Foretelling the Crisis:
HIV/AIDS, Sexual and Reproductive Health & Women in India


Report prepared by: India HIV/AIDS Alliance
The India HIV/AIDS Alliance (Alliance India) was established in 1999 to expand and intensify the International HIV/AIDS Alliance’s global strategy of supporting community action to reduce the spread of HIV and mitigate the impact of AIDS. Since its inception, the Alliance has been committed to fostering and supporting the development of community-driven approaches to HIV/AIDS prevention, care and support and impact mitigation in India, with an emphasis on local leadership and responsibility.

Alliance India currently provides programmatic, technical, strategic, organisational development and financial support to a country-wide network of over 100 NGOs through a national Secretariat based in Delhi and six linking organisations (or, Lead Partners) and State partner organisations working in Delhi, Tamil Nadu, Andhra Pradesh, Manipur, Punjab and Orissa.

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Alternatively, please write to:

India HIV/AIDS Alliance
Third Floor, Kushal House
39 Nehru Place
New Delhi 110 019
India
Telephone: +91 11 4163 3081
Fax: +91 11 4163 3085
Email: info@allianceindia.org
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# Table of Contents

Acknowledgements

Acronyms 5

Executive Summary 6

Introduction 8

The Crossroads of HIV/AIDS and Sexual and Reproductive Health 9

Integration of Sexual and Reproductive Health and HIV/AIDS Services
   – Challenges to integration 11
   – Facilitating the intersection of HIV/AIDS interventions and SRH services 12

The Baseline Survey – Knowledge, Attitudes and Practices (KAP)
   – Objectives and methodological dimensions 13
   – Using the survey to empower and improve: Key findings 14

Recommendations 21

Conclusion 24

References 26
**Acronyms**

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AIDS</td>
<td>Acquired Immuno-deficiency Syndrome</td>
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<tr>
<td>ANC</td>
<td>Ante Natal Care</td>
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<td>ANM</td>
<td>Auxiliary Nurses Mid-wife</td>
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<td>BCC</td>
<td>Behaviour Change Communication</td>
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<td>DFID</td>
<td>Department for International Development</td>
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<td>HFW</td>
<td>Health and Family Welfare</td>
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<td>HIV</td>
<td>Human Immuno-deficiency Virus</td>
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<td>IDU</td>
<td>Injecting Drug User</td>
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<td>IEC</td>
<td>Information, Education and Communication</td>
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<td>IFA</td>
<td>Iron and Folic Acid</td>
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<td>KAP</td>
<td>Knowledge, Attitudes and Practices</td>
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<td>MTP</td>
<td>Medical Termination of Pregnancy</td>
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<td>MSM</td>
<td>Men who have Sex with Men</td>
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<td>NACO</td>
<td>National AIDS Control Organisation</td>
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<td>NACP</td>
<td>National AIDS Control Programme</td>
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<tr>
<td>NGO</td>
<td>Non-Governmental Organisation</td>
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<td>NRHM</td>
<td>National Rural Health Mission</td>
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<td>PLHA</td>
<td>People Living with HIV/AIDS</td>
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<td>PMO</td>
<td>Programme Management Office</td>
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<td>PPTCT</td>
<td>Prevention of Parent-to-Child Transmission</td>
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<td>RCH</td>
<td>Reproductive and Child Health</td>
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<tr>
<td>RTI</td>
<td>Reproductive Tract Infection</td>
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<td>SACS</td>
<td>State AIDS Control Societies</td>
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<td>SRH</td>
<td>Sexual and Reproductive Health</td>
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<td>STI</td>
<td>Sexually Transmitted Infection</td>
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<td>UNAIDS</td>
<td>United Nation Joint Programme on AIDS</td>
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<td>VCT</td>
<td>Voluntary Counselling and Testing</td>
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<tr>
<td>VCTC</td>
<td>Voluntary Counselling and Testing Centre</td>
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<tr>
<td>WLHA</td>
<td>Women Living with HIV/AIDS</td>
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</table>
New HIV infections worldwide continue to be acquired mostly through sexual activity or are in some way linked to reproductive health issues such as pregnancy, childbirth and/or breast-feeding. In resource-poor settings, increased vulnerability to HIV and poor sexual and reproductive health both share common causes, including lack of access to affordable, sensitive and non-judgemental prevention services and medical care, gender-based discrimination and lack of political will to assure needed resources for what is often seen as women-only issues.¹

In 2006, the India HIV/AIDS Alliance (Alliance India) undertook a Knowledge, Attitudes and Practices (KAP) survey in five² of the six States in which it supports community-led initiatives. A total of 2,284 women and 987 male partners of women was interviewed to create baseline information on the situation of women to understand better the vulnerability to HIV/AIDS. Foretelling the Crisis: HIV/AIDS, Sexual and Reproductive Health & Women in India is an analysis of the survey results and recommends specific actions to help alleviate the negative impact of HIV/AIDS on women and their families in India.

Since the start of the AIDS epidemic, there has been a separation between HIV/AIDS work and the delivery of sexual and reproductive health (SRH) services. The data in the Alliance India KAP baseline survey illustrates that there is a unique and urgent need to combine HIV/AIDS interventions with SRH outreach, and vice versa, in the areas where these two services intersect, including:

- **STI/RTI prevention, care and treatment:** Medically unattended STI/RTI accelerates HIV progression in people living with HIV/AIDS (PLHA) and facilitates HIV transmission. A majority of both women and men was reported to have had such symptoms at the time of the survey interview or in the preceding twelve months.³ The overall understanding of RTI among the women and men was very low and most have a misunderstanding of how an RTI may be transmitted.

