

Women & HIV/AIDS: The Changing Face of the Epidemic in India

This paper culls some of the key findings and lessons about the gendered impact of HIV from programmes and research. It represents the views of the India HIV/AIDS Alliance (Alliance India), the Alliance's Lead Partners in India and the International Center for Research on Women (ICRW). These views stem from the Alliance India's programmatic experience with its partners and ICRW's research expertise on the gendered impact of HIV/AIDS. Several of ICRW's research findings on the underlying causes of women's vulnerability to HIV/AIDS resonate with the programmatic lessons from Alliance India's work on issues of women and HIV/AIDS. ICRW and Alliance India believe that listening carefully to women's voices and engaging closely with them is central to slowing down the epidemic.

Background

There is growing evidence in South Asia that women are disproportionately vulnerable to HIV/AIDS. Gender norms and gender inequality, which manifest in unequal access and control over resources, limited decision making and the experience of violence, fuel the growing numbers of women becoming infected with the virus. HIV infections in South Asia have spiraled upwards, from 6.4 million in 2002 to 7.1 million in 2004, of which 5.1 million live in India -- the highest in the world except for South Africa.¹ The latest estimates and surveillance data show that the incidence of HIV/AIDS is increasing among women, with heterosexual transmission being the single most common mode of transmission. At the end of 2003, there were 1.9 million women living with HIV/AIDS.² 100,000 HIV infected pregnant women give birth to children every year and one out of every three passes the infection to their offspring. There are an estimated 2 million women involved in sex work in India, one-quarter of whom are below the age of 18.³ According to the National Family Health Survey (NFHS 2), 60% of women in India have never heard of AIDS and of those who have some knowledge, 33% do not know how to avoid HIV infection.⁴ Women are still seen as 'vectors' of HIV infection and are blamed for their family's sickness and, consequently, suffer stigma, rejection, and expulsion from family and community structures.

The links between poverty, patriarchy and women's vulnerability to HIV/AIDS have never been clearer. The Human Development Report (2004) indicates that 80% of India's population lives on less than one hundred rupees (\$2) a day. Furthermore, India is ranked 103rd (out of 144 countries) in the gender-development index (GDI), which captures inequalities in achievements between men and women.⁵ Only 46.4% of adult females are literate, opposed to 69% of adult males. Despite the rising age at marriage and laws prohibiting early marriage (Child Marriage Restraint Act of 1929 and its amendment in 1978), half of all women aged 20 to 24 are married by 18 years and a quarter by the age of 15.⁶



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Women's vulnerability to HIV in India

Women's enhanced vulnerability to HIV/AIDS in India is directly linked to gender inequality and a low economic and social status. The lack of women's equality in the family, work-place and the community bears a direct relationship to the spread of the infection among women in India. Existing social and gender norms stemming from the caste system and a patriarchal society have a profound effect on the sexual activity and risk behaviour of both men and women, which ultimately affects women more than men. Such systems increase women's vulnerability to HIV by denying them rights to education, inheritance, protection from violence and access to appropriate prevention and health services.

Gender norms define socially desirable roles for both men and women and often act as deterrents for the adoption of safe sexual behaviour. A lack of adequate knowledge on sex and sexuality is common to both men and women, and arises for different reasons. For instance the social expectation that men should be sexually knowledgeable and active may prompt them to seek information from unreliable sources such as pornographic magazines and peers or experiment with sex workers and casual sex partners. Similarly, the social norm that women and girls should be kept in the dark about matters related to sex and sexuality essentially translates into lack of knowledge about sexually transmitted infections and safe sexual practices.

Poverty

Poverty, coupled with the far-reaching gender inequalities in India, dramatically increases the vulnerability of women to HIV. Many young girls are forced to leave school to find work to support their families or to provide care to family members, and thus lose the opportunity to gain an education and acquire the skills required to rise out of poverty. 69% of girls in India between the ages of 15-17 do not attend school. This lack of educational opportunity curtails women's access to information about health issues including HIV, and is often the reason that women resort to sex work to augment the family income. Economic stress and poverty often pushes young women and girls to sell sex under highly unsafe conditions, thus placing them at risk of contracting HIV/AIDS.

Intimate partner violence

There are several ways in which HIV and violence overlap in the context of women's lives. For one, coercive sexual intercourse may directly increase women's risk for HIV through physiological trauma.⁷ Violence and threats of violence may limit women's ability to negotiate safe sexual behaviour.⁸ Also, women who have been sexually abused in childhood may participate in more sexual risk-taking behaviour as adolescents or adults, thereby increasing their risk for HIV infection.⁹ In addition, women's sero-positive status can lead to family violence against them because of the common perception that they are the 'vectors' of the infection.

