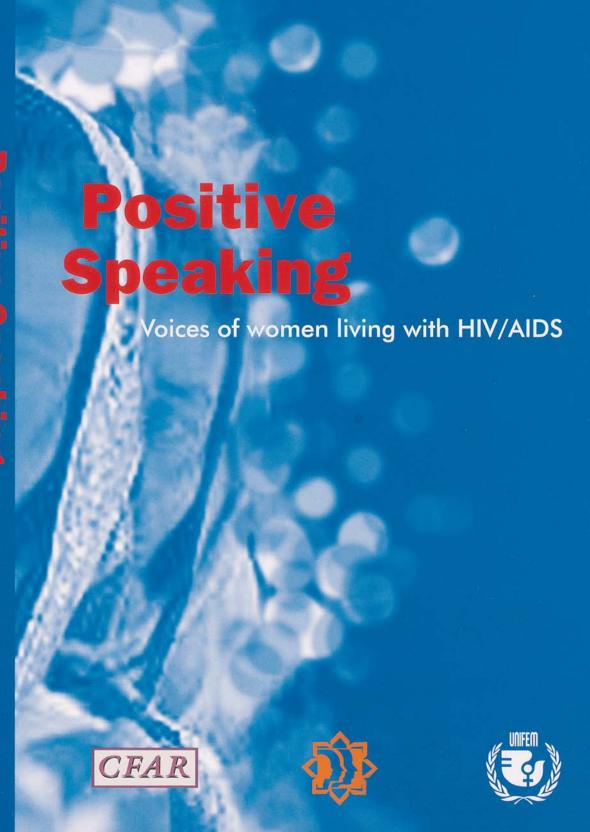
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# Positive Speaking Voices of women living with HIV/AIDS

Study conducted by

Centre for Advocacy and Research, New Delhi Positive Women's Network, Chennai

Supported by



United Nations Development Fund for Women UNIFEM South Asia Regional Office New Delhi, India

Positive Women's Network
Council of People Living with HIV/AIDS in Kerala
Karnataka Network of Positive People
Centre for Advocacy and Research
and
United Nations Development Fund for Women

Would like to thank
All the Women

for sharing their experience with the conviction that it will better the lives of other women

This documentation is a tribute to their strength and courage

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#### **Foreword**

The national consultation 'Positive Faces and Voices of Women from India', on women living with HIV/AIDS, organized by the Positive Women's Network (PWN+), Chennai supported by NACO, UNAIDS and UNIFEM at Chennai in March 2002, was a historic moment in the lives of many women. Not only did it profile women's leadership and struggles, it also provided the space and the mandate to deepen the understanding of the gender dimensions of HIV/AIDS within the rights framework. Key recommendations included legal awareness and literacy, documentation of human rights violations of women affected by HIV/AIDS, learning about CEDAW so as to advocate for rights and find ways of addressing stigma and discrimination.

The study, 'Positive Speaking: Voices of Women Living with HIV/AIDS' was initiated by the Centre for Advocacy and Research, New Delhi in collaboration with Positive Women's Network, Chennai and their members in the three states of Karnataka, Kerala and Tamil Nadu. The entire process has been one of learning and reflection, painful and joyful, as it continually brought forth new challenges and showcased the courage, determination and leadership of the women living with HIV/AIDS as well as that of their support networks.

UNIFEM's work on HIV/AIDS addresses gender inequalities and women's rights as well as responses to the gendered impact of HIV/AIDS. The trajectory of HIV/AIDS is clearly demonstrating that gender inequality fuels the epidemic. Feminized poverty and discrimination against women and girls intersect to contribute to increasingly higher prevalence rates as also that there is a large unrecognized burden of care that women shoulder in providing support to family members. Women need to play a central role in HIV/AIDS, prevention, treatment and care. They have the experience, insights, skills and expertise and they need to be an integral part of policy and programme formulation.

We greatly value our association and partnership with PWN+. They have guided our thinking, challenged us, provided expert inputs at consultations and trainings and have led the many advocacy processes. They are determined that their personal struggles become the basis of transformation in the lives of all women. Besides they have catalyzed strategic linkages with women's organizations, media,

UN agencies as well as the National Commission for Women, to leverage support for women living with HIV/AIDS. We are also very privileged to partner CFAR in this study and appreciate their deep commitment in creating the spaces for many women to travel together in this learning and transformative journey.

I take this opportunity to congratulate and applaud the courage and commitment of members of the PWN+, most particularly Kousalya, Bindu and Asha. I extend my appreciation to Akhila Sivadas, Aarthi Pai and Shyamala Shiveshwarkar and their team at CFAR. I would specially like to thank Dr. Poornima Advani, Chairperson, National Commission for Women, in extending support to the study.

I would like to extend my appreciation to Dr. Meenakshi Dutta Ghosh, Additional Secretary and Project Director National AIDS Control Organisation, Ministry of Health and Family Welfare for her valuable contributions. A special thanks to Dr. P.L. Joshi, Additional Project Director, NACO and to the Project Directors of the State AIDS Control Societies, in the three states, for taking keen interest and responding creatively to the challenges that emerged from the study.

My heartfelt appreciation to the members of the Technical Team - Dr. Shalini Bharat, Tata Institute of Social Sciences Mumbai, Ms Vaishali Mahendra, Population Council; Geeta Ramaseshan, Advocate, Tripti Tandon, Lawyers Collective, Mr. S. M. Afsar, ILO for their expert inputs.

I am sure that the recommendations that have emerged from the study will be useful in effectively advocating for and advancing women's rights. Women have the right to live a life free from violence and stigma.

We, at UNIFEM, believe that 'Equality is Positive and that there is much more to Positive than HIV'.

Chandni Joshi

Regional Programme Director

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#### **List of Abbreviations**

**ARV** : Anti-Retro Viral

**CEDAW** : Convention on the Elimination of all forms of

Discrimination Against Women

**CFAR** : Centre For Advocacy and Research

CPK+ : Council of People Living with HIV/AIDS in Kerala

CRC : Child Rights Convention

**CSW** : Sex Worker

DFID : UK Fund for International Development

FGD : Focus Group Discussion

GH : General Hospital

HIV/AIDS : Human Immune Virus / Acquired Immune Deficiency

Syndrome

KNP+ : Karnataka Network of Positive People **KSAPS** : Karnataka State AIDS Prevention Society

KSACS : Kerala State AIDS Control Society

LIC : Life Insurance Corporation

**PMTCT** : Prevention of Mother- to- Child Transmission

MTP : Medical Termination of Pregnancy NACO : National AIDS Control Organisation **NFHS** : National Family Health Survey

**NIMHANS** : National Institute of Mental Health and Neurological

Sciences

PHC : Primary Health Centre **PLWHA** 

: People Living With HIV/AIDS

**PPTCT** : Prevention of Parent to Child Transmission

PWN+ : Positive Women's Network STD : Sexually Transmitted Disease STI : Sexually Transmitted Infection

**TANSACS** : Tamil Nadu State AIDS Control Society **UNAIDS** : Joint UN Programme Aagainst HIV/AIDS **VCTC** : Voluntary Counselling and Testing Centre

## **Glossary of Indian Terms**

Ayah A woman taking care of children

Ayurveda Traditional system of medicine practiced in India

Beedi Local cigarette made of tendu leaves

Coolie Person engaged in physical labour of loadingand

unloading heavy goods

Gram panchayat /panchayat Elected council at the village level

Jatha Folk theatre

Lakh 10 lakhs = 1 million Mama Maternal uncle

Mangalsutra /thali Chain or thread worn by women as a symbol of

marriage

Mela Local fair
Pujari Hindu priest

Rakhi Indian festival celebrating the bond between

brother and sister

Siddha Traditional system of medicine practiced in

southern India

Sovereign A measure to weigh gold

Taluka Sub-district
Tola 1 tola = 10 gram

UNIFEM is the women's fund at the United Nations. It provides financial and technical assistance to innovative programmes and strategies that promote women's human rights, political participation and economic security. UNIFEM works in parternship with UN organizations, government and non-governmental organizations (NGOs) and networks to promote gender equality. It links women's issues and concerns to national, regional and global agendas by fostering collaboration and providing technical expertise on gender mainstreaming and women's empowerment strategies.

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## **Introduction**

"Women living with HIV/AIDS are often blamed, ostracised or thrown out of their homes, while care is provided to the infected male partner. They are also denied access to training, shelter, and care and support."

Dr. Shalini Bharat

#### **Background**

Existing studies on Gender and HIV/AIDS, have extensively documented such factors as low levels of awareness, spiralling violence within the home and limited access to healthcare, as being responsible for the growing incidence of HIV/AIDS among women. These studies emphasise that in the context of gender and HIV/AIDS these vulnerabilities translate into a lack of negotiating power and capacity to regulate or minimise the risk of exposure to HIV/AIDS. This not only heightens the chances of being affected by HIV/AIDS, but also makes it quite evident that many of the rights conferred on women remain in the realm of *de jure* rights rather than *de facto* rights.

A sample of the major data presented in support of this argument is:

- A behavioural study conducted in 2001¹ found that although 75 per cent were aware of the benefits of using a condom to prevent transmission, a break up of urban-rural and male-female responses showed a skewed picture. While 80 per cent of the urban men were aware of the protective value of condom use, in contrast, a mere 43 per cent of rural women knew about this.
- A UNIFEM supported community-based gender study<sup>2</sup> conducted in Delhi,
   Pune, Chennai and Guwahati, found that men learnt of the protective value

<sup>1.</sup> National Baseline High-Risk and Bridge Population Behavioural Surveillance Survey, Ministry of Health and Family Welfare, NACO, New Delhi 2002.