- **Promotion of safer sex practices, family planning, ante-natal and post-natal care:** Condom use has long been a key element for family planning and HIV prevention. Furthermore, HIV transmission from mother to child can be nearly eliminated by increased education for mothers or mothers-to-be and their partners. Almost all respondents (women as well as men) have been through a live birth.

- **Community health promotion:** Integration of HIV/AIDS with SRH at all levels (personal, family, neighbourhood, community, state and national) including advocacy intended to increase resources, rights-empowerment and reduce stigma and discrimination. The survey also revealed the urgent need to start health promotion and education at the early vulnerable ages of adolescence.

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¹ HIV/AIDS and sexual and reproductive health - linking the response; InterAction, FPA International Development, March 2006

² The five States surveyed were Andhra Pradesh, Delhi, Manipur, Punjab and Tamil Nadu

³ For those interviewed in the survey, 12% of the women and 22% of the men reported to be living with HIV; however, all others were considered to be at high risk for HIV
The feminisation of HIV/AIDS is well documented in India as it is throughout the world: nearly 40% of the HIV positive people in India are women. Women, especially young girls approaching or those currently in their reproductive years, are at the highest risk for HIV. More than four-fifth of new infections in women in India is caused by sex with their husbands or male partners. Without swift action, women living with HIV/AIDS will quickly become the majority of PLHA. This feminisation of HIV/AIDS stems from what is lacking in the lives of the women, as evidenced in the survey data:

- Empowerment to take control over what happens to their own bodies
- Equality in all aspects including relationships, health access and legal status
- Basic knowledge of SRH, HIV/AIDS and related rights

The recommendations drawn from the data in the baseline survey can be summarised in one word: Knowledge. Fairly simple actions that would have immediate and positive results are recommended, such as:

- Increasing the knowledge of health care providers, particularly those involved in maternal/infant/child health-care and HIV/AIDS treatment in addition to social service and development agencies, credit clubs, legal services and so forth, at places where most of the surveyed women are reported to access services. Cross-train service providers to increase the quality and consistency of messages and to create new or better linkages between these services.
- Through creative and innovative methods like street theatre and at unique locations such as markets, places of worship and primary schools, increasing knowledge of the women themselves about their own SRH issues and rights. In addition, involving the women in both the design and delivery of educational campaigns to increase the effectiveness and relevance of the messages.
- Educating, through advocacy to all sectors of the community such as local, regional and national community leaders, community organisations and local and mass media, so that all will understand and prioritise SRH and access to treatment and care for all women. At the same time, the need is to work towards improved governance of public health care facilities.

One of the very basic rights that all people have and share is the right to sexual and reproductive health, free of ailments as well as judgemental outpourings from others. These rights are enshrined in international treaties on human rights in addition to the Constitution of India, State legislation and national policies. Yet, without basic knowledge, these rights go unrealised. Lack of knowledge, or having incorrect knowledge, perpetuates environments that leave women, in particular, as well as their families and communities at high risk for a spate of STI and RTI in addition to HIV/AIDS. The KAP baseline survey by Alliance India shows that HIV/AIDS, SRH and gender issues are directly linked and present tremendous opportunity for immediate and effective integration of prevention strategies within seemingly divergent fields of social service and care.

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4 http://www.breakthrough.tv/teach_detail.asp?TeachId=9; accessed as of November 2006
As the HIV/AIDS epidemic moves into the second half of its third decade, India now has a burgeoning number of cases of HIV/AIDS, with over 5.1 million people living with HIV/AIDS\textsuperscript{6}. Of these, over 38\% constitutes women. Projections estimate that even with only a small increase in the HIV rate, this number could increase to 20–25 million in only three years.\textsuperscript{7} Since its inception in 1999, Alliance India has worked to expand, adapt and intensify the International HIV/AIDS Alliance’s global strategic framework of supporting community action to reduce the spread of HIV and to mitigate the impact of AIDS. Alliance India has been instrumental in building on international experience and supporting NGOs for the mobilisation, facilitation and scaling up of innovative community responses to HIV/AIDS. Alliance India has led the way in implementing its programmes attaching high significance to the involvement and active engagement of the community. It has taken constant inputs from the community as a prerequisite to an effective response to HIV/AIDS.

Alliance India undertook a Knowledge, Attitudes and Practices (KAP) survey in five of the six states where it supports community-led initiatives. The five states were Andhra Pradesh, Delhi, Manipur, Punjab and Tamil Nadu. The survey helped in creating baseline information on the situation of women and in understanding their vulnerability to HIV/AIDS, specifically those women who are involved with programmes undertaken by the implementing partners of Alliance India.

A total of 2,284 women and 987 male partners of women was interviewed in the KAP survey. Those surveyed were asked questions to understand the depth and quality of knowledge pertaining to women’s sexual and reproductive health and rights; personal, family, community and societal attitudes about SRH and about women living with HIV/AIDS, including access to necessary HIV/AIDS and SRH services; and, current practices that either help or hinder women to reduce their risks to HIV and other sexual health problems that have a direct effect on one’s quality of life.

This report is an analysis of the results of the said KAP baseline survey. It also contains recommendations for actions that need the attention of different stakeholders in order to help alleviate the negative impact of HIV/AIDS on women and their families. It must be understood at the outset that some of the recommended actions may already be underway in some places, albeit on a smaller scale. The idea could be to draw lessons from such initiatives and examine their appropriateness for replication or up-scaling.