Research studies in Africa and the United States highlight a strong and consistent association between a history of domestic violence and HIV infection.¹⁰ Domestic violence in India is pervasive and very common. National surveys report that 40 percent of married women in India experience physical abuse.¹¹ Fifteen percent of these women have also reported being coerced into sex by their husband. Research in India has shown that women have very little power to negotiate sexual relationships and that the taboo on even discussing sex places them at high risk of contracting STIs and HIV.¹² Social norms around masculinity endorse the use of force during sex. A recently conducted research study showed that 60% of youth and middle class men legitimized the use of force to sexually satisfy their wife/partner.¹³

The role of intimate partner violence and stigma in transmission of HIV/AIDS

Although the international community recognizes the impact of stigma and intimate partner violence on the spread of HIV and access to services, data that could help guide appropriate interventions is lacking in India. ICRW has initiated the Stigma and Violence Reduction Intervention Project (SVRI) project to design and field test an intervention model to address these two important drivers of the HIV epidemic. The project engages the mobile and mobility-affected populations and their communities to develop culturally acceptable responses to address stigma and discrimination and intimate partner violence. Findings from these community-led responses will be synthesized into a toolkit for prevention programmes. A unique methodology of the project is Community-Led Action Research (CLAR), wherein the communities go through a reflective analysis process and articulate action plans to combat stigma and Intimate Partner Violence (IPV) and undertake participatory M&E.

Anecdotal field evidence suggests that sex workers find it difficult to negotiate condom use with their regular sex partners. Intimate partner violence is observed to be a pervasive phenomenon among women – whether sex workers, wives or girlfriends. According to survey data from Andhra Pradesh, 92% of sex workers and 44% of trucker's spouses have reported experiencing intimate partner violence (ICRW, 2004).

Gender norms

Gender roles heavily influence sexuality and sexual behaviour in India. There is a strong expectation that women and girls should remain virgins until married and assume sexually passive roles with their intimate partners. Male sexuality on the other hand is often associated with notions of pleasure, sexual dominance and prowess. Such as-



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sociations pose serious difficulties for women, who are unable to communicate with their male partners on issues such as extra-marital relationships, use of barrier methods and protection, timing and safety of sexual contact, access to necessary health services and their own sexual pleasure. The belief that women have sex solely to reproduce while men need sexual release also creates obstacles for HIV/AIDS prevention programmes that promote female negotiation with their partners. The outcomes of decisions in heterosexual relationships frequently leave the female partner with less power and an increased vulnerability to sexually transmitted infections (STIs) including HIV/AIDS. Even when a man admits to having sexual relationships with sex workers, the burden of blame still falls on the wife for failing to "satisfy" her husband.¹⁴

Seen as the causes of HIV infection and blamed for the family's sickness, women suffer stigma, rejection and expulsion from their families and communities. In a recently conducted study, 48.7 percent of Indian women living with HIV experienced violence in the home.¹⁵

Child marriage is still common in many parts of rural India. For a large part, the practice of early marriage of girls stems from the fear of female sexuality and the need to control it. Young girls are often married to older, sexually experienced men who may already be infected. Most of them know very little about sex, HIV, or how to protect themselves - their youth also deprives them of power in the relationship. The risk of infection among young girls is significantly higher because their reproductive tracts contain fewer layers of epithelial cells than found in adult women, offering a less effective barrier against viral infection.

Low Legal Status

It is important to recognize that the risk of HIV/AIDS falls along a growing continuum of vulnerabilities women face in society. Denial of decision making and control over resources results in a denial of rights in key areas such as health, reproductive choices, choice of partner and the right to own and inherit property. Indian laws on property and inheritance do not provide women the same rights as their male siblings. Women who test positive or are suspected of having HIV encounter difficulty in inheriting property after their husband's death. They are often thrown out of their homes and stigmatized by family and community members and if allowed to stay with their in-laws, are subjected to various forms of physical and sexual abuse.

