settings continues to be a barrier to treatment. Management issues act as a stumbling block in access and provision of treatment. NACO has placed ART centres in government hospitals but these are monitored by a medical college leading to a lack of coordination and hierarchical issues. Presence of inexperienced doctors in the ART centres and a high turnover of doctors is another issue. Patients who are on second line treatment in low prevalence states have to go to other states for treatment which involves a lot of strain and travel expenses.

HIV among IDUs and sex workers

Participants from most states except those in the North-East did not know much about IDUs and harm reduction. North-Eastern participants mentioned the availability of safe needles, condoms and opioid substitution therapy (OST) using Buprenorphine in Nagaland, Manipur and Meghalya but the number of women availing these services is very low in comparison to men. The IDU community is highly stigmatised and this stigma worsens if the IDU is also a sex worker. Most members noted that NGOs are the only sanctum for an IDU. They treat IDUs fairly and provide services, information and support.

None of the FGD participants seem to have been involved in sex work. The participants said that sex workers do not participate actively in the network activities because they are scared to be identified with the network and this might affect their business. It was mentioned that awareness on issues like HIV, testing and other services is low among sex workers. Often network members are invited by Sex worker NGOs for awareness sessions on HIV. Sometimes, sex

In 2008 in Rajkot, a pregnant positive woman was brought to a government hospital as she was not attended by any nurse and was refused a bed. The patient delivered the baby in a corridor. The newborn was not cleaned. The positive network members helped the woman with the sanitation of the baby.

In Kohima, the network took a positive IDU to the hospital. He needed IV fluid but the government doctor said that he has HIV which is incurable so why give him IV fluid. The Network then took him to a private hospital.

workers do call up the positive network's helplines and ask questions. The sex workers in the North-East are very difficult to reach as they have hidden means of solicitation such as beauty parlours and even their own homes. Church holds is very judgmental towards the sex workers community. A woman from the Meghalaya network shared:

"A positive sex worker in Shillong came to me for help. I approached her community church which refused to help her as she was a sex worker."

REMOVAL OF PUNITIVE LAWS, POLICIES, PRACTICES, STIGMA AND DISCRIMINATION

Messages in the media regarding HIV

About 70% of participants mentioned the large scale communication campaigns launched by NACO such as RRE, *Zindagi Zindabad* or "Life is to Live". About half of the participants could recall the condom promotion campaigns such as *Jo Bola/ Samjha Wohi Sikander*. Participants also noted the awareness generation through advertisements in provincial newspapers and ground level activities such as rallies, poster and essay competitions as well as partnerships with the youth groups (Nehru Yuva Kendra) and other community-based groups.

Participants stated that portrayal of PLHIV is fairly good in the media and even celebrities come out in support. Sometimes incomplete information and misinterpretation of news can lead to misconceptions. There is no specific information with regard to women related issues.

There is a belief among general public that positive women are immoral.

While government owned channels telecast a large number of HIV programmes, private channels limit them to special occasions like World AIDS Day.

Disclosure of status and stigma and discrimination

FGDs showed the highest rate of HIV related stigma and discrimination in government healthcare settings where PLHIV face a lot of harassment by hospital staff and comments like "*Where have you brought this disease from*?". Doctors and nurses hesitate to touch PLHIV and often avoid operating upon PLHIV. A few participants reported of stigmatisation by ART counsellors. All FGDs brought forth a very high degree of stigma in dental care.

Participants mentioned that NACO has initiated a nurses training programme where network members train nurses on a PLHIV module. This helps dispel myths and misconceptions and at the same time also acts as a bridge between PLHIV and nurses. It also works on making them understand PLHIV issues in a non-threatening manner.

Network members are more open to sharing their status than others as being a network member instills them with confidence to deal with the situation.

"I can say that if I have HIV, you have diabetes. I can eat anything, you cannot eat sugar."

Participants said that they can lead a normal life despite HIV especially after they become part of the network as it minimises the fear of HIV. Most participants shared that initially they tried to hide their status.

"I did not tell the family and tore the test report."

"We do not tell that we have HIV but take names of other diseases like TB. People usually suspect those who are thin as PLHIV. So we take good care of ourselves, eat a nutritious diet and maintain a healthy weight."