\textsuperscript{6} Sentinel Surveillance estimates, 2003; http://www.nacoonline.org/facts_overview.htm

\textsuperscript{7} http://news.bbc.co.uk/2/shared/spl/hi/africa/03/aids_debate/html/key_countries.stm; accessed as of December 2006

“… it [is] beautiful to be a woman but after living as women we know what community support means and it is for men; whatever they are… IDU, HIV positive…” (a female IDU)
It is well known and fairly well documented that, globally, the number of new HIV infections is by and large transmitted sexually and/or linked to some or the other reproductive health issues such as pregnancy, childbirth and/or breast-feeding. As has been echoed elsewhere in the paper, the increased vulnerability of women to HIV/AIDS and their poor SRH, particularly in resource-poor settings, has to be seen in the backdrop of a variety of causative factors. The pitfalls of gender-based discrimination, lack of political will and resources to address what is often seen as women-only issues, as well as lack of adequate information and access to affordable, sensitive and non-judgemental medical care are some of the conditions that only aggravate the susceptibilities of women. Further, partners’ objection to testing for HIV on the one hand, and women’s ostracism holding them responsible for bringing in the virus, on the other, add to their miseries. All these act as deterrents for women in addressing their own risks, taking preventive measures and seeking early diagnosis and treatment for HIV. The constraints that stem from such circumstances act as a barrier for women in seeking the much-needed information and services on their SRH, HIV/AIDS, legal remedies, and for entitlements provided within welfare schemes.

Until very recently, there has been a separation of HIV/AIDS work, focussed largely on key populations seen as high-risk groups such as sex workers or men who have sex with men, from sexual and reproductive health issues whose services have been traditionally focussed on planning for families, birth control and gender-based rights. Programmes related to both HIV/AIDS and SRH have been led vertically, i.e. the Reproductive and Child Health (RCH) programme for SRH issues, and the National AIDS Control Programme (NACP) for HIV/AIDS, both via the Ministry of Health and Family Welfare of the Government of India.

Simply put, HIV/AIDS interventions involve prevention, care and support, and treatment and include activities for increasing the access for at-risk and HIV positive people. SRH services involve family planning, maternal care, ante-natal and post-natal care, prevention, treatment of RTI and STI, and management of other related problems. However, since SRH issues are an important gateway for HIV/AIDS, the increase in the HIV/AIDS epidemic has accentuated the vital need to converge the SRH and HIV/AIDS programmes. This would enhance the coordination of efforts to prevent sexual transmission of HIV, and provide SRH services to HIV positive couples.

The opportunity exists to combine HIV/AIDS interventions with SRH outreach in the areas where these two services intersect, including:

1) STI prevention, care and treatment: HIV, after all, may also be sexually transmitted. Also, unattended STI/RTI accelerates HIV progression in PLHA, as well as facilitates HIV transmission.
2) Promotion of safer sex practices: Condom use has long been a key element of family planning. Furthermore, HIV transmission from mother to child can be nearly eliminated by addressing HIV prevention and sexual health improvement, and,

3) Community health promotion: Integration of HIV/AIDS with SRH at all levels such as advocacy to improve the lives of all women through increased resources or to reduce stigma and discrimination that directly and negatively affects access to care and support.

It is pertinent to mention here that the government efforts in establishing necessary linkages between HIV/AIDS and SRH were quite visible in the recent planning process for NACP III. The National Rural Health Mission (NRHM) envisages the convergence of the NACP with over a decade of experience and technical competence in HIV/AIDS prevention and care, and the Health and Family Welfare (HFW) programmes with its infrastructure, human resources and capacity to reach out to every village and community. This convergence is indispensable for ensuring effective service delivery.
Challenges to integration
Significant challenges exist in promoting better sexual and reproductive health among women and mitigating the spread of HIV/AIDS. These challenges, widely illustrated in the Alliance India baseline survey, also show other areas where the needs of HIV/AIDS and SRH intersect.

The devaluation of women is common in many cultures around the world. Unequal power relations between women and men leave women with much less access to resources like health care, property rights, employment and income. Such lack of access points out that women are unable to negotiate for things that might protect them, and thus leaves them vulnerable to effects of poor health. It also leaves them open to unwanted pregnancy, STI/RTI and even violence in and outside the home.

Social pressures constantly drive men to demonstrate their masculinity and power over women. Such unequal gender relations are also manifested in the way men view and establish sexual relations, including seeking multiple sexual partners. These are adequate reasons for men and boys to take risks, putting them and their partners at a higher risk for HIV/AIDS and other STIs and RTIs, particularly given the women’s inability to deny sex to their partners, even when they suspect that they may have an STI or HIV or both, as reported by almost one-half of the women respondents.

The influence of poverty on the sexual and reproductive health needs of women and men alike, in addition to HIV/AIDS prevention and care, is overwhelming. Lack of resources, including low nutrition and limited education, result in lack of access to health care (particularly related to ante-natal care and STI/RTI treatment), when it is needed the most. Social services programmes also have a difficult time in reaching out to these families.

When power structures in communities lack understanding of SRH and related rights, there is little interest in supporting interventions that can positively impact the public health of these communities. Certain gendered perceptions and cultural notions, such as, a ‘good’ mother must breast-feed her newborn baby, can also be a challenge in the way of effective service delivery of SRH and HIV/AIDS. As aforementioned, the lack of power on the part of a woman in denying sex to her husband even when she knows that he is engaging in multiple sexual relationships (reported by 50% of the women surveyed) is another such challenge.

“I used to think I am spending all my time with these women who have sex with other men for money or job or some pressure. Why am I calling them ‘amma’ (mother) and ‘akka’ (elder sister)? And then I realised, why not? These are brave women making the best efforts in the worst conditions. First, women have to respect themselves, then only something can happen...” (A field worker from an implementing NGO of Alliance India)
It is paramount that when treatment of STIs/RTIs and/or HIV/AIDS interventions are not offered by SRH programmes, or vice versa, a strong, sustained referral network with sufficient follow-up be put in place to ensure the delivery of such care when needed.