While these inequalities do not take place in isolation, they often overlap and intersect. Reducing the vulnerability of women to HIV/AIDS requires an integrated and holistic approach to prevention and care that reduces gender based inequalities, and promotes effective prevention behaviour while addressing the question of human rights.¹⁶

Women Living with HIV in India

Gender influences the prognosis of HIV/AIDS and access to social services and treatment. Women face a number of barriers to HIV prevention, testing and counselling. These include the threat of violence, embarrassment, fear of rejection and stigma, a partner's objection to testing, a lack of access to financial resources, reliable information, and transportation. These obstacles deter women from accurately assessing their own risks, taking preventive measures, and seeking early diagnosis and treatment for HIV. Socially marginalized HIV positive women such as women in prison, sex workers and women who use drugs tend to face greater violations of their rights.



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Women rarely access treatment of any kind because they put themselves last, after their children and husbands. Being the main care givers and home-makers, they have to take on an extra burden when other family members fall ill. For HIV positive women, coping with their own illnesses and facing up to the stigma of the disease are especially challenging tasks.

Living Positively

In 1998, Anandi was diagnosed with HIV after her husband admitted to having unprotected extra-marital sex. After her diagnosis and divorce from her husband, Anandi moved forward to create a new life for herself. She had a positive outlook and was sure that she could live a normal life with the disease, as so many others did. She soon found work with an NGO whose mission was to increase awareness on HIV/AIDS. Not content with her limited responsibilities as an office assistant, Anandi began work on a HIV awareness project and counselled people living with HIV/AIDS (PLHA) in a hospital. This, however, was where Anandi came face-to-face with discrimination. After watching a colleague being shunned due to his HIV status, Anandi decided to reveal her own status. At this time she was ready to contribute more to helping educate women about the disease and their rights. She took forward the ideas and concerns expressed by other PLHA and helped to establish the Positive Association Network for People Living with HIV.

Although Anandi is just one of the nearly 2 million women infected with HIV in India, her story is one of courage. Her personal evolution shows the importance of standing up for who you are, especially as a woman living with HIV. Today, Anandi is a Programme Officer at the India HIV/AIDS Alliance, and is proud to live life unashamed of her HIV status and help others do the same. She is also a member of the Board of the Global Fund to Fight AIDS, TB and Malaria, representing the communities living with the diseases.

Reducing Women's Vulnerability

Gender issues arising from unequal relationships between men and women have much to do with women's greater vulnerability to HIV/AIDS. To minimize the impact of HIV and AIDS, programme responses must address and even challenge the unequal distribution of power and resources between men and women. Other factors that influence women's vulnerability should also be tackled:

Place women's health at the center: Prevention programmes cannot succeed until women's health and rights are placed at the very center of HIV/AIDS strategies and women's realities actually inform programme design. HIV prevention efforts take effect when they are based on the realities of women's lives. For example, abstinence is not an option in a setting where women are sexually exploited and/or have very little control over their sexual lives.

Savings and Credit Group: A catalyst for reducing discrimination

Valarmadi is full of energy and is the coordinator of a Savings and Credit Group (SCG). In the nine months they have worked, the group has already saved Rs. 9000 from their limited earnings.

Valarmadi's SCG has 20 members that meet twice a month. After listening to an outreach worker from the local NGO, The Society for Rural Development and Protection of the Environment (SRDPE), the SCG decided that they needed to do something for women affected by AIDS. Discussions followed and the members of the SCG decided to provide educational support to a child. This action was followed by a resolution to include HIV positive people into their savings and credit group. The group also decided to put aside a handful of rice whilst preparing the family meal. The rice collected is distributed to families affected by HIV/AIDS, who are unwell and cannot work.

The group Valarmadi coordinates strongly feels that their solidarity enables them to stand fast against larger social discrimination. They have also instilled in their children the idea that all people are alike, helping empower individuals and communities to look beyond HIV/AIDS, caste and race discrimination.

Target Young People: Men must learn at an early age to respect women, and young women must learn to respect themselves. All young people must have access to full and accurate information about their own sexual health and how this affects the sexual health of their partners. It is critical to provide young people the information, skills, and strategies to protect themselves against HIV/AIDS and to advocate for policies that mandate comprehensive, gender-sensitive sexuality education that will enable future generations to protect themselves.

Involve men: In India, boys and men do not have access to accurate information about female sexuality, contraception, fertility and transmission of infections. In addition, notions of masculinity and sexuality are closely intertwined and it is particularly relevant to change the norms of discourse on gender to include men in a constructive way. It is important to reach men in the workplace or where they socialise, instead of relying on traditional clinical settings. Social marketing campaigns can promote male involvement in sexual and reproductive health and above all, reach out to adolescents and young men through creative marketing. Considering the needs of men who have sex with men in HIV/AIDS programmes and including these groups in project design, implementation and monitoring is also essential.