Nearly 80% of the participants appeared to be more comfortable sharing their status with families and close friends than relatives and neighbours for the fear of stigma and discrimination. Some instances shared during the study, spoke of the absence of discrimination by the family when the husband was alive but the situation changed drastically with his death, wherein women faced a lot of stigma and mental stress.

"We have our siblings or children who are yet to be married/children studying in the school or college. They may suffer because of us."

While PLHIV in networks and NGOs have shared their status with their employers but others who do not belong to the networks have not shared it with colleagues or employers, and then PLHIV make excuses to ask for leave for the collection of ART. Most of these employers do not maintain confidentiality and PLHIV have lost their jobs because of this. There were only two cases in the FGDs where PLHIV were not asked to leave the job on disclosure of their status.

"I went to Guwahati Dental hospital for removal of a tooth. The dentist came without gloves but when I told him my status and asked him to take precautions he started making excuses and called me the following day. Though r several days passed by, he still did not extract my tooth. So I approached another private doctor who said that she had been warned by the staff of dental hospital not to treat a patient with my name. Finally, I have been able to find a good dental doctor who in spite of my status has been providing me treatment." - A woman from the Assam Network.

Some participants mentioned that NACO has undertaken to train its staff, at the national and state levels, who will interact with people accessing services rendered under the NACP in stigma and discrimination. However, despite NACO's directives, states such as Karnataka are yet to establish grievance redressal mechanism.

Most participants said that they often go to private hospitals if they want immediate attention. Usually they do not reveal their status to the doctors and feel that the onus is on the doctors to take universal precautions while treating the patients. A participant said,

"*There are no laws in the country that inhibit us from leading a normal life but discrimination from people makes it very difficult to survive*."

One of the participants was working as a Sales Girl in a Textile Showroom. She did not reveal her status for the fear of losing her job. Somehow the news leaked and all her colleagues started behaving differently. She was then forced to disclose her status to her employer, who did not ask her to leave but gave her employment in another branch.

Enhanced social/economic protection for people affected by HIV

Participants mentioned that because they were a part of the network, they were aware of the numerous welfare schemes like Antyodaya Anna Yojana (AAY), farmer package in Maharashtra, Tamil Nadu State government's OVC fund and the Department of Women and Child welfare scheme in Nagaland. Corruption and lack of information is a hindrance in accessing the schemes. For instance, one has to register for widow pension scheme within two years of the husband passing away or else many a times women miss out on this opportunity.

People tend to learn about networks through the counsellors at ICTC and PPTCT centres and network members. The Church invites PLHIV for their testimonies. PLHIV are also invited for HIV sessions in nurse and Police training sessions. Support group meetings of networks provide PLHIV an opportunity to share their experience.

"Through these platforms we have gained confidence and got hope to live against all odds."

There is not enough information about these group meetings and schemes, making it difficult for PLHIV to attend them. It is when patients go for counselling that they get to know about these services. People have to travel to the state capital to attend DIC meetings because of the absence of DICs in many districts. Networks have limited scope and are unable to reach out to the entire needy population. If the information does reach people, they are sometimes not open to sharing their status or are too far to access the services.

Role played by the government, media and civil society in providing social support to PLHIV

Networks and NGOs provide services, raise awareness and celebrate events like World AIDS Day and International Women's Day, and in some cases also provide monetary support for transportation, STI medicine, assistance in ART centres, nutritional support, educational support, and in emergencies even medical support. Nagpur district level network supported its members in getting ration cards. Insurance is not an option for PLHIV, as insurance companies step back once the HIV status of the individual is known.

Corporate Social Responsibility is another resource for getting support. A participant cited the example of Colgate, which supports education for children of PLHIV. There is cash support from SHGs and legal support from Tamil Nadu State AIDS Control Society (SACS) provisions under BPL scheme and child education support from NGOs.

Provision of free treatment by the government has reduced the mortality rate. However, participants said that the work done by the government is inadequate, essentially because it is limited to the delivery of treatment services only. However, they acknowledged that this government is considering the HIV and AIDS Bill which gives a comprehensive coverage to PLHIV and HIV epidemic needs.