**Facilitating the intersection of HIV/AIDS interventions & sexual and reproductive health services**

With the recent disclosure of the dramatically increased estimates of the number of HIV positive people in India, ensuring access to treatment and care remains top priority. However, the question remains as to how to best combine HIV/AIDS prevention, treatment, care and support with the delivery of SRH outreach and services. This paper proposes that by following the idea of mainstreaming, that is, making HIV care a part of daily medical and social service care, SRH service providers will have less difficulty integrating HIV/AIDS interventions into their programming. A point that merits attention is that an effective integration of SRH and HIV/AIDS issues and services can only be achieved if approached at all levels – personal, family, community, programme and policy.

The present baseline survey shows that HIV/AIDS, SRH and gender issues are directly linked and present tremendous opportunity for integration of activities targeting the same populations. Ultimately, the integration of HIV/AIDS prevention, treatment, care and support, and SRH outreach and services, will provide significant socio-economic benefit to the community as well as to the individuals who need them.
Objectives and methodological dimensions

The baseline study was carried out with certain specific and clearly outlined objectives. The study purported to assess the Knowledge, Attitudes and Practices (KAP) of women, including women living with HIV/AIDS and vulnerable groups, on means of contraception, pregnancy and contraceptive usage, a whole host of areas related to ante-natal, natal and post-natal care, prevention, identification and management of RTI and STI, transmission risks of HIV associated or exacerbated by certain behaviours and its perception, knowledge of prevention of parent-to-child transmission (PPTCT) and Voluntary Counselling and Testing (VCT). The study also intended to broaden understanding with regard to knowledge and prevalent practices on certain services relating to sexual and reproductive health, HIV-related services as also existence of health care providers.

There is numerous literature that has highlighted the usefulness of support systems at the community level, which enhance and further the health-seeking needs of various groups in the society. The study further aimed to closely look into support environments at the community level, whether community-led or facilitated by intermediaries like NGOs.

An understanding of the existing policy and legal framework is crucial to demand articulation and informed action by the community in relation to issue of rights and entitlements. Keeping this in mind, the study set out to understand the knowledge and practice dimension of community’s access to the government’s social welfare schemes besides its endeavours on accessing legal support services. Succinctly, the objectives set out by the study had crucial health-related components but were fairly aligned with such ‘real’ community issues that have a bearing on health outcomes for the poor, discriminated and the vulnerable sections of society.

The KAP survey is a methodology that has been in use for over twenty years and is most often used in developing countries to obtain information on fertility and birth control. KAP is used to show trends with regard to selected topics and in particular locations about what people (the research subjects) actually do and what they know they should or could do when compared to actual knowledge and customs. Data is obtained through interviews using open and closed-ended questions and, as in the case of the baseline survey, through both spontaneous as well as assisted responses for key questions. Data from a KAP survey is often used to provide programmatic direction and guidance for creating or improving interventions to address health-related problems such as SRH and HIV/AIDS.

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The KAP baseline survey conducted by Alliance India in its SRH and HIV/AIDS integration programme intervention sites of Andhra Pradesh, Delhi, Manipur, Punjab and Tamil Nadu, interviewed 2,284 women and 987 men, selected from the registered beneficiaries of Alliance India’s seventeen NGO partners in the aforementioned five States.

Selection of respondents for this survey was based upon a set criteria; while women and men being considered were either vulnerable (at high risk) or were living with HIV. Risk was judged to be highest for women who reported one of the following criteria:

1) Partners’ absence from home (occupation, husband’s place of stay, place of work, frequency of travel, duration of stay outside)
2) Women reporting any of the following symptoms:
   a. Vaginal discharge
   b. Urinary tract infections
   c. Abdominal or vaginal pain during intercourse
   d. Observing blood after intercourse

The male respondents selected were those who were partners of women who had reported having any of the symptoms in the second condition but who had not been selected for interview. The female respondents’ age ranged from 14 to more than 45, with an overall, five-State, average of 29 years. The men were slightly older, with an average age of 35 years. As for the women, over 36% belonged to Other Backward Castes and 37% to the Scheduled Castes or Scheduled Tribes.

The survey was performed by a team of nine female and three male investigators, who were provided training in preparation for the project as well as to assure familiarity with the issues of HIV/AIDS and SRH. Study subjects were selected from the registered women beneficiaries or their male partners at each of the seventeen Alliance India partners. One-on-one interviews were conducted in private settings and the data entered and analysed. A first analysis was performed independently of this paper.

Using the survey to empower and improve: Key findings
For the KAP survey, those surveyed were asked questions to assess and understand the depth and quality of knowledge pertaining to women’s sexual and reproductive health and rights. It also covered questions on attitudes about SRH as also about women living with HIV/AIDS. Specific questions on access to and use of services were posed to the respondents. The survey also intended to learn more about current practices and customs that help or hinder women in reducing the risks to HIV and other sexual health problems.