<sup>2.</sup> Gender dimensions of HIV/AIDS: Community based studies, ISST, UNIFEM, New Delhi 2000.

of condoms only after they were affected. Consequently, they found it difficult to initiate condom use because they did not want to make their wives suspicious.

- A study done in Karnataka<sup>3</sup> on the effect of violence on women's health, revealed that a shocking 31.4 per cent of the respondents had been subjected to marital violence. With the National Crime Records Bureau reporting a steady increase in incidence of violence against women<sup>4</sup>, the linkage between this adverse development, women's health and HIV/AIDS is becoming increasingly evident.
- The National Family Health Survey II, found that between 1995-99, only 34 per cent of women had taken recourse to institutional delivery and care. Clearly, structural constraints like work status, distance, affordability, status within the household and the community are seriously impeding women's access to quality health care and discouraging health-seeking behaviour. (For further details please refer to Annexure 1).

#### What are the implications of these findings?

These findings indicate that the pervasive fear of violence and lack of access to basic services not only compounds the problem of low levels of awareness but also contributes to women's vulnerability. It limits women's ability to negotiate safe sexual practices, essential in protecting themselves against HIV. In fact, there is ample evidence that when a woman tests positive, she is more likely than not to experience violence, intimidation and abandonment by her friends, family and community.

Moreover, the dismal record of health care services combined with the unacceptable levels of stigma and discrimination impact women more forcefully and preclude them from carrying out their day-to-day activities and caring for affected partners.

Given these imperatives, UNIFEM decided to support the efforts of positive networks to deal with gender discrimination, by empowering positive women using a human rights approach. In a consultation organised by the positive networks in 2002<sup>5</sup>, participants living with HIV/AIDS described their experiences vis-à-vis the denials of basic services. Consequently, the network expressed a need to document these denials within a human rights framework.

<sup>3.</sup> Reported in "Violence against women and HIV/AIDS: Setting the agenda". WHO - Geneva, October, 2000.

<sup>4.</sup> National Crime Records Bureau, India 2000.

<sup>5.</sup> Reported in 'Positive faces and voices of women from India'. Supported by UNAIDS, UNIFEM, Chennai, India March 2002.

Given this assessment, the purpose and objective of the study was to identify and formulate the following:

- To document how the intersection between individual and social vulnerability takes place and impacts the lives of women living with HIV/AIDS.
- To find out to what extent positive women feel confident that institutions managing the response have an adequate appreciation of the complex challenges that they face.
- If they regard the response as inadequate, to get them to examine the factors contributing to it. Do they attribute it to a lack of understanding and sensitivity to their circumstance? Or do they feel, that it is because of deep-seated structural constraints?
- To elicit the views of stakeholders on their strengths, limitations, opportunities
  and the challenges they face in managing, administering and implementing
  interventions to prevent the spread of HIV/AIDS among women.

To meet these objectives, the Centre for Advocacy and Research (CFAR) and the Positive Women's Network (PWN+), conducted a primary documentation of experiences of women living with HIV/AIDS in Karnataka, Kerala and Tamil Nadu.

#### **Preparatory process**

The first step in the process was to evolve a shared mandate on the study. A National Consultation conducted in January 2003 helped to shape this mandate. A cross-section of concerned people, institutions drawn from diverse stakeholders were present at this Consultation.

Key official focal points and institutions including the National AIDS Control Organisation, Department of Women and Child Development, and the National Commission for Women provided their inputs at the deliberations. So also the Tata Institute for Social Sciences, Lawyers Collective, Population Council of India and donor agencies such as ILO and UNAIDS.

#### The main objectives of the Consultation were:

- To ensure that the study reflects a continuity, learns from past initiatives and takes it forward.
- To enable the sharing and exchanging of experiences about on-going initiatives on this issue.

• To evolve a consensus on the framework, approach, checks and balances that should inform the study design.

Given these objectives, it was decided at the Consultation that CFAR would present a review of available literature and PWN+ would present a situational assessment.

#### Presenting a situational assessment

Having internally reviewed their experiences and prioritised their concerns, *PWN*+'s situational assessment highlighted the major day-to-day challenges that positive women were facing while raising concerns about how their voices can be heard and acted upon. *(For details please refer to Annexure 2).* 

Their central concern was that though the situation had altered over the last few years and stigma and discrimination had been reduced to some extent with an increase in levels of acceptance, yet much of this was the exception rather than the rule. Moreover, while some of this change could be attributed to the intense work that different stakeholders including positive networks were doing, the scale was not critical enough to enhance the confidence of a large number of positive people, encourage them to reveal their status, demand services or strengthen the preventive efforts. Some examples of the quandaries they face was evident in the kind of testimonies that they presented as a part of their situational assessment.

In one instance, they pointed out that although a leading eye hospital in Chennai was willing to provide clinical services to people living with HIV/AIDS, they insisted that positive people self-administer their eye drops. In another instance, a leading doctor in charge of the STD department of a Government hospital tried his best to get his specialist colleague to do surgery on a positive woman suffering from an acute gastro-intestinal problem. Despite repeated requests, the concerned practitioner was unwilling to undertake the surgery, compelling the hospital to transfer the woman to a TB Sanatorium, where she was temporarily administered anti retro-virals and finally, discharged without appropriate treatment. According to the network members, she, like countless other women, was not only denied her rights, but was also a victim of callous medical negligence.

Therefore, the *two major challenges* that they emphasized were:

 Given the entrenched gender discrimination that women face in their private and public sphere, the challenge of living with HIV/AIDS was daunting. The existing social practice of burdening women with all the responsibilities
of a caregiver, without extending any social support to her, not only persisted
but assumed inhuman proportions for positive women.

#### Adopting a rights-based approach

From the situational assessment, it was amply clear to them that any future efforts to document the **experiences** should be based on a rights-based approach. More importantly, it must stand the test of reflecting the daily experiences of positive people and be able to use a pragmatic approach.

However, it was also necessary to *empower* CBOs like positive networks, so as to enable them to adapt the approach to their experiences and *assess* the relevance and potential of various legal instruments in transforming their lives. It was suggested that the documentation should not only highlight the stigma and discrimination that positive people face but also examine the causative factors leading to these discriminations and the solutions and strategies necessary to deal with these challenges.

#### Stakeholder response

**Stakeholders** provided a range of **responses** to the **dilemmas** presented by the network. In this connection Dr. Joshi, Joint Director, National Aids Control Organisation (NACO) opined that positive networks could be key partners in implementing responses such as the Prevention of Parent to Child Transmission (PPTCT) and voluntary counselling and testing programmes. Reiterating this statement, Ms.Meenakshi Dutta Ghosh stated that the issues surrounding stigma and discrimination raised by the positive women's network are indeed compelling and no one even remotely concerned with managing the response to HIV/AIDS can underestimate its centrality.

Dr. Poornima Advani, Chairperson of the National Commission for Women, extended the support of the Commission to the documentation process and in taking forward negotiations with stakeholders<sup>6</sup>.

Sharing the findings of a recently concluded study, on the socio -economic impact of HIV/AIDS, Mr. S.M Afsar, National Project Co-ordinator, ILO, stressed

<sup>6.</sup> In July, 2003, the National Commission for Women and UNIFEM facilitated a meeting to discuss the findings of the present study with key stakeholders such as State AIDS Control representatives, Department of Women and Child officials and representatives from donor agencies and non governmental organisations.

the necessity for studies to include the stories of women outside the network. This would ensure that they could partner the network.

Drawing on earlier studies on stigma and discrimination, Dr. Shalini Bharat, Tata Institute of Social Sciences, said that such studies on the experiences of positive people had clearly indicated that discrimination against people living with HIV/AIDS was part of a larger process. However, many issues were specific to certain categories such as women. Consequently, there was a need to understand what these women were seeking and how they were negotiating with programme implementers.

To make the design of the study sensitive to the needs of positive people, the following **suggestions** were made:

- Nest the concerns and experiences of women living with HIV/AIDS, in the context of larger issues and every day realities.
- Since a multi-sectoral effort is required to eliminate stigma and discrimination the documentation must engage with the experience of different stakeholders.
- Document overt and more subtle forms of discrimination and positive and negative experiences so as to understand the exact manifestations and forms of stigma and discrimination.
- Include within the individual testimonies a section of women outside the organizational framework of the network.

#### **Exploring the human rights framework**

The major challenge for the research process, was to develop an approach that could factor in the historical marginalisation of women, the life cycle approach to women's problems and the inter-generational dimension of discriminations that women experience at the household and societal level.

At the Consultation, there was a consensus amongst activists and people living with HIV/AIDS that given a polity that constantly affirms democratic values and yet, harbors the most discriminatory practices, it was essential to work within a legal framework that will centre-stage gender rights and entitlements<sup>7</sup>.

<sup>7.</sup> Centre For Advocacy and Research and the Positive Women's Network undertook four separate training sessions on understanding human rights instruments, centre- staging CEDAW to negotiate gender concerns, and conducting a documentation process. The initial training consultation in Chennai was facilitated by Population Council, Lawyers Collective and Geeta Ramaseshan who provided a legal and research framework within which the documentation could be conducted.