Positive women also avail the General Widow Pension Scheme. PLHIV are provided with 50% rebate in the general train fare when travelling for medical purposes and 50% reduction will also be given in government hospitals for critical surgery. All infected and affected are eligible for AAY card which provides 25 kg rice, dal (pulses) and oil every month. In Nagaland, the state planning department has provided funds for income generation like plying taxis. Here, FXB supports education and nutrition needs of affected and infected children. Naga Women's Association supports two positive children per district.

Violence against women

About 90% of the participants said that they often encounter physical, sexual and emotional violence both within the house by male family members and outside by others.

"My father when drunk often abuses me. He threatens to tell my status to everyone. He says, do not touch and feed your children."

Most participants underlined that women are afraid to report physical or sexual abuse because the police demands money or sexual favours. Some participants who are counsellors had referred women clients to the legal advisors of the network but very few women have information or access to police, courts or lawyers.

Sexual and reproductive rights of women

A few years ago, my husband after consuming alcohol beat me up badly. My family reported this to the police who arrested him but he was released soon. I even sought help from the elders at my Church but that was not of much help.
- A woman from Shillong

Most participants had limited knowledge about sexual and reproductive health (SRH) rights. Healthcare workers and enforcement agencies often do not educate others on these issues. Members said that authorities are sometimes themselves involved in the harassment of women.

Most participants in FGDs noted that doctors, both in government and private clinics, encourage abortion among positive pregnant women. A HIV+ woman from Assam said,

"When I was pregnant, my doctor asked me not to give birth to my child and to abort it."

Networks have tried to address this issue by motivating positive women to continue their pregnancy and also meet doctors, counsellors and SACS, and advocate on these issues.

Participants stated that there are laws to protect rights of women in India but implementation is poor or delayed. A large number of women do not have information of these rights. Most women said they would take no action because reporting will victimise them and even if they want to report, others in the family do not allow them because of stigma. Bribes and long procedures also stop women from reporting abuse.

"The law is useless. When my neighbour abused his niece I reported it to the police but he was out on bail before the blink of an eye, literally."

About 10% did say that they will report.

"Now we will not tolerate because now we know our rights."

Women's property and inheritance rights

A woman in general does not get any part of the property and after the family comes to know that she is HIV positive, she is completely denied of her property rights. Even if a widow after the death of her husband claims her right to property, she is told by the in-laws that they have already spent a lot of money in the treatment of her husband and therefore, she will not be given anything.

"*You infected our son and he passed away. Why should we give you the property*?"

According to the Indian law, women are eligible for equal inheritance rights. Nearly all participants said that the law was not even worth the paper it was written on since women had to file a suit in court to get their property right. Women rarely go to court as they are scared of complaining against their in-laws and relatives. Lack of funds, no access to legal help and corruption also discourage women from approaching the court. For claiming the husband's property, a marriage certificate is required which widows usually do not have and they cannot prove their marital status. In Meghalaya, it is matrilineal society where a woman specifically the youngest daughter gets the property. Networks and NGOs provide legal support to women who are facing this situation. About three-fourths of the participants were aware of their legal rights but only two cases came to light where women had taken a legal course of action to get the property of their husband.

A positive couple was forced to evict their dwelling inspite of inclement weather and they were denied access to the common well for drawing water. Ultimately they were forced to flee from their village and migrate to another place.
- A woman from Kerala Network

Nearly half of the participants have had to change their residence once their status was revealed to the landlord. However, this is not seen in case of self-ownership, as the people do not leave their house. But some women moved to their parents' house from their in-laws home and a few were even thrown out by their own parents.

"I *was thrown out of my in-laws as well as my parental house in Moregaon*."

A network in the North-Eastern part of India had to move its office because the landlord refused to give his property to a PLHIV network. There was only one incident where the positive woman was denied access to her children.

Girls enrolment in secondary education

All the participants who had school going daughters spoke of them attending school. Responses from the groups showed that being a girl child did not stop her from

continuing her education. Barring financial constraints, the women were eager to send their daughters for higher education. A woman from Maharashtra shared:

"*I want my daughter to become a pilot.*"

Traditionally, women take care of sick people in the family, but in certain homes men have come forward and taken the responsibility.