Legal Literacy and Legal Aid Services: A comprehensive and sustainable response to the epidemic must include the establishment of a legal and regulatory framework that acknowledges and addresses the different impact of the threat on men and women. Legal literacy and legal aid services are essential to promote and enforce women's rights. Sensitisation of law enforcement officials, police and the judiciary about the gender and legal dimensions of HIV/AIDS is required to reduce women's vulnerability.



Reduced tolerance to gender based violence:

Challenging community norms that sanction or tacitly support violence against women in any form is imperative in the creation of an environment in which women can negotiate safe sex and resist sexual coercion. Recent research studies have shown that men who engage in violence are more likely to resort to high-risk behaviors, including having multiple sexual partners.¹⁷ Rewriting the script around masculinity and femininity by recasting notions of power and control is essential to bring about positive, long-term change that helps in promoting gender equality.

Fostering Partnerships: NGOs should support national governments and civil society organisations in focusing on the specific problems associated with gender inequalities. Groups of men and women living with HIV should also be included in consultation processes. Partnerships should meet domestic and international commitments and work towards effective HIV/AIDS policy implementation, with a focus on policies that impact gender inequality.

Responding to the Challenges

The experience of the Alliance in India has shown that a focus on understanding the context of vulnerability through participatory community assessments is central to developing programme strategies that address the diverse dimensions of vulnerability, gender and HIV/AIDS. This process encourages women to share their concerns, needs and ideas and to participate in developing, implementing and monitoring programme responses. Working to reduce the vulnerability of women to HIV/AIDS, Alliance India has initiated the integration of PPTCT into the home and community based care and support (HCBCS) programme in Delhi, Andhra Pradesh and Tamil Nadu. Alliance India also works to empower key populations of women - those vulnerable to and living with HIV/AIDS - by providing appropriate health services, care and support, and behaviour change communications designed to reduce stigma and discrimination. Women affected by HIV also work as Technical Service Staff, constantly informing the programme about the needs and responses required, and educating other vulnerable women about HIV/AIDS.

Alliance India and its network of partners have realized that increasing the participation of women in various programmes provides them with the knowledge, confidence and peer support needed to make positive changes in their lives. Once women are aware of HIV/AIDS, they are keen to reduce the risk of transmission and demand equitable access to effective and adequate health and support services. Self-help and savings and credit groups are not just a way of accumulating savings, but a means for empowerment and providing support to community members. They allow members to interact with lenders and provide decision making power, thereby increasing their confidence. Many groups reach out to those infected and affected by HIV/AIDS, helping to foster community unity and resist social discrimination.

ICRW is engaged in research and policy advocacy with a wide range of development practitioners, so that programme design, development planning and policy making are informed by in-depth research findings on women's needs and a broader understanding of their socio-economic status. ICRW believes that meaningful programmes on HIV/AIDS can be developed by "listening to the experts"- women, men and communities effected by AIDS. It recognizes that strong formative research to identify fundamental issues related to women's status is essential for developing meaningful, community specific programmes.

Their Tomorrow is Today

Mala lives deep in Tamil Nadu's Theni district. Her husband died of HIV/AIDS and her in-laws blamed her for giving him the disease. They forced Mala and her children to leave their home. As it happened, an Alliance programme was in operation in that little village. Sensitized members of the savings and credit group heard about Mala and visited her to offer support. Initially she refused to discuss the issue. Several visits led to a building of her trust and she was able to lay bare her tale of woe, stigma and denial of rights and economic impoverishment. The women decided to discuss the issue with Mala's in-laws as a group and demand that her property be restored to her. Weeks and months of negotiations led to the return of the property. Mala and her children finally had a roof over their heads.

The savings and credit group in Theni is unique. While they discuss savings, loans and sort out non-repayment issues, each meeting begins with personal stories, problems of illness and discrimination they may face, and worries they have about their children's futures. All of the members are women living with HIV/AIDS. The group provides a safe environment where they can openly talk, listen and support each other. This has led to their empowerment and desire to help other women situations like their own.

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About Us



India HIV/AIDS Alliance

The India HIV/AIDS Alliance (Alliance India) is a part of the International HIV/AIDS Alliance and was established in India in 1999. Its vision is a world in which people do not die of AIDS. The strategic goal of Alliance India is to reduce the spread of HIV and to mitigate the impact of AIDS. This is achieved through strong internationally linked, national organisations working effectively together to:

- Improve coverage of effective community focused AIDS action;
- Strengthen the leadership and capacity of civil society to respond to AIDS; and,
- Improve institutional, organisational and policy environments for community HIV/AIDS responses.