#### Building a perspective on human rights

The focus of the capacity building of network members was to move beyond imparting legal education to strengthening their conviction about law as an instrument of social transformation. Therefore, the workshops provided a space to brainstorm on the relevance of human rights instruments and to arrive at an understanding of how specific concerns related to access to law, precedence and the capacity to negotiate with State obligations can be strengthened. This was not an easy task for the positive women, given their reality check. Having experienced the mismatch that exists between *de facto* and *de jure* rights, their confidence in being able to leverage such instruments was not very strong. Consequently, the women began with a high level of diffidence. They felt that it was not realistic for them to expect that they could access legal provisions and safeguard their day to day rights and entitlements.

In order to address the gaps in knowledge and remove the mental blocks that prevail on accessing the law, the workshops imparted legal education as well as information about legal struggles, waged by different groups. These groups often used instruments such as writ petitions and presentation of alternative reports to expand the interpretation of rights. Having understood the complexities of national and international law, the interactive process began to deal with the application of these instruments, within the realm of women's experiences. Indian and international case laws, that were interpreting the rights of individuals affected by HIV/AIDS within *existing* legal structures, such as their right to confidentiality; non-discrimination in employment, health care and marriage were discussed in detail. These deliberations helped the women to realise that the *efficacy* of *law* was not determined by just the *quality* of the *statute*. *And that Civil society* structures were also needed to actively *engage* with the *law* and get it interpreted favorably, so as to address the multi-faceted discrimination they faced.

However, the critical turning point for the women came, when they learnt about the process of reporting by the State to the International Committee that monitors the progress on the implementation of CEDAW. In the year 2000, the Committee on the Status of Women had lauded the numerous efforts made by the Indian Government to empower women and also listed the many unfinished tasks and obligations they had to fulfill.8 Women living with HIV/AIDS, were specially mentioned as a group requiring unflinching support from the State, in order to combat the unbearable levels of stigma and discrimination. Suddenly,

<sup>8.</sup> Report of the Committee on the Elimination of all forms of Discrimination Against Women, United Nations, New York, 2000.

there was a feeling amongst the network members, that they had to deal not with uncertain outcomes, but with the process and instrument of negotiation and reaching out. Emerging from this newly-found conviction, the women identified *six significant concerns* that needed placing within a rights discourse. These were:

- Health care and treatment: Their main concerns were mandatory testing under PPTCT without consent, abortion without adequate counselling and denial of information on ARV (Anti-Retro Viral).
- Property, succession and inheritance within their natal and marital homes,
- · Access to reproductive rights and health.
- · Livelihood opportunities.
- Decision-making powers.
- Access to benefits.

In keeping with this imperative, the network found that the Convention for the Elimination of all forms of Discrimination Against Women (CEDAW) was the most inclusive and comprehensive human rights instrument.

#### **Appropriateness of CEDAW**

The network found that CEDAW recognized a range of circumstances, challenges, forms of discrimination and subordination as inimical to human rights and equality. The Convention also recognizes the fact that along with civil and legal rights, it is necessary to address 'dimensions of human reproduction as well as the impact of cultural factors on gender relations.' It further imposes obligations on the State and makes it centrally accountable for the process of delivery of rights for reducing and eliminating these discriminatory practices.

The broad area of concerns that needed to be documentated emerged as the following :

- Discrimination against women.
- Access to basic rights including right to life accentuating vulnerability of the girl child.
- · Freedom from violence and abuse.
- Sharing with men the burden of care and the economy of care.
- Property and inheritance rights.
- Women's access to HIV/AIDS care and treatment.

#### Ethical norms guiding the research process

From the onset, a key concern that has defined and underscored the research has been the development of ethical norms to guide the process. Given the fact that the research was primarily a qualitative process of documentation of experiences, some overarching issues needed to be addressed. These were extensively debated during the consultative process and the interactions with network members. They were broadly categorised as the need to:

- · Maintain the confidentiality of participants.
- Ensure that no harm comes to the participants during the research process.
- · Benefit the participants in the process.
- Maintain the rights and the dignity of the participants.
- · Respect the privacy of the individual.

**Maintaining confidentiality** of women participating in research also had attendant concerns of informed consent. Given the fact that often women participating in the research were from the rural areas, accessibility was a key factor in devising the methodology.

To ensure that the consent obtained was informed and participatory, the research team met the respondents over two or three sessions. This encouraged mutual sharing of experiences and provided the respondent ample opportunities to withdraw from the documentation process. From the network member's point of view, sharing her experiences and reflecting from a rights-based perspective on the violations and infringements, helped the respondent locate her violations within a framework of entitlements.

It was recognized that the process of documentation would often cause renewed grief and re-living the trauma. Hence, the dilemma of ensuring that **no harm** came to the participants was a difficult issue to tackle. Many network members who participated in the research, were also trained counselors, who on numerous occasions saw the need to stop the process. Additionally, **participatory sharing** by network members, helped the respondents realize that they were not "alone" in their predicament, which lent further strength to their resolve to participate.

To ensure that the **respondents benefit** from the process, it was decided during the consultative process and at the brainstorming sessions, that the research team should be equipped with information about a referral network of Voluntary Counselling and Testing Centre(VCTC) counsellors, supportive doctors, lawyers and other people.

At all points of time, the *dignity of the respondent and her rights* were of paramount importance. This principle was understood and translated by explaining the process of research and its objectives, and encouraging the respondent to question the research team on its applicability.

Further, during the course of defining the parameters of the study, it was established that the research study would only dwell on the respondent's perspective of key violations in her experiences, her struggles to emerge from those violations and her process of negotiations with the systematic denials.

However, given the inextricable links between the personal story and the larger struggles to cope with denials, the brainstorming sessions dealt with the dilemma of avoiding potentially 'voyeuristic' details, which would amount to an invasion of *privacy of the individual*.

Extensive training and brainstorming sessions were held with the members of the network in the three States to train and enable them to undertake the research study, with the CFAR technical team playing only a facilitating role.

#### Tools of research

The research process was conducted through three tools – *focus group discussions*, *case studies* and *informant interviews* with stakeholders. Detailed guidelines were prepared on the areas of inquiry for the tools of research, which were developed after a series of consultations held with stakeholders and amongst members of the positive networks.

The efficacy of the guidelines for each of the tools was reviewed by the research term during a mid-project review. The qualitative tools used, sought to strengthen the experiential sharing and to facilitate the exploration collectively and individually of the relevance of human rights at the level of self or collective analysis, drawing lessons and seeking alternatives.

The **research team** included one member of the Centre for Advocacy and Research (CFAR) and one or two members of the positive network. The representative of CFAR provided a technical check for the network members.

Case study documentation through in-depth interviews would be carried out with the respondents. The process of identifying and conducting these interviews included:-

#### 12 Positive Speaking

- Given the growing shift of the epidemic, from a predominantly urban to a
  more rural 'face', it was necessary to locate a greater representation of
  respondents within a *rural set up*.
- To access respondents, the research team contacted various civil society organisations, local networks and support groups.
- After explaining the research process and the requisite profile of the respondent, the organisations were asked to seek consent from women who matched the required profile, to meet with the network member on the research team.
- The network member made first contact with the respondent to clarify
  the purpose and method of the research, the process and type of information
  sought from the respondent.
- A preliminary session between the research team and the respondent
  was undertaken, wherein the individual respondent provided a brief sketch
  of her experiences.
- After giving the respondent time to withdraw from the research study, the second and third sessions were conducted.

Many respondents individually revealed a high degree of self-analysis, using the process to critically evaluate their own experiences and the presence or the lack of a human rights instrument there in.

Twenty-one case studies were undertaken in the three states. There were many instances when the respondents became too emotional mid -way through the sessions and the process had to be abandoned. This was much more evident during the Kerala leg of the study which is consequently reflected in the lower number of case studies that have been documented in that state. However, the network members did refer the respondents for counselling, legal advice and appropriately followed up on them.

Fifty-five informant interviews were undertaken with key stakeholders. They included people:

- Affected by the concern.
- Engaged with the concern over an extended period.
- Defining and developing policies and strategies.
- Implementing these policies at various levels both within the government structure and at programmatic levels.

The people interviewed were located under three broad categories:

- Policy makers: These included State ministers, members of Parliament, members of legislative assemblies, State AIDS officials, district level officials.
- Health Care Professionals: Doctors, nurses, paramedics, field level health workers, counsellors.
- Civil Society Organisations/Opinion makers: Lawyers, academicians, community based-organisations.

Participants in the informant interviews, not only sought to establish their own roles individually and for the entire group, but also extended it to draw lessons for their entire group and seek alternative strategies. In the process decisions were taken about the relative strength of the tools and its appropriateness. To make the study cohesive and purposeful, it was decided to use individual testimonies and informant interviews. The focus group discussions with a cross-section of the stakeholders and people affected by HIV/AIDS, were used to validate both these tools.

Six focus group discussions were held with people affected by the concern and professionals working on related issues such as health professionals, State AIDS control representatives, academics and social workers and the media. The discussions sought to highlight key concerns, which had emerged during the documentation, the strategies that had been evolved to effect change and recommendations for future approaches. Issues that were discussed threadbare and included:

- Care and treatment.
- Counselling and consent.
- · Sensitivity of health care professionals.
- Insurance claims and benefits.

#### Recording data

The case study documentation was recorded on tape with due informed consent obtained from the respondent. Interviews and case study documentation were conducted in Malayalam, Tamil and Kannada and handed over to the network for transcription and translation. Network members also translated field notes compiled by the research team to facilitate analysis by the research team. The mid-project review also incorporated suggestions from the research team to improve the format of recording data.