"*Women take care of sick members but as I do not have a daughter, my son takes care of me when I am sick.*" *- shared a participant from Chennai.*

Improve women's access to income and control over household assets

When Chaiya's community got to know her HIV status, they stopped her father from doing the daily wage work he was engaged in an NGO organised an awareness meeting with the community and then they allowed him to continue his work. - A woman from Assam Network

Most women started working after they became HIV positive. A large number of them work in the networks. Household income of the families affected with HIV had a setback because the father died or he stopped working due to illness. To meet additional expenses, women started to work, registered for widow pension, and got educational support for their children. Some had to sell off their jewellery.

"I *am a widow so all the responsibility fell on my shoulders after the death of my husband. I had to work.*"

One woman had to change her job due to HIV. She left a physically demanding job in a spinning mill to work in a NGO.

Earlier there was a lot of expenditure on medicines as women did not know that ART was available free of cost in the government hospitals. Now these women spend on a nutritious diet, OI medicines and transport for ART collection.

"*Even for this meeting I had to mortgage jewellery for travel. People do not trust us.*"

It came to be known through FGDs that women in families with no adult male member have full control over finances and household expenditure. Participants shared that they have become more careful and try to save more through postal savings etc. to meet the increased expenditure.

"*We do not spend on unnecessary things. We do not eat out in hotels; we buy clothes when needed and not on festivals. Children are also aware of the economic status and help in cutting the expenses.*"

Support from positive networks, NGOs and government, widow pension scheme and family support are different sources of financial support for women. For instance, a woman from Meghalaya is taking help from her mother while another woman from Assam is taking help from her father. The community has given emotional support while the Church provides spiritual counselling and calls for prayers for PLHIV.

Implications of Findings

- There is an urgent need for the reduction of stigma and discrimination in healthcare settings.
- Evidence reiterates need for integrating HIV services within SRH care.
- The environment in which women and girls live and work plays an important role in a woman's vulnerability to HIV. Community-based interventions are effective in overcoming the challenges women face.
- Positive networks provide HIV and life skills education however, the quantity and quality of the information needs to be standardised.
- The North-Eastern states report high abortion rate, limited PPTCT services, access of sex workers to services and no life skills education in schools, and require urgent attention.
- Rural areas have limited access to information on PPTCT, life skills, sex education and SRH rights as also the lack of skilled counsellors and counselling.
- Evaluation of messages in the media; women and youth focused messages are needed. Convey the message of married women getting infected from their partners with an aim of not degrading men but cautioning women to be careful.
- Marginalised populations especially sex workers' access to health services including HIV prevention support and treatment has to improve.
- PLHIV require more avenues to congregate and voice their concerns. We should consider more women-centric programmes in the national response to HIV and issues related to OVC like education, life insurance and hostels.
- Livelihood for women living with HIV is an urgent priority. "*We want to work but cannot…we do not have finance or the skills.*"

Conclusion

A review of UNGASS report, India MDG findings and feedback from FGD participants brings out that the last 5 to 10 years have borne witness to unprecedented achievements in improving access to HIV treatment. However, much remains to be done in order to achieve the two targeted MDGs. The NACP-III has not been effective in translating the principled commitment to gender equality within the national HIV response into reality. It overlooks the dynamics between gender disparities and HIV and needs to incorporate women's issues within the national response to HIV. Furthermore, funds and efforts are largely focused on prevention than on care, support and treatment.

While applying the findings of this study to understand the extent of access to treatment of PLHIV, it appears that there may be a gender bias in the accessibility of ARV treatment in India. Women living with HIV continue to face double stigma. Gender and other inequalities have made it harder for HIV positive women to realise their rights. FGD participants were reasonably satisfied with counselling and testing facilities for HIV but the stigma and discrimination especially in healthcare settings is high and is a significant deterrent to access to services. The quality and form of testing, treatment and care services at times violate the SRH rights of HIV positive women (for example, pressuring a positive pregnant woman to abort her baby). While information provided to, in and out-of-school youth on HIV prevention is limited, girls are less informed than boys. Adolescent girls seldom have access to youth-friendly, quality HIV and SRH services. Because women tend to use health services in greater numbers than men, particularly during prenatal and postnatal care, they are more likely to know their HIV status than their male partners. The potential risk of HIV transmission during pregnancy, childbirth and breastfeeding feeds a pattern of societal blame in which women are viewed as solely responsible for infecting their children. In many instances, women's disclosure of their positive status encourages the perception that they are vectors of the disease.