Demographics: Adding to the spiral of vulnerabilities
The high vulnerability of women and lack of access to quality services with respect to HIV/AIDS and sexual and reproductive health is directly related to women’s lack of resources. The same can be ascertained from the fact that most of those surveyed through the baseline survey maintained a low standard of living, as reflective of low-wage earners. Most respondents had a household income of less
than Rs.3,000 per month or about $2 per day. Lack of resources was also reflected from the fact that almost one-half of the women used firewood to cook the family meals and 80% relied on municipal tap water as the main source for drinking water. 57% of the women were not working; of those who were, over half worked as day labourers. It was also understood through the survey that travel-related work for women was not common; however, 68% of the currently married women reported that their husbands were often away from the home for work. Also, 55% of working men reported working away from home ‘temporarily’ and 45% as working ‘mostly away from home’. This clearly states the increased vulnerability of women to various STIs/RTIs and/or HIV due to their husbands’ likelihood to look for other avenues away from home for sexual relationship. This can be corroborated by the fact that amongst the respondents, more men (22%) were HIV positive than women (only 12%); and although more women (88%) were at the risk of HIV than men (78%), the difference between the two was only 10%.

As regards the literacy level amongst the female and male respondents, 65% women and 74% men were found to be literate, i.e. they knew how to read and write. Amongst the five target States of the survey, Manipur had the highest literacy rate, i.e., 89% amongst women and 95% amongst men. A point of relevance here is that since the five States not only exhibit decent literacy rate but also high levels of vulnerability, thus a high literacy rate does not necessarily mean high level of understanding on issues related to HIV/AIDS and/or SRH. Just the ability to read and write does not ensure a high level of awareness. Thus, it could be said that high vulnerability to SRH and HIV is more to do with the attitudinal and behavioural issues of men and women (e.g. the risk behaviour of men leave their wives vulnerable). However, it cannot be denied that literacy is a prerequisite for effective learning, and, once literate, individuals and communities could better acquire the knowledge and skills necessary for preventing themselves from HIV as well as transmitting it to others, including knowing their HIV status and of the range of related prevention, testing and information services available to them.

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<tr>
<th>Demographics</th>
<th>Women (n=2,284)</th>
<th>Men (n=987)</th>
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<tbody>
<tr>
<td>HIV positive</td>
<td>12%</td>
<td>22%</td>
</tr>
<tr>
<td>At risk (vulnerable)</td>
<td>88%</td>
<td>78%</td>
</tr>
<tr>
<td>Usually living at home</td>
<td>94%</td>
<td>81%*</td>
</tr>
<tr>
<td>Currently married</td>
<td>88%**</td>
<td>Almost 100%</td>
</tr>
<tr>
<td>Ability to read and/or write</td>
<td>65%</td>
<td>74%***</td>
</tr>
</tbody>
</table>

* 55% of working men reported working away from home “temporarily” and 45% as working “mostly away from home”
** 71% of women living with HIV/AIDS are widows
*** 95% of the men in Manipur reported to be literate

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Access to care
A lack of basic knowledge about sexual and reproductive health and HIV prevention as well as access to quality services for care, treatment and various social service schemes is not surprising, given the education and income levels of the respondents. However, what is surprising is that almost all of the respondents have been in someway involved in or at least exposed recently to community-based HIV services. For instance, almost all have been through a live birth (92% of the women and 95% of the partners of the men surveyed).

For knowledge related to ‘safe days’ from getting pregnant during the menstrual cycle, only 25% of the women could identify the second cycle (roughly days 10 – 20) as being the time when a woman is most likely to conceive, with 41% having no idea about when these days occur. For the men, 71% had no knowledge of safe days and of those few who did have, only about one-half of them knew the correct days within the menstrual cycle. Aside from study findings, it could be said that men acquiring such knowledge has nothing to do with income level or education since many educated and successful men also may not have any idea about women’s safe days.

Awareness about the need for ante-natal care visits was relatively high; however, the timing of when to begin these visits was unclear with both women and men. Only 59% women and 57% men knew the optimum time to begin ante-natal care visits, i.e. at the first sign of pregnancy. It is also interesting to note that nearly one-fifth of the men could not identify any danger sign that could indicate a life-threatening complication or illness during pregnancy for a woman. One-fifth of all the women respondents and even 22% of those who were pregnant (at the time of the interview) also could not identify or mention any of the danger signs. It is significant to note here that the respondents demonstrated a weak understanding of the importance of accessing timely and periodic visits for antenatal care. For example, of the average five ANC visits made by the women, the percentage of those who accessed ANC in the first trimester was 58%, whereas 29% of pregnant women were those who accessed their first ANC directly in the second trimester, which is however the basic minimum.

Knowledge of medical termination of pregnancy was high (64%) and of the 206 women who had sought ‘post spontaneous abortion’, 82% had done so through a government facility, such as, at a community or public health clinic, or from private medical practitioners. 33% of women were recognised using tablets or pills prescribed by a doctor for home use as a method of termination, while 42% women living with HIV/AIDS were using contraceptives to avoid pregnancy. Worth noting is the fact that 35% of all female respondents had undergone sterilisation as a method to avoid pregnancies. Sterilisation usually leads to non-usage of condoms. Low usage of condoms clearly shows that condoms are usually perceived only as a contraceptive method rather than also a means for HIV prevention. Therefore, sterilisation could well lead to unsafe sexual practices with regard to HIV and STI transmission and it needs to be addressed when sterilisation services are sought. Another important finding points towards the gap between awareness and
knowledge about various contraceptive methods on the one hand, and between knowledge and practice of contraceptive usage on the other.

With reference to the level of ignorance of the women respondents, it was found that their knowledge on areas of maternal health was quite minimal. For instance, only 30% of all women and 20% of those pregnant knew the importance of taking IFA (Iron and Folic Acid) tablets. As regards advice during pregnancy, most of the women (90%) had received advice on diet, 76% on breast-feeding and 70% on newborn care; however, only a little more than one-half had received any information about family planning (including birth spacing), danger signs or costs of delivery.