#### Areas of study

The study was undertaken in three states in southern Indian—Kerala, Karnataka and Tamil Nadu—where the networks of positive women have gained some ground in addressing issues of women living with HIV/AIDS. Of these Karnataka and Tamil Nadu have been declared as high prevalence states by the National AIDS Control Organisation (NACO). By the same criteria, Kerala is still a low prevalence state. Three districts each were chosen in Karnataka (Bangalore, Mangalore and Mysore) in Kerala (Tiruvananthapuram, Thrisshur and Ernakulam) and in Tamil Nadu (Chennai, Namakkal, Coimbatore, Perambalore and Erode).

#### Area profiles

**Karnataka** (all statistics provided by KSAPS - Karnataka State AIDS Prevention Society unless otherwise specified):

Karnataka's geographic position is to some extent responsible for the high

#### Karnataka:

Area: 1,90,498 sq. km.
Ranks 8<sup>th</sup> amongst states in terms of size.
Population of 5,27,33,958

Rural Population: 66%
67% are literate.
59.7% in rural areas.
76.3% are males.

Source: Government of Karnataka.

prevalence of HIV/AIDS in the state located as it is in the centre of the southern peninsular with three high prevalence states on its borders — Maharashtra, Tamil Nadu and Andhra Pradesh. According to KSAPS, 14,325 cases were recorded between 1987 and December 2002, of which, 35 were in December 2002 alone.

Railway lines and several national highways criss-cross the state, enabling high rates of mobility. Non-government organisations (NGOs) working among truckers say that almost 50 per cent of truckers who come

into the state belong to the town of Nammakal in Tamil Nadu. Tourism also brings in a huge floating population, while poverty and the lack of job opportunities are forcing thousands to migrate into and from the state.

Compared to figures for the state's 27 districts, *Bangalore*, the state capital and India's 'IT City', has the highest prevalence of HIV+ cases in Karnataka—4,156 of the 14,325 cases recorded in the state between 1987 and December 2002. And this is only increasing. Regarded as a city of opportunities, it is accessible by air, road and rail and its cosmopolitan ambience is indicative of large-scale mobility and migration both inter-state and intra-state. Better access to testing and care, and support facilities have also contributed to the rise in

prevalence rates. Though VCTC (Voluntary Counselling and Testing Centre) facilities are available in all districts, people tend to prefer the health care services - ranging from allopathic to *siddha* - available in Bangalore. Patients come not just from all parts of the state but also from Andhra Pradesh and Maharashtra, often for reasons of confidentiality.

According to statistics provided by Kidwai Cancer Hospital, the number of positive cases among its patients has gone up from 34 in 2000 (of which 21 were from urban areas and 13 from rural) to 60 cases in 2002 (35 urban and 25 rural). The city also has numerous NGOs running clinics and counselling services, among which there are four well-known care centres for people living with HIV/AIDS. Many also avail of the counselling and referral services being provided by KNP+ since its inception in 2001.

**Mangalore**, the second biggest city in the state after Bangalore, accounts for 1,097 of the cases recorded during 1987- 2002 and for much the same reasons as the high prevalence in the capital. Its busy harbour and related commercial activities brings in thousands of migrant labourers from north Karnataka with high-risk activities. An additional factor that is contributing to the high prevalence rates is its proximity to Mumbai and Kerala.

The availability of good health care facilities and excellent care and support services by NGOs and religious missions like the Camillus Brothers for people living with HIV/AIDS is another factor influencing the high-prevalence records. KMC Hospital is, for instance, regarded as being particularly HIV friendly and it draws patients from all over the state and elsewhere. According to Dr. John (KMC Hospital), over a 1,000 patients have been treated at KMC since its HIV facilities were started in 1997 and anywhere between 40 to 50 patients come regularly for follow-up treatment. Earlier, they saw about two cases a week. Now it is four or five a day.

*Mysore*, the former state capital, is also reporting increasing incidence of HIV. The number of Tuberculosis (TB) patients with HIV/AIDS has gone up from four in 1995 to 100 in December 2000, according to statistics provided by the hospital superintendent, Dr Y. Lakshman, while KSAPS registered 259 new cases. Tourism is seen as a major contributing factor to the incidence of HIV/AIDS in Mysore, as also the fact that Bangalore is just three hours away by road. Mysore also has the distinction of having the only temple to HIV/AIDS in the world.

**Tamil Nadu** (All statistics provided by Government of Tamil Nadu web site unless otherwise specified).

Tamil Nadu has the highest number of HIV/AIDS cases<sup>9</sup> among all Indian states. The first diagnosed case of HIV/AIDS (as early as 1986) in the country, was in Chennai.

Given the HIV/AIDS situation, the state government set up a State Project Cell in 1992. Two years later, the Tamil Nadu State AIDS Control Society (TANSACS) was formed for smooth implementation of HIV/AIDS prevention and control activities. Besides TANSACS, many NGOs are involved in creating awareness and implementing intervention programmes. In fact, at 388, Tamil Nadu has registered the highest number of NGOs working on HIV related issues.

District cumulative of HIV/AIDS cases	-
Chennai	1457
Namakkal	352
Erode	371
Coimbatore	161
Perambalore	145
Source:Department Govt. of Tamil Nadu	-

Several demographic groups with risk-prone

lifestyles such as sex workers, truckers and migrant workers have been identified for targeted intervention projects to promote safe sexual behaviour in the 30

administrative districts.

 Tamil Nadu:

 Area
 : 130.058 sq. km

 Population
 : 62,11,839

 Literacy
 : 73.5 %

 Urban Population
 : 43.9 %

TANSACS is currently seeking participation of private hospitals in training and sensitisation programs.

Source: Govt. of Tamil Nadu

**Agriculture Sector Workforce:** 

The state capital *Chennai* has the second highest population. According to the National AIDS Control Surveillance Report 2001,

Chennai was registered as having the highest number of HIV cases in the state. The non-agricultural sector employs most of the working population.

49.5 %

Industrial production is focused around Chennai and includes textiles, engineering and petrochemicals. Given the large influx of workers from the neighboring districts and states, it is vulnerable to HIV/AIDS.

Chennai: 2<sup>nd</sup> highest population in the State divided into 5 *talukas*Literacy 80.1 % (4<sup>th</sup> in the state)

<sup>9. 24,667</sup> as per the HIV/AIDS Surveillance data, reported by NACO, 31 May 2003.

The state government run 700-bed Tambaram TB sanatorium, has the largest number of people living with HIV/AIDS housed in a single hospital in India. Today, it is a recognized institution that draws people from several other states

Perambalur: Six talukas
1700 villages
82 % people dependent on
agriculture (highest in state)
Major crops: Paddy, groundnut,
sugarcane, millets and cashew.

including Maharashtra, Andhra Pradesh, Karnataka and Kerala. Though supported by the state government, the hospital is also funded, mainly for treatment drugs, by TANSACS.

Perambalore is divided into six talukas (sub-divisions). A semi-arid region, despite the Cauvery river flowing through the district, agricultural activity is dependent on rainfall patterns and the economy of the area is often disturbed due to this dependence. Consequently, agricultural activity is on for only six months in a year, and thereafter people have to look for other sources of employment. Given the paucity of jobs, there is a high degree of migration to the nearby gypsum guarries and cement factories.

According to district officials in Perambalore, the presence of nearby cement factories, the garment industry in nearby Karoor and the traffic running along the national highway contribute to the large migratory population in the district. A small and remote area accessible only by bus from the nearest railway station at Ariyalor and Tiruchurapalli, Perambalore has many people visiting it on account of the nearby quarries. However, facilities such as PPTCT are yet to reach this district and women living with HIV/AIDS often have to be referred to Tiruchurapalli even for regular ante-natal care and delivery.

The land-locked *Erode* district lies in the extreme north of Tamil Nadu. The seven *talukas* forming this long, undulating plain are characterized by scanty rainfall and a dry climate.

On the industrial map of Tamil Nadu, Erode occupies the 15th position with 45 per cent of the population dependant for their livelihood on the non-agricultural sector (Census 2001). Being a prominent trading centre in the state, it is well connected with all modern means of transportation and communication.

**Namakkal** district, with a population of more than 1.5 million, is among the hardest hit by HIV/AIDS in the country, both in terms of prevalence and impact. A prominent trucking and rig center of southern India, men migrate for work to states as far as Uttar Pradesh and Rajasthan. The high mobility and relatively high disposable income, are factors contributing to the high HIV prevalence rate.

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Currently, according to the project director of TANSACS, a 'special ward' has been created in the General Hospital at Namakkal to ensure that people living with HIV/AIDS are not refused treatment. The special ward has health care personnel trained in 'Universal precautions'<sup>10</sup>. According to the Project Director of TANSACS, efforts are currently underway to replicate the process and impart universal precaution training to health care personnel in other district general hospitals.

**Coimbatore** district lies in the western part of Tamil Nadu. Surrounded by the Nilgiri hills it shares a border with the neighboring state of Kerala. Coimbatore is the third largest city of the state and one of the most industrialized. Known as the textile capital

Coimbatore: Population 42 lakhs 3<sup>rd</sup> largest city of Tamil Nadu Nine *talukas*Literacy – 77 % (9<sup>th</sup> in state)

of South India, the city is located on the banks of the River Noyyal. Over 70 per cent of the population is engaged in the non-agricultural sector, placing the district in the fourth position, economically within the state.