Another worrying trend is that women continue to experience both psychological and physical violence. Most participants said that "we are slaves to men". A woman's decision about whether or not to be tested, and then whether to disclose the results, may be influenced by the actual or perceived threat of violence from her partner.

There are effective HIV messages relayed in the media but there are no women-focused messages. Other concerns raised by women were:

- Positive network community members, especially women, were not involved in the Mid-Term Review of NACP-III.
- Mainstreaming HIV with the MWCD is still not a reality.
- Social welfare schemes are for general public, there is no specific scheme for positive women.
- Free legal cells for women are not functional.

Most women acknowledged that PPTCT programme has been a success by averting HIV among newborn babies of HIV positive mothers. There has been a substantial increase in access to PPTCT in India. However, this programme has not worked well in low prevalence states. Another highlight has been how the PLHIV networks have helped in empowering women and instilling confidence in them. The capacity building ability of the networks is impressive.

"Working in the network has built my capacity, I can earn a living anywhere."

Therefore, the next phase of NACP (phase IV) will need to address the issue of gender sensitive response to HIV at all levels and areas of fund allocation to help the process of monitoring and evaluation.

Annexure

Indian Network for People Living with HIV/AIDS (INP+)

http://www.inpplus.net/

The Indian Network for Positive People (INP+) was formed in 1997 and is registered under the Tamil Nadu Societies Act. INP+ is a membership based organisation of the People Living with HIV and AIDS and has 22 state and 235 district level networks in India with a membership of 1,29,000 PLHIV.

The mission of INP+ is to improve the quality of life of PLHIV as well as provide a sense of belonging to PLHIV and their families for active participation in the society and also prevent further HIV transmission. INP+ focuses on three critical areas of Advocacy, Network Building and Services for PLHIV. The members are from marginalised sections of the society that include sex workers, MSM, IDUs, trans-genders (TGs) apart from the affected/infected people from the general population. Its primary emphasis is to ensure that there is a continuous supply of ART. It has developed a Positive Speakers bureau, publishes material on positive living with special emphasis on nutrition, positive prevention and ensures that legal and psychosocial support is made available for the affected and infected communities. It has pushed for Greater Involvement of Positive People (GIPA) with the State while the civil society has contributed towards helping NACO to adopt the GIPA policy.

INP+ was nominated as a member of the UN theme group Country Coordinating Mechanism (CCM) for the Global Fund and its president has served as the vice chair of the CCM. It is also affiliated to Global Network of Positive People (GNP+), International Community of Women Living with AIDS (ICW) and Asia Pacific Network of Positive People (APN+). INP+ has also formed a National Women's Forum (NWF) through which it advocates for the issues of positive women. It has 15 state and 60 district women's forums in the Networks. Thirty three percent of the Executive Board members are women. INP+ is one of the very few CBOs that is certified under the ISO 9001:2000 quality systems.

Positive Women Network (PWN+)

http://www.pwnplus.org/

Positive Women Network (PWN+) is an All-India network of HIV positive women, focused on improving the quality of life of women and children living with HIV/AIDS. PWN+ is based in Chennai (Tamil Nadu, India) and presently has state-level member networks in seven states of India. The women support one another, fight for their rights, and sensitise the society about their needs. PWN+ builds capacities, increases access to rights, develops partnerships and advocates for programme and policy changes. To serve its mission and achieve its vision, it has formulated five core strategies for its programmes, projects and other initiatives.

All PWN+ strategies are deeply rooted in GIPA and sensitive to gender issues as well as work towards reducing stigma and discrimination through a rights-based approach. The five core strategies of PWN+ are:

- Strengthen community outreach systems to identify and enhance the greater involvement and participation of women living with HIV.
- Scale up advocacy initiatives based on the experiences of women living with HIV, and the innovative strategies and interventions undertaken by the PWN+ Network and each of the state chapters.
- Network with like-minded, supportive and influential institutions, stakeholders and groups that can address the concerns of women living with HIV.
- Improve delivery mechanisms and modalities of all types of services for women vulnerable to, and living with HIV/AIDS.
- Expand capacity building programmes and to work through women living with HIV wherever possible.