For breast-feeding, 51% of the women felt that breast-feeding was important for a baby’s health; however, only a minuscule 2% mentioned that colostrum, a form of breast milk produced during late pregnancy and few days after giving birth, which contains high concentrations of nutrients and natural immunities, is good for a newborn baby. There is a disparity between the current international guidelines on breast-feeding and the customs and public health practices in India, particularly for the mothers who are HIV positive. Certain traditional and cultural notions in this part of the world look down upon bottle-feeding as well as mothers who do not breast-feed their children. Thus, a community-led process to understand the complexities of this matter, arrive at equitable and affordable methods and standards, and to alter and correct public health messages, needs to be undertaken immediately. Further, breast-feeding or bottle-feeding should be an informed choice.

Another highlight of the baseline survey was that the PLHA, including women and men, seemed to either not know about, or were uninterested in, seeking available support in their communities; 89% of the women and an astounding 84% of the men were not members of any support group. A plausible reason for this could be inhibitions on the part of the women and men because of undue stigma attached to HIV/AIDS. This behaviour leads to their missing the opportunities to interact with other community members suffering from or affected by similar problems and thereby attaining greater information on SRH and HIV/AIDS as well as services related to them.

Clearly, medical personnel are involved in the daily lives of these women in the community. Even for home-based birth deliveries, women sought medical care at clinics on an average of three times before giving birth. This presents an opportunity to reach out to medical providers, including auxiliary nurse mid-wives (ANM), and to integrate simple sexual and reproductive health information and IEC materials into their services. When it is not feasible to integrate the services, cross-linkages for HIV care, prevention services including VCT and choice counselling, family planning, safe birth care and safe breast-feeding education for HIV positive pregnant women should be established. In addition, there is both the opportunity and need to involve male partners in these services.

“We are not able to sleep the whole night and scary thoughts come in the mind, we feel miserable physically as well as mentally...” (Young woman beneficiaries reflecting on isolation during menstruation)
Knowledge and education

An essential aspect of sexual and reproductive health rights is the right of a woman to have complete control over her body. Less than half of the women respondents said that they have no difficulty in discussing sex with their husbands but even fewer (44%) agreed with the statement: “Women cannot refuse to have sex with husband even if he has an STI.” Of the men, 81% of those whose wife had given live birth in the past 24 months reported that they had wanted the wife to get pregnant; however, cross-analysis revealed that of these men, 22% reported that the wife had not wanted to get pregnant. Only 42% of the men said they had discussed the use of contraceptives once or twice in the past year; 13% of the women said that the decision of what contraceptive method to be used, mostly, rests with the husband. The aforesaid data not only aptly captures the feeble voice of women in matters related to sex, pregnancy and contraceptive methods, it also directly indicates the need for enhancing the involvement of men in SRH and HIV/AIDS issues and programmes.

The overall understanding of RTI among the women and men was very low; only 33% and 36% respectively had heard of RTI, most had a misunderstanding of how an RTI may be transmitted and only 29% felt that RTI is curable (25% of the men). Although a higher percentage had heard of STI (70% of women and 65% of men) including a high percentage at all study sites that recognised HIV as an STI (women and men), as many as 33% of the women and 43% of the men could not name any STI symptom. One-third of the men could not describe any STI-related symptom in women. It is a point of concern here, especially in the context of the fact that the respondents were recruited for this baseline survey due to their being either HIV positive or at high risk due to reported symptoms of RTI/STI.

The baseline survey attempted to assess the overall knowledge, opinions and attitudes towards HIV/AIDS, including transmission modes. To the question whether they had ever heard of HIV and/or AIDS, around 95% of all respondents answered “yes”. However, awareness of the modes of transmission of HIV was much lower, despite the fact that the respondents were recruited from local HIV community organisations, and that 12% of the female as well as 22% of the male respondents were themselves HIV positive.

<table>
<thead>
<tr>
<th>HIV Transmission Route</th>
<th>Women</th>
<th>Men</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heterosexual intercourse</td>
<td>76%</td>
<td>63%</td>
</tr>
<tr>
<td>Needles/blades/skin puncture</td>
<td>69%</td>
<td>49%</td>
</tr>
<tr>
<td>Transfusion of infected blood</td>
<td>65%</td>
<td>48%</td>
</tr>
<tr>
<td>Mother to child transmission</td>
<td>57%</td>
<td>24%</td>
</tr>
<tr>
<td>Homosexual intercourse</td>
<td>1%</td>
<td>17%</td>
</tr>
<tr>
<td>Don’t know</td>
<td>2%</td>
<td>4%</td>
</tr>
</tbody>
</table>

The aforementioned findings demonstrate the lack of knowledge about HIV transmission and highlight some key differences in knowledge between women and men.
men, particularly related to mother-to-child transmission as well as heterosexual and homosexual intercourse. It also shows the need to target men as well as women in educational campaigns.

As the data suggests, there is a stark difference in the awareness levels of men and women. Further, it could be seen that the women have much higher awareness than men, despite several prevention programmes focussing more on men for decades. It is surprising to note that although there is an increased level of awareness in women, especially with respect to heterosexual intercourse, mother-to-child transmission, transfusion of infected blood and needles/blades/skin puncture, the present level of sexual and reproductive health indicators for women in India remains grim. This is because when it comes to practice, as also revealed by the survey, women are unable to negotiate with their partners for safer sex practices, and/or practise their sexual and other rights due to their subjugated and dependent socio-economic status.