**Kerala** (all statistics provided by Government of Kerala, 2001, web site unless otherwise specified).

Kerala, is the most advanced state in India in terms of literacy, health and education. In fact, it has a much better physical quality of life index than the average for the country. But agriculture - with an emphasis on agricultural exports - being the main contributor to the state's economy, large numbers of literate people from Kerala migrate to metropolitan centres like Bangalore and

Kerala: 14 districts
Total population: 31,838,619
74 % people live in rural Kerala
Life expectancy: 72 years against Indian
average of 61 years.

**Literacy: 90.1 %** 

Mumbai for better prospects. This factor heightens the vulnerability of the population, especially within the younger age group, to HIV/AIDS.

Bound on the east by the Western Ghats and in the west by the Arabian Sea, agriculture contributes most to

<sup>10.</sup> Universal Precautions, are a set of precautions designed to prevent transmission of human immuno-deficiency virus (HIV), hepatitis B virus (HBV), and other blood borne pathogens when providing first aid or health care. Under universal precautions, blood and certain body fluids of all patients are considered potentially infectious for HIV, HBV and other blood borne pathogens. Universal precautions apply to blood, other body fluids containing visible blood, semen, and vaginal secretions, and cerebrospinal, synovial, pleural, peritoneal, pericardial, and amniotic fluids. Universal precautions do not apply to feces, nasal secretions, sputum, sweat, tears, urine, and vomit unless they contain visible blood.

Blood screening cumulative figures, 2001 Trivandrum 640 Ernakulam 227 Thrissur 635

Source: Department of Health, Govt. of Kerala

the state's income in the primary sector. *Trichur* is an important railway station on the southern railway and is linked to most major towns inside and outside Kerala.

On the basis of the existing Sentinel Surveillance data<sup>11</sup>, Kerala falls within Group II, indicating moderate

HIV prevalence, with the rate of 5 per cent or more among high HIV risk behaviour groups but below 1 per cent among ante-natal women.

In the 14 districts of Kerala, there are 20 STD clinics identified by NACO, of which, 16 have been provided with counsellors by the Kerala State AIDS Control Society (KSACS). The Kerala State AIDS Control Society works in partnership with the State Management Agency (SMA), supported by DFID. The State Management Agency, constituted in 1997,

provides project support for targeted intervention strategies to the Kerala State AIDS Control Society.

**Ernakulam** district, ranks 8<sup>h</sup> in terms of size in the state. The gender gap in the literacy rate is 5 per cent. It is the most industrially developed district in the state, with the highest number of registered working factories and industrial workers. Kochi is the commercial and

Ernakulam District Area 10,852 Population 3,098,378 Thiruvananthapuram Area 2,195 sq. km. Population 29 million

industrial capital of Kerala. It has one STD clinic identified by NACO, namely the General Hospital, Ernakulam. *Thiruvananthapuram* has three NACO identified STD clinics.

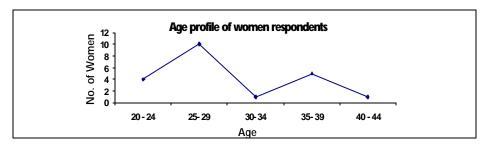
In terms of health care, Kerala has been able to ensure at least one health centre for every 1.5 village enabling it to provide ante-natal care to 97.3 per cent of women.

Universal precautions involve the use of protective barriers such as gloves, gowns, aprons, masks, or protective eyewear, which can reduce the risk of exposure of the health care worker's skin or mucous membranes to potentially infective materials. In addition, under universal precautions, it is recommended that all health care workers take precautions to prevent injuries caused by needles, scalpels, and other sharp instruments or devices.

<sup>11.</sup> During the year 2002, the sentinel surveillance was conducted from 1st August to 15th November in 384 sentinel sites. The risk group wise distribution of these sites is - 166 sites in STD clinics, 200 sites in antenatal clinics, 13 sites among IDUs, 3 sites for MSM and 2 sites for sex workers. Based on the HIV prevalence rates in these risk groups, the number of HIV infections was estimated at the national level.

#### **Profiling the respondents**

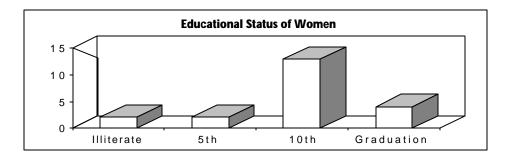
Diverse voices of women living with HIV/AIDS and a multitude of stakeholders were obtained across the three states.



#### **Individual testimonies**

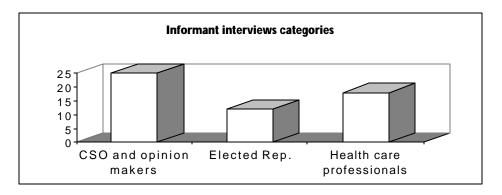
Four testimonies were taken from Kerala, eight from Tamil Nadu and nine from Karnataka. The individual testimonies of the women reflected that they had grappled with early instances of vulnerabilities in terms of:

- · Lack of access to education.
- · Economic deprivation forcing them to work to supplement family income.
- · Lack of opportunities for building vocational skills while studying.
- · Early marriage due to familial force and pressure.



Women recognize the role of these detrimental influences in shaping the course of their lives. However, when these challenges extend to more immediate concerns being faced by them such as lack of access to treatment or property rights after the death of their spouses; many of the women chose to pro actively engage with the violations and seek redress.

The women participating in this study represented varied socio-economic backgrounds, ages and marital status. Twenty-one women participated in this documentation process across the three states. An emerging profile of the average respondent is rural, in her mid-twenties, educated up to the 10<sup>th</sup> standard, currently widowed and supporting a child. Many of the widowed women sought refuge in the maternal homes after being stigmatized or ill-treated. The women were married at an average age of 19 years. Most of the women gave up education after the 10<sup>th</sup> standard, to pursue some income generating endeavors. Only a couple of women had early knowledge of and access to vocational



training facilities, which they were able to utilize. More than half the respondents were married against their wishes, either under emotional pressure or fear.

Fifteen respondents had no knowledge of HIV/AIDS when they were married. Six women had some understanding of HIV/AIDS before marriage by virtue of having done nursing training or having read advertisements in newspapers but *even* amongst them there were misconceptions regarding the nature of the infection. One of these women spoke of the tremendous impact left by advertisements depicting people with HIV as skeletons, to the extent that even after receiving information about HIV when she was tested positive, she remained convinced that suicide was her only alternative. Ten women received *counselling before and after testing*. However, of these *eight* were from *Karnataka*, indicating that only *two* of the 12 cases *in Tamil Nadu and Kerala* were *given* some *counselling*.

Among the women who participated in the study, 13 had lost their husbands, two to three years before the study, from HIV-related causes. The women's

voices reflected their ensuing struggles for rights within their matrimonial homes and with their in-laws and sometimes, within their natal homes.

#### Focus group discussions

Focus group discussions were held with a cross section of people affected by HIV/AIDS and numerous stakeholders including state AIDS officials, medical and legal professionals, academicians and members of civil society. Participants for the focus group discussions were chosen with a view to their **association** with the responses to issues of HIV/AIDS both as infected and affected stakeholders.

#### **Informant interviews**

Fifty-five interviews were conducted with numerous stakeholders, members of civil society organisations and individuals who were integral links for people living with HIV/AIDS.

These include State AIDS Control officials, elected representatives at the *Panchayat* and at the state legislative levels, lawyers, doctors, counsellors, academicians and various non-governmental organisations working at the community and district levels.

Stakeholders working within civil society organisations and as opinion makers constituted a major segment of the total interviews (45.4%). They represented a varied segment of concerns including:

- Legal assistance.
- Care and rehabilitation.
- Support groups providing assistance to individuals living with HIV/AIDS.
- Organisations that were engaged in providing preventive services.
- Religious groups providing rehabilitation facilities to young affected children.
- Organisations working on economic empowerment strategies.

Individuals also represented varied peripheral domains like the legal structure, education, media and social work. The civil society organisations and individuals had been engaged in numerous concerns surrounding HIV/AIDS for the last 3-4 years and had personally witnessed a reduction in stigma and discrimination. Consequently, their work reflected this understanding and sensitivity. However, as the interviews revealed, the *individual responses* were often shaped by their own poor initial understanding of the issues and indeed, by common misconceptions of HIV/AIDS as an infection.

Health care professionals (32.7%) from the three states represented government hospitals and those engaged in private practices or in private institutions in urban and the rural settings. Though a large portion of representation was accorded to professionals engaged as part of the programmatic response such as VCTC, ante-natal care and STD departments, a significant number of professionals came from specialised departments like cardiology, ophthalmology and paediatrics. These professionals had consciously chosen to provide medical skills related within their department to PLWHAs. These doctors were also attempting to bring their long years of professional experience into devising strategies at the individual and departmental level to respond to the challenges. An example, was an interview with the head of the infectious disease unit in a private hospital who had specialised in HIV/AIDS care and treatment. She was the official focal point for all HIV positive patients who visited the hospital for opportunistic infection treatment.