Alliance India, with offices in New Delhi and Hyderabad, provides technical, programmatic and financial support to four Lead Partner organisations and 64 implementing NGOs (iNGOs) in the states of Delhi, Andhra Pradesh and Tamil Nadu. Alliance India's Lead Partners are:

- Vasavya Mahila Mandali
- MAMTA Health Institute for Mother and Child
- Palmyrah Workers Development Society
- LEPR India

Our priorities over the next 3 years include Home and community based care and support; Children orphaned and made vulnerable by HIV/AIDS; Positive and meaningful involvement of people living with HIV/AIDS; Focused prevention with marginalised groups and populations key to the dynamics of the HIV epidemic; and, Community mobilisation and engagement on treatment, and the facilitation of ownership and sustainability of HIV/AIDS efforts.

Alliance India and its partners work in support of the National AIDS Control Programme in India and in collaboration with the National AIDS Control Organization (NACO), State AIDS Control Societies and other key stakeholders.



The International Center for Research on Women

The International Center for Research on Women (ICRW) ICRW is a private, nonprofit organization dedicated to improving the lives of women in poverty, advancing equality and human rights, and contributing to broader economic and social well-being. ICRW accomplishes this, in partnership with others, through research, capacity building, and advocacy on issues affecting women's economic, health and social status in low- and middle-income countries. ICRW fulfills its mission by:

- Conducting high quality research and analysis that offer true insight into issues
- Translating research into policy and action options, advocating and building support for policies by informing experts, leaders and policymakers of our findings and experience.
- Building capacities of partnering organizations in gender sensitive research methods and analysis in order to inform programmes based on the reality of women's lives.

About Us

The Alliance's Lead Partners in India



Vasavya Mahila Mandali (VMM): Located in Vijawayada, Andhra Pradesh and established in 1969, VMM is a community development NGO that focuses on women and children. Their programmes center on health, economic support, education and social welfare. VMM empowers women and children through counselling, micro-credit projects, provision of care, shelter and food, emancipation of street children and the development of women's groups.

As part of the HCBCS programme in coastal Andhra Pradesh and working with a network of implementing NGOs (iNGOs), VMM focuses on the reduction of stigma and discrimination by mobilising communities and building the capacities of NGOs and community-based organisations (CBOs) to create an enabling environment to improve the quality of life of PLHA, families affected by HIV/AIDS and children affected by HIV/AIDS.



Palmyrah Workers Development Society (PWDS): Created in 1975 and located in Madurai, Tamil Nadu, PWDS is a community development NGO providing integrated services in the areas of health, income generation, women's issues, rural development, education and habitat. PWDS works to empower marginalised sections of society, such as women and children and enables them to build self-reliance. Major programme activities include childcare and education, skills training, community health, shelter development, income generation and resource mobilisation.

The HCBCS programme is the first of its kind in Tamil Nadu and is currently working with 22 implementing organisations (iNGOs) with the mission of creating an enabling, sustainable and supportive environment in the community.



MAMTA Health Institute for Mother and Child: Located in New Delhi and established in 1990, MAMTA focuses on reproductive and child health issues with a commitment to integrated health and development. MAMTA's mission is to empower marginalised individuals and communities through gender sensitive participatory processes in order to achieve optimal and sustainable health and development.

Under the HCBCS programme in Delhi State, MAMTA aims to provide appropriate and adequate support to PLHA, families affected by HIV/AIDS and children affected by HIV/AIDS. MAMTA works to mobilise, enable and empower community-based organisations (CBOs) to deliver care and support within the community. MAMTA also actively advocates with state and national government institutions on various issues related to HIV/AIDS and has initiated a state and national level policy review examining child centred policies in relation to HIV/AIDS.



LEpra India: Located in Secuderabad, Andhra Pradesh, LEpra is a health and development organisation working to restore health, hope and dignity to people affected by leprosy, tuberculosis, malaria and HIV/AIDS. LEpra's activities combine strategies that enable individuals, families, groups, organisations and communities to play active roles in protecting and sustaining their own health and empowering people to make decisions, modify their behaviour and change social conditions.

LEpra India is responsible for implementing the Frontiers' Prevention Programme in Andhra Pradesh. As part of the programme, LEpra works to reduce STI prevalence among key populations of sex workers, men who have sex with men (MSM), injecting drug users (IDU), PLHA and clients of sex workers; empower and mobilise individuals, groups & communities; and, support the creation of enabling environments through individual and organisational capacity building.