The issue of childbearing is of critical importance to women in India. Social pressure and economic need were cited by both the female and male respondents. Therefore, given the high rate of HIV in the five study States, the desirability of enhanced level of knowledge about HIV transmission related to pregnancy and childbirth is critical. Women (89%) knew better than men (76%) that an HIV positive mother may transmit the virus to her unborn child, but fewer women (77%) knew that anti retroviral (ARV) drugs like Nevirapine can reduce the risk of transmission from mother to child. This was evident from the fact that about 42% women living with HIV/AIDS were found avoiding pregnancy.

For breast-feeding by an HIV positive mother, only 60% of the men compared with 81% of the women knew that this also posed a risk of mother-to-child transmission. It is worth noting that 36% positive women have breast-fed their newborns up to six months and none of them has used contraceptives, in the belief that the chances of conceiving during this period are minimum. It is pertinent to mention here that out of the total 278 HIV positive women respondents, only 14 were pregnant in the past 24 months. Respondents stated that it could be very difficult for a positive woman not to breast-feed. The possible reasons cited by them were – first, the cultural norms of society pressurise her, chiding her as ‘not a good mother’ for not giving mother’s milk to her newborn child; second, this departure from standard practice could disclose her HIV positive status that she otherwise wants to keep confidential; and finally, many women living with HIV/AIDS do not have access to breast-milk substitutes. It could be added here that exclusive breast-feeding is advisable for the first six months in resource-limited settings. What is important is to provide infant-feeding counselling to HIV positive women with options of breast-feeding and timings as well as to help them in making the decision most feasible for them.

“I inherited nothing but disease from my husband. After being totally depressed, I am trying to do my best. I might not come in the forefront but I will definitely try and explore options for good lives for at least my daughters...”

(Widow of an IDU)
Addressing gender inequalities must also include discussion, understanding and supportive services for the rights of women as they are assured in local and national laws, policies and international treaties. The survey also assessed general knowledge about legal rights and participation in community groups and services. Almost all the respondents understood and agreed that a woman has the right to inherit her husband’s property and possessions including the right to own farmland. However, 94% women and 92% men had almost no knowledge of specific laws, policies, rights or entitlements. Further, none of the women had ever asked for or sought legal advice or services. It is surprising to note that despite the socio-economic disparities between men and women resulting in numerous problems faced by women especially with regard to SRH and HIV/AIDS (as found out in the baseline throughout), none of the women had ever sought legal advice or services, which clearly talks about the patriarchal stranglehold that prohibits and inhibits women from exercising their rights.

The survey findings have thrown some remarkable insights into the complexities of sexual and reproductive health faced by women in India. The widespread gender disparities arising out of an entrenched patriarchal order have only served to make things worse for women in as much as accessing and exercising their health rights are concerned. But this understanding has to be seen in conjunction with supply-side constraints of quality health care avenues for a woman, which can bridge the existing separation between SRH and HIV/AIDS services.
The survey findings have guided our way into an area of far-reaching importance of SRH, HIV/AIDS and their integration. Some of the survey findings have made startling revelations with regard to growing dangers to women at risk. It is important that we urgently take notice of these findings in order to help alleviate the negative impact of HIV/AIDS on women and their families in India. Building on the findings, some recommendations for actions are suggested here:

**Care, access and community participation**

It is important to closely examine ways and means of mainstreaming SRH issues, align and integrate them closely to all HIV/AIDS-related action, learning and discourse. Our health care and social services delivery mechanism must rise to the occasion in taking the right first step in this direction. Some of the illustrative areas for timely alignment and ultimately integration would be HIV/AIDS and STI prevention and care with those of family planning clinics and ante-natal care services. In effect, this could mean integration of VCTC with family planning, ante-natal care and STI services. Even at the cost of repetition, it is imperative to underline here that promptness of integrating SRH and HIV/AIDS interventions holds the key.

Another facet of improved care involves standardisation of protocols that directly impact women’s health. In doing so, an effort should be made to ensure community-driven consensus efforts that involve women at risk, people living with HIV/AIDS and their partners, on the one hand, and care providers and researchers, on the other, working in close cooperation.

The standardised protocols will have to essentially cover areas of women’s health as, birth spacing and family planning, ante-natal care, breast-feeding and post-natal care and legal age of marriage for women and men.

Another important area emerging from the analysis is strong outreach to PLHA, both women and men, to bring them into care and support programmes. Deepening our commitment to vibrant local peer support groups is crucial to an improved outreach mechanism.

**Knowledge and education**

There is an increasing realisation that our response to concerns towards women’s health issues must seek answers in improved quality of knowledge production and dissemination. SRH and its related rights with its entire link to HIV/AIDS should form the core for education targeting different sections of society using behaviour change communication10. Effectively, STI, RTI and HIV/AIDS in general have to be

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seen from the standpoint of prevention, diagnosis and treatment. There is a need to create widespread awareness of SRH rights of women, including HIV positive women through creative means at public spaces in rural and urban areas alike. Such awareness campaigns must be grounded in an understanding of gender inequalities and should promote the right of women to take control of their own bodies. Experiences tell us that inclusion of men in the design of SRH campaigns as also targets holds the key to wider success of such a campaign.

Advocacy
It is time that meaningful engagement with and support to policy makers is stepped up. Together with policy makers, our interface with community leaders and media at local, regional and national levels for improved understanding of SRH and its related rights along with issues of people living with HIV/AIDS is crucial to the success of initiatives in the area of women’s health. This would require devising an action agenda that creates opportunities for participation of women living with HIV/AIDS at all levels of policy and programme formulation. In addition, support to women to understand and act on their rights by using guarantees enshrined in national laws and international instruments will deepen the process. In real terms, this would mean creating enabling and facilitative conditions for women to access quality legal services locally. It is time to clearly define and inform women in local communities about the existing inheritance laws and conjugal rights. The success of this approach is also incumbent upon support to creation of new knowledge on human rights abuses of women at risk and those living with HIV/AIDS.