A smaller group of informants (21.8%) included decision-makers and professionals devising administrative strategies, implementing programmes and charged with the overall management of the responses. These included, elected representatives at the district and state level, key district administration officials and State AIDS officials.  $\Box$ 

## Key findings: Analytical report

## Speaking up

#### What did the positive women tell us?

The Indian Constitution has clearly enunciated its commitment to women's equality. As a signatory to the CEDAW Convention, India has also affirmed the obligation of the State to uphold the Constitutional commitment, to prevent any form of "discrimination, exclusion or restriction" on grounds of sex. However, despite the Constitutional provisions, legislative enactments, legal rulings, international conventions and instruments, legitimizing women's rights and entitlements, what finally counts is the capacity of the women to be able to use these instruments to challenge deep-seated inequities. Marginalised by a host of debilitating circumstances, what matters is women's capacity to speak up, demand that they be heard and succeed in motivating everyone concerned to take responsibility and to address the concerns. Most importantly, to recognize their unique needs, shape the provision of women-centered service and strengthen the safety net for women facing multiple vulnerability.

Therefore, this documentation sought to strengthen this process, facilitate the process of speaking up and enable the positive women to shape a gender sensitive response. The study enabled them to examine the experiences that led to their becoming positive. They were able to locate these experiences within a given construct of rights and establish the linkages between the various deprivations and the inexorable effect these had on their lives.

#### The respondent's experiences:

How she exercised her rights? Which specific rights were violated? What she saw as the critical turning point in her life, when despite being aware of the consequences of a particular decision, she could not prevent it? How she dealt with the subsequent challenges that she faced? What lessons can be drawn from these experiences? How should institutions managing programmes address these challenges? What types of enabling processes should they facilitate?

The individual testimonies reflected four dominant concerns. They are:

- 1. Unacceptable levels of gender disparity, acute deprivation and discrimination as a girl child.
- 2. Denial of the basic right to live a life of dignity, subjected to domestic violence and abuse.
- 3. Absence of guaranteed access to services in the area of information, counselling and health care.
- 4. Denial of legal rights such as right to property, lack of right to entitlements and benefits.

#### **Testimonies**

#### 1. Acute deprivation and discrimination as a girl-child

One of the most "nullifying" and "impairing" experiences that positive women faced was the acute extent of deprivation and discrimination as a girl child. A logical outcome of the process was a series of disabling decisions, which, only further heightened her vulnerability and, in these instances, culminated in her becoming positive.

The experience of childhood deprivation and discrimination occurred at many levels. In one instance, the respondent experienced the extreme plight of destitution and growing up in an orphanage. Some found themselves forced into child labour. Many had to drop out of school, and were forced into marriage either as minors or as young adults, denied information and guidance as adolescents and exploited within the family by male siblings and others.

#### MARIA (28) - DESTITUTION/ORPHANED

Orphaned at six, she has been subjected to violence, abuse and denials from every quarter, be it her teachers, family, employers or colleagues. Since she was detected six years ago, she has been working relentlessly for the rights of PLWHAs to live with dignity. She has a daughter and she is presently attached to an NGO that works among positive people.

# Discrimination against women CEDAW

Article 1: Discrimination Against Women means any distinction, exclusion or restriction made on the basis of sex, which has the effect or purpose of impairing or nullifying the recognition, enjoyment or exercise by women irrespective of their marital status, on a basis of equality of men

and women, of human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.

**General Recommendation No. 19:** The definition of discrimination includes... violence directed against a woman because she is a woman... It includes acts that inflict physical, mental or sexual harm or suffering, threats of such acts, coercion and other deprivations of liberty.

#### **Child Rights Convention**

**Article 19 (1):** State Parties shall take all appropriate legislative, administrative, social and educational measures to protect the child from all forms of physical or mental violence, injury or abuse, neglect or ... while in the care of ... or any other person who has care of such a child.

**Article 19 (2):** Such ... measures... should include effective procedures for the establishment of social programmes to provide necessary support for the child and for those who have the care of the child...

#### Core deprivation

- "My mother died when I was two and my father who was blind, died when I was six."
- "I was left in a convent from the age of 2 to 18. I was like a slave to the nuns."
- "The nuns were cruel. They would oil our backs and hit us with a stick if we did not study...once I had to eat the food I had thrown into the dustbin as punishment for wasting food."
- "All day long I had to clean windows in the three-storey building for which I got Rupee 1 a day..."

"I went to the hospital for a job. The doctor there offered me Rs. 200. She expected me to help in the clinic and also do her housework."

#### **Exercising rights?**

- "The paltry amount of Rs. 30 that I got every month for cleaning the windows I used to enrol in a night school."
- "When I started working in a private hospital I was given just Rs.100. Since
  this was much less then what others were getting and I was doing the
  same amount of work I asked the doctor why he was paying me less. He
  said it was because I had no experience. I refused to be exploited in this
  manner and just left."
- "The doctor just said Mrs.\_ you have tested positive like your husband and walked off...the next day she counselled me. I then asked her why she had broken the news to me in that manner...she apologized."

#### SANDHYA (35) - POVERTY

Father a poor fisherman. She was the only one among her five siblings who went to school. When she failed in class 10, she went to work in a prawn-cleaning factory. Due to financial constraints, she married late at 28. Her father forced her to marry, because he was dying of cancer and the rest of the family was indifferent to her well-being. Husband had already tested positive but her family did not know about this. She has two young children. She now lives in her marital home and supports the family by doing odd jobs for the network.

## Right to treatment. Right to access health care.

#### **CEDAW**

**Article 12:** All women have the right to access health care services including those of family planning.

#### **Constitution of India**

**Article 14:** All women are entitled to equality before law and shall not be denied equal protection of law.

Article 15: No person shall be discriminated against on grounds of

religion, race, caste, sex, place of birth or any one of them.

#### **Core discrimination**

"My father was a fisherman and we earned our income this way. If one day
we did not get fish we had to starve."

#### What followed in her life?

- "My marriage took place in 1986. I did not agree to it because he didn't
  have the health to stand on his feet. But I had to consent because my
  father said if he dies, (he had cancer) there would be no one to look after
  me and that no one would marry me."
- "When my husband fell ill after we got married, I asked him why he had married me even after knowing his status. He said the doctor had told him he was alright."
- "We approached the Kaloor ESI local office for benefits and were subjected to another test. But even after going through the test results, the doctor there did not give us any benefits. Now our ESI registration has been cancelled."

#### **Exercising rights?**

- "There, (in the network) after attending many classes, I understood about HIV/AIDS."
- "Whenever I get newspapers and magazines that speak about HIV, I give them to the doctor at the ESI because he does not know anything about HIV/AIDS. I feel it will help him to develop his knowledge. He has also realised it and now asks me to bring him books about HIV."

### VRINDA (24) - DENIAL OF ADOLESCENTS' RIGHT TO INFORMATION

She had a lonely, troubled childhood because her mother was mentally ill and father was tense and depressed. One of two siblings she was forced at 17 to discontinue her studies and marry an auto driver. Two years after marriage her husband tested positive. It has left him shattered and in need of psychiatric treatment. She supports the family on her earnings as a pharmacist.

## Right to information on sexual and reproductive health

## General recommendation No. 24. Women and health

State Parties to ensure without discrimination the right to sexual health information, education and services for all women and girls... In particular ... should ensure the rights of female and male adolescents to sexual and reproductive health education by

properly trained personnel in specially designed programmes that respect their privacy and confidentiality.

- "My mother's condition was such that she used to alternate between attacks of depression and euphoria, so me and my brother had to do all the housework on our own."
- "Unlike other girls who used to share their secrets with their mothers, I just couldn't do that that. When I got my first periods, since I did not have an elder sister, I did not know what the real problem was. I did not even know how to fold a napkin. My dress used to often get stained. Even on matters of hygiene and cleanliness, I did not know what to do."

#### What followed in her life?

- "I was very interested in studying, but I could do so only up to class 10 because of an incident in my life.... I needed somebody with whom I could share all my secrets. In this case, I chose to have a male friend. More than a good friend he was a good listener. All the people started giving it the name of an affair."
- "Because of the rumours my father stopped my education and didn't want
  me to go out of the house. He wanted to marry me off at the age of 18.
   I always hated drivers but was forced by the family to get married to him."
- "For a long time he (her husband) couldn't go to work and the whole family ran on my salary (assistant in a pharmacy)."

#### **Exercising rights?**

"When my husband tried to return to work after a long period of lay off, the
organization where he works insisted that he undergo an HIV test. I
threatened to go to court and told them that such a test was not required
for him to prove his fitness to do the job. Since then, they have agreed and
he has returned to his job."

#### PARVATI (22) - DENIAL OF EDUCATION

An only child. She lost her father when she was five. She was forced to discontinue her studies when she was in class 8 and was married against her wish to an electrician. A year later, a daughter was born. When she was two and a half years old she was hospitalised. She, her husband and the baby were tested and found positive. She now has a four-year-old son who is negative.

### Right to education

#### **CEDAW**

Article 10: Women are entitled to opportunities ...for access to studies and for achievement of diplomas in educational establishments of all categories in rural as well as in urban areas. This equality shall be ensured in pre-school, general, technical,

professional and higher technical education as well as in all types of vocational training.

#### Core discrimination

 "When I was in class 6, I attained puberty...When I was in class 8, she (her mother) said you are not a boy so there is no need to pursue further education. From that day, my mother did not let me out of the house."

#### What followed in her life?

- "Then she called the boy's family...At that time I told her I was not ready for marriage...but then I was married off under a lot of pressure."
- "My first child was born when I was 16. From the age of three months, she
  had a problem of diarrhoea. When she was two and a half, she had severe
  pain in the urinary tract and was hospitalised. The doctor asked all three
  of us to be tested."
- "My in laws accused me of infecting their son. For a while, I stayed with my mother, then I returned to my in-laws. They tortured me a lot. Then my mother bought a house and we shifted here."

#### **Exercising rights?**

- "At that time, (when she was being forced to marry) I said that if you wish I will stop my studies but I will not get married."
- "The doctors told me to abort my second child as I was positive, but I told
  them that there were ways of protecting the child and anyway I had the
  right to decide. Your work is to advise me, the rest you leave to me."

 "I went to the police station and gave a complaint about the torture inflicted by my in-laws and asked the police to help me in bringing back my child, whom my in laws had forcibly taken away from me."

#### VIDYA (27) - FORCED MARRIAGE

One of three children. She discontinued after class 9, to care for her ailing mother. But while caring for the household, she also joined nursing class. At 19 she was married though she did not want to. Her husband was in government service. Three days after the marriage he had high fever. She also discovered he was alcoholic. When he died two years later, she tried to get his job but was refused on account of her status. She also lost her daughter to HIV/AIDS.

# Right to marry of own choice CEDAW

**Article 16:** Women have the right to freely choose a spouse and to enter into marriage only with their free and full consent.

#### Core violation

- "At the time my 9<sup>h</sup> class exams were going on my mother had to undergo surgery. ...Since I was the eldest I had to do the housework and simultaneously study. Somehow I finished my 9<sup>h</sup> and joined the nursing class and started working."
- "My mother was scared she would die and wanted to see me married. I refused and cried. Then I also thought people would think I did not understand my mother's situation so I agreed."

#### What followed in her life?

- "Two days after the marriage he got fever...A year later my daughter was born. When I went back three months later he was admitted in hospital with loose motions. That was when he was tested and found positive."
- "After his death I tried for his job. I got a medical certificate but the employer refused saying I was medically unfit."

#### **Exercising rights?**

 "When I told the doctor that my husband's employer was refusing me the job on the grounds that I was medically unfit, he suggested I go to the consumer court. I thought if I did that everyone would come to know and there will be problems in society so I dropped the idea of claiming the job and started staying with my mother."

#### **RENU (36) - EARLY MARRIAGE**

Has studied up to class 5. One of six children she was married at the age of 12. Her husband worked in a liquor shop. Fourteen years later he vomited blood one day and was hospitalised. He was diagnosed as having TB. It was then that both were tested and found positive. He died seven years ago. She tested positive five years ago. She sells flowers to support the family. She also gets a small income from her husband's property and her sister is caring for one of the daughters. Though she finds it hard to work she has nevertheless decided to move to the city so as to earn more.

# Right to marry of own choice CEDAW

**Article 10:** Women have the right to freely choose a spouse and to enter into marriage only with their free and full consent.

#### **Child Marriage Restraint Act**

An Act to restrain the solemnisation of child marriages.

Any male marrying a minor, person solemnising such a marriage, parents or person(s) in charge of the minor

who promote such a marriage, permit it to be solemnised or negligently fail to prevent it shall be punished...

#### Core violation

- "I was one of six children...I wanted to study but I was married off at the age of 12, three months after I attained puberty."
- "My father was an alcoholic. He used to gamble and drink and mortgaged all our property and lost it all."

#### What followed in her life?

- "My first delivery was one of twins but both died. I was then 14. For three years after that I had no children. Then these children were born."
- "Fourteen years later he (husband) fell ill and tested positive. When I took
  the reports to my in-laws my father-in-law said that it is not possible for
  my son to get such an illness and it is because of 'you' that he got it."

#### **Exercising rights?**

 "When my father-in-law said that my husband became positive because of me I pointed out that I was not unwell at the time of marriage or after that

- so how he could say that. He realised that he could not cow me down so he came to the hospital and gave us some money and left."
- "Since things were bad in my maternal home I went and saw my in-laws who gave me my husband's share of the property....My father wants me to sell the property and give him the money. I have refused saying this is my husband's property. My mother and brother are also angry about this. They tell me to go and die somewhere else."
- "Earlier the doctors were very helpful but once they took photographs of me
  in a self help group without my permission. I did not like that and told them
  so. Since then they haven't helped me to find a job either despite all my
  pleadings."

## 2. Denial of basic right to services, life of dignity and freedom from violence and abuse

# SINDHU (28) - DENIAL OF THE BASIC RIGHT TO A LIFE OF DIGNITY, A "SURVIVOR" OF DOMESTIC VIOLENCE AND ABUSE

One of nine children she never went to school and was rolling beedis from the age of eight to supplement the family income. Her father was a coolie who worked in a shoe factory. At 20 she was forcibly married to a truck driver. What followed were years of violence and abuse by both her family and husband. He used to be constantly ill from the day they were married and repeatedly walked out on her. She now lives in a corner of her family house and ekes out a living rolling beedis and painting pots.

## Right to be free of violence CEDAW

Article 1: Discrimination Against Women means any distinction, exclusion or restriction made on the basis of sex which has the effect or purpose of impairing or nullifying the recognition, enjoyment or exercise by women irrespective of their marital status, on a basis of equality of men and women, of human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.

#### General Recommendation No. 19. Women and violence

The definition of discrimination includes... violence directed against a woman because she is a woman... It includes acts that inflict physical, mental or sexual harm or suffering, threats of such acts, coercion and other deprivations of liberty.

#### Core violation

- "I am one of the nine children that my parents had. I never went to school.
- "I was rolling beedis from the age of eight to supplement the family income."
- "At the age of twenty I was forcibly married in my everyday clothes to a very sick man."
- "He had such a bad stomach ache that he could not even tie my thali."
- "Given his condition we were forced to live with my brother."
- "Every time my brother would throw us out, my husband would cheat me, pawn my jewelry and leave me."
- "I was ill treated by my brother. I did all the house work yet, they burnt me with tongs if I asked for food."

#### What followed?

- "My husband became so ill I had to care for him."
- "He had TB and I used to beg at the bus stand to buy him medicines."
- "When he died nobody came, I performed the last rites."
- "Soon after my family learnt about my positive status, they told me to leave."
- "They told the entire community and isolated me."
- "I am not allowed to use the village well. If I need water, they pour it from a distance."
- "I live in a corner of the house, roll beedis and paint pots."

#### **Exercising rights?**

- "Now my brothers are trying to get me out of my natal house. I have quarreled and refused to leave."
- "The last time they told me to leave and threw my things out, I threatened
  to complain to the police. Now there is a police station in my village and
  I will certainly complain if they do it again."
- "I have now decided to take my life in my own hands and earn to feed myself. I have also decided not to let my brothers and sisters take away what is my share. I will fight to stay in this house."
- "I have not signed the second paper (regarding the grandfather's property) because I am afraid they are trying to take my share from me."

"I have also been doing self disclosure counselling at the hospital. They
say they will pay my conveyance but I have not received anything. But I
continue to do it because I want to help others like me."

## SARASWATI (35) - DENIED AFFORDABLE HEALTH CARE SERVICE

One of four daughters. Could study only up to class 8 due to the family's financial constraints. Worked as a maid to supplement family income. It was after her four-month old baby tested positive that she and her husband were tested. She does field work in an NGO to support her husband who is too ill to work and her 7-year-old daughter.

## Right to access health care, treatment, and medicines

#### **CEDAW**

**Article 12:** All women have the right to access health care services including those of family planning.

#### **Constitution of India**

Article 14: All women are entitled to equality before law and shall not be denied equal protection of law.

**Article 15:** No person shall be discriminated against on grounds of religion, race, caste, sex, place of birth...

#### **Core violation**

- "I could only study up to class 8. My family used to run on the income that I used to bring from my work as a maid servant."
- "After two years of marriage, my husband and I started developing different diseases."
- "It is three years since we became aware of our status."
- "Both of us need medicines but we have no money. When we go to the hospital they say that they have no medicines."

#### What followed?

- · "My younger child was in the government hospital for nearly six months"
- "When he (younger son) tested positive, they told us and asked us to leave the hospital."
- "The nurses made a big issue and asked us to leave."
- "The word spread around. People in the hospital gathered to see the child with HIV/AIDS in Ward no 4."

#### **Exercising rights?**

 Now I feel that all the people who face such kind of treatment must come together and complain about the kind of violations that happen in a government hospital

# ARTI (27) – DENIED BASIC INFORMATION, REPRODUCTIVE HEALTH SERVICES, EXPLOITED BY ALTERNATIVE PRACTITIONERS.

Father a tailor, mother a coolie. Discontinued studies after failing in class 10. Father sent her to a tailoring institute but she discontinued for health reasons and started to do coolie work with her mother. She was married with her consent. She has lost both her children to HIV/AIDS. The doctors refused to treat her second child, but she was able to get him admitted with the support of the network women.

# Right to information, proper counselling, and rights to their reproductive choices

#### **CEDAW**

Article 10h: Women are entitled to specific educational information to help to ensure the health and well –being of families, including information and advice on family planning.

Article 16 1e: Women have the right to decide freely and responsibly on the number and spacing of their children and access to information, education

and means to enable them to exercise these rights.

# General recommendation No. 15 – Avoidance of discrimination against women in national strategies for the prevention of HIV/AIDS

States must intensify efforts in disseminating information to increase public awareness of the risk of HIV/AIDS infection and HIV/AIDS, especially in women and children, and of its effects on them.