Participation and greater involvement
The success of a large and widespread awareness and education-centred programme would be largely contingent upon active and engaged participation of affected or at-risk women and men at all levels of efforts in addition to prevention, care and support. Women living with HIV/AIDS have, in numerous instances, demonstrated their skills as effective community-level trainers and peer counsellors. It is important that these women living with HIV/AIDS are provided continual training opportunities and compensation to become active peer leaders, inside and outside existing PLHA support programmes, networks and groups. The participation of women and men as primary stakeholders has to go beyond training and counselling. Their active involvement in planning, design and periodic review of programmes would be the key to a result-based framework of educational initiative and responsive service delivery mechanism.

Working on improved supply-side response
The greater participation of women and men in local communities will help in clear and unequivocal articulation of demands. The premise here is that it will definitely work towards an accountable and responsive service delivery mechanism, as indicated in the preceding recommendation. However, the success of this approach will largely hinge on the strengthening of supply-side response. This, to all intents and purposes, means that persistent and resolute efforts are made to enhance
the ability of health-care providers to offer effective, quality and timely care and treatment services. These health-care providers should also be seen as information clearing houses on SRH issues for all women, including women living with HIV/AIDS. As a prerequisite community-based service, delivery staff in all related fields and services should be cross-trained on issues of SRH and HIV/AIDS. Apart from health care providers in public and private realms, efforts should be made to bring civil society organisations within the fold. As has been noted earlier, public and private health-care providers would require persistent education and training support on SRH and its rights-based dimensions, STI, RTI and HIV/AIDS, and would have to be strategically targeted on such care and support institutions that are often accessed by women at-risk and women living with HIV/AIDS for such services as abortion care, sterilisation, medical termination of pregnancies (MTP), RTIs and STIs treatment, and other related services.
As stated before, the feminisation of HIV/AIDS is well documented in India as it is throughout the world. According to this, nearly 38% of the people living with HIV/AIDS in India are women. Women, especially young girls approaching or in their reproductive years are at the highest risk for HIV. More than four-fifth of new infections in women in India is sexually transmitted. Without swift action, women living with HIV/AIDS will quickly become the majority of people living with HIV/AIDS.

The data contained in the Alliance India baseline survey illustrates causative factors behind increasing feminisation of HIV/AIDS in India and gives significant evidence of actions that could lead to a lessening if not a reversal of this trend. The reasons are numerous and complex, as shown in the baseline survey. More than one half of the women have difficulty discussing sexual issues with husbands and almost half do not feel that they have the right to refuse sex to a husband who they suspect having a sexually transmitted infection. While most of the women and men know that consistent condom usage can protect them and their partners from STIs and HIV/AIDS, they largely lack knowledge of proper use of condoms and/or symptoms that indicate that an STI or RTI is present. A majority of both women and men reported to have such symptoms at the time of the survey interview or in the preceding twelve months.

Stated simply, the reason for the feminisation of HIV/AIDS is about what is lacking in the lives of the women, as evidenced in the survey:

- Lack of empowerment to take control over what happens to their own bodies.
- Inequality in all aspects including relationships, health access and legal status.
- Little knowledge of sexual and reproductive health and their right to enjoy it.

The key recommendation suggested by the data in the baseline survey is increased knowledge and awareness, of the women as well as their partners, of SRH and HIV/AIDS issues and available services. The recommendations offer fairly simple actions that would have immediate and positive results, such as:

- Increase the knowledge of the health-care providers, particularly those involved in maternal, infant and child health-care and HIV treatment, and sensitise them to the issues of women and their SRH.
- Increase knowledge of the women themselves about SRH, their rights, and using creative methods like street theatre and at unique locations such as market places in addition to primary schools.
- Involve women in both the design and delivery of educational campaigns to increase the effectiveness and relevance of the messages.

11 http://www.breakthrough.tv/teach_detail.asp?TeachId=9; accessed as of November 2006
• Cross-train service providers at existing HIV/AIDS, SRH, social service agencies, development NGOs, credit clubs, legal services and so forth to increase the quality and consistency of the message to empower women and girls as well as to create new or improved linkages amongst these services.

• Advocate and educate to all sectors of the community such as local, regional and national community leaders, community based organisations and the media in order that they understand and prioritise SRH, HIV/AIDS and access to treatment and care for all women with greater focus.

What is needed next is the ongoing support and participation of policy makers and planners, government and private medical care providers, community-based groups and the people they serve, together with the continued passionate participation of HIV/AIDS and SRH service providers.

One of the very basic rights that all people have and share is the right to sexual and reproductive health, free of disease as well as judgement from others. These rights are also enshrined in several international treaties on human rights to which India is proud to be a signatory. Again, throughout the KAP baseline survey, respondents revealed a lack of basic knowledge. The survey reinforced that without basic knowledge, these rights are unrealised by many. Lack of knowledge or having incorrect knowledge, perpetuates environments that leave women, in particular, families and communities at risk for a number of epidemics of sexually transmitted and reproductive tract infections in addition to HIV/AIDS.

Knowledge is power, and it is both knowledge and power that are needed to improve the lives of women in India, to reduce their risk of HIV and other sexually transmitted illnesses and reproductive tract infections, and to improve the quality and quantity of the lives of those women who are now living with HIV.

“Women and girls in India face a crisis of growing, yet unaddressed, health needs. From the moment of conception to the end of life, the challenges to the female sex are enormous, especially poor women who have limited access to health care...”

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