#### General recommendation No. 24 - Women and health

State parties to ensure without discrimination the right to sexual health information, education and services for all women and girls... In particular .. should ensure the rights of female and male adolescents to sexual and reproductive health education by properly trained personnel in specially designed programmes that respect their privacy and confidentiality.

#### Core violations

 "From the third month of pregnancy till the seventh month I underwent antenatal check ups."

- "After the test they suddenly stopped my check-up. I did not ask them why because I did not know that I had the right to the service."
- "My husband became aware of his status only after my second child was tested."

#### What followed?

- "We went for nature cure. My brother-in-law referred us to a doctor and even paid for our medication."
- "We spent Rs. 2,00,000 in buying Siddha medicines."
- "We continued treatment for seven months after the delivery of the second child."
- "For one year the child was fine. Then he started having fever and vomitted.
  He was in hospital for 22 days. After one week he suddenly developed dysentery and died."
- "Soon my elder child also became ill. Unlike the second child this time I decided to reveal the child's status."
- "Doctors did not discriminate but one nurse was very hostile. She wondered how a positive child could be in a paediatric ward. She insisted that I take the child home and nurse him there. He soon died."

#### **Exercising rights?**

 "Having developed my own knowledge of HIV/AIDS I was able to insist that the doctors treat my child. I developed a rapport with the doctors".

#### MEENAKSHI (25) - DENIED PRE-TESTING COUNSELLING

When she failed her tenth class examination she went to tailoring class for a while. Then went to work in a coffee blending shop. At 20 she was married to a truck driver. For two years she was happy. A daughter was born and she had no problems. When she was expecting her second child first she and then he (her husband) tested positive. He also started to fall sick and six months later he died. Three days after his demise her son was born. She now lives with her parents and is trying to find work so as to support herself and the children.

#### Core violation

"When I conceived again I went for a test. The hospital said that everything
was fine. Three months later my husband had severe pain. We took him
to the government hospital. There he tested positive."

- "I tested myself the next day in a government hospital. They told me I was pregnant and since my husband was infected I should get tested myself."
- "They did not say anything before doing the test but after testing they came and said "you have HIV" and gave me some medicine. They told me to take it when I got labor pains and in the 10<sup>th</sup> month. The doctor said this tablet is good for your child. But I was afraid and thought let anything happen I will not have the medicine."
- "Before that nothing was told to me. My status was revealed to my uncle first. I was not aware that they should not do that. He went out and told people."

#### What followed?

- "Three days after my husband died my son was born. At that time we went
  to the nearby hospital but the nurses there said that they would not look
  after my delivery. A few of the nurses who knew did not come to my room
  and said "you go to some other hospital because we are not going to give
  anything to the child after birth."
- "Then one sister said you wait here because you will deliver within 10 minutes. She said, "I will look after you."

#### **Exercising rights?**

- My uncle said we should go to another hospital but I said that I will not leave this place and I know that I will have a safe delivery here.
- If I had known about HIV before or even after marriage I could have done something about it. I would have known the need to do a test.

#### 3. Denial of entitlements, legal rights - Property, social benefits

## LAKSHMI (27) - DENIAL OF PROPERTY, DUES AND ENTITLEMENTS

Eldest of three children of a middle class agriculturist family. She had completed her degree in commerce and though she was not interested in getting married she was forced to do so to a machinist in a local factory. Problems began the day after she was engaged with the in-laws demanding a larger dowry. Her parents conceded to their demands and she was happy with him despite the problems she had with his family. Her parents admitted her to the hospital due to pregnancy related complications because of which she lost her child. It was then that her status also became known. She stayed with her parents after her husband refused to accept her status.

After that her husband also started falling sick and it was only after he died a few months later that she was told that he had learnt of his status a year earlier and had not revealed his status to her. She and her daughter continue to live with her parents. She is presently teaching in a school and preparing for the civil services examination. She is also trying to get back the property that was bought with her money from her in-laws as also the provident fund and ESI dues from her husband's company.

#### **CEDAW**

Article 15: State Parties to accord to women in civil matters a legal capacity equal to men and the same opportunities to exercise that capacity. They shall give women equal rights to conclude contracts and to administer property.

**Article 16:** State Parties shall ... ensure women same rights for both spouses in respect of the ownership, acquisition, management, administration, enjoyment and disposition of property whether free of charge on for valuable consideration.

#### Core violation

- "I told him that now we have a daughter and we need to save something for her future. His father suggested that we buy some land. I had already sold all my jewels to arrange money for buying a house."
- "My father-in-law said we can buy a house later. Right now we will buy land."

- "I agreed to give the money but told my husband "the land should be in my name or your name or on our girl's name. It should not be on your father's name."
- "His sister also agreed to give some of her jewels. My father bought those jewels and gave Rs.1,70,000 for it."
- "Finally, the land was written on my husband's father's name."
- "My husband nominated his father for the two insurance policies of one and a half lakhs in each of our names."
- "My in-laws also asked my husband's company for his gratuity, but when they were told everything would come to me, his mother filed a case saying that after the death of her son neither I nor her husband were giving her any money."
- "The issue was settled out of court and though they said they would give me a share of the Rs.1,50,000 I have got only Rs.50,000."
- "Till now his provident fund and Employee State Insurance money has also not come."

#### What followed?

- "Then in the 10<sup>th</sup> month I conceived for the second time. My husband and his mother told me to have an abortion I agreed to it."
- "After four years he even started beating me. Then once I said very strongly 'if you beat me again I would leave this house. I didn't marry you so that you can beat me. Everything has a limit.' From that day he reduced the beating."
- "Once after I had conceived for the third time, he hit me and I fell. I was very scared so I went to see my mother and my parents took me to hospital."
- "When they were getting ready for the operation, the doctor called my father and told him that I was HIV positive. My father got scared."
- "The doctor then called my husband and spoke to him. He refused to accept it."
- "She then said that she couldn't perform the operation and recommended us to another hospital."
- "We went there and the delivery took place. The child was dead. Everything that was used for me was thrown out later."

- "The doctor then said that I am HIV positive. I couldn't accept it."
- "I knew something about HIV through the television how it spreads. So after I came back home I was very upset. We both were."
- "My husband knew one year earlier that he was positive. All the medical reports were kept in his sister's home. I learnt of this after his death."

#### **Exercising rights?**

- "I have started studying for the IAS examination. I feel it will give me the clout to get my due."
- "My father gave everything to his father. I feel bad...I will fight till I get it."

#### **SHOBHA (28) - DESERTION**

One of eight children born to an agriculturist. She studied up to second PUC<sup>2</sup>. At 25 she was married with her consent to a pan shop owner in Mumbai. She soon discovered that he was an alcoholic and was very suspicious of her. When he learnt she was positive he walked out on her. She has now filed a case in the police station and the court for maintenance.

#### Core violation

- "When I was seven months pregnant I went back to my mother's house, as is the custom."
- "When my blood was tested at five months it was negative but when it was tested in the ninth month the doctor told me there was some problem with my blood."
- "I became suspicious because I was repeatedly told that there was something wrong with my blood."
- "I saw the prescription and immediately understood that it was HIV. I had read about it."
- "I realised I got it from my husband. I was shattered"
- "After a long labour I had a caesarean section."
- "When my husband came for the delivery the doctor spoke to him for a long time."
- "When I saw him I told him to get his blood tested but he refused and just left the city."
- "He did not even take leave of me and I have not seen him since."
- "When three months had passed after my delivery my family asked his family to come and take me back. They refused and said "she is not good for us we don't want her back."

#### What followed in her life?

- "I also suffered a lot of discrimination in the government hospital."
- "The sweepers and ward boys wore extra gloves when they had to do anything for me and kept staring at me."
- "Even the doctors and nurses from other departments came and looked at me. They talked in English and I knew it was because of my status."
- "My case file also had HIV written on it and I was kept in a separate room."
- "My parents also mentioned my status to his family and told them their son was responsible. They said - we know exactly what is wrong with our son and we have got the right medicines for him. He is going to be okay."

#### **Exercising Rights**

- "I think something must be done and doctors must be educated so that people like me can be saved from such stigma."
- "Two months ago I filed a case in the police station for desertion. I want to teach him a lesson."

### MEENA (35) - DIFFICULTY IN SETTLING RIGHTFUL CLAIM TO PROPERTY

Comes from a poor, rural background. She works with an NGO that is very supportive and is struggling to get the property that rightly belongs to her. She has two daughters.

#### **Core Problem**

- "When our joint family broke up we had paid Rs. 75,000 to the four others and it was decided that after my mother-in-law passes away the house would come to us."
- "We kept no papers to prove that we paid this amount. No one told us."
- · "After he died with the help of my NGO I went to some lawyers."
- "The lawyers convinced them that the property is mine."
- "Soon it was found that I have to pay dues worth Rs. 40,000 for unpaid tax."
- "My in-laws said they would not pay it off."
- "When I think of what my families have done to me I get very angry."
- "How am I with my small salary going to pay off Rs. 40,000?"

#### What happened in her life?

"Five months after we moved out my husband started to fell sick."

- "Each time I took him to a family doctor he gave him some medicines. For a while he would be all right then he would fall sick again."
- "Since he was not working I was finding it very difficult to feed the family and to send my two daughters to school."
- "There were times I had no money even to take my husband to the doctor."
- "Finally, I admitted him in hospital. They treated him for this and that and it all cost a great deal. The doctors would not say what really was wrong with him."
- "One day he developed high fever and became unconscious. I rushed him to NIMHANS."
- "For six months he remained in a coma. I struggled between the hospital and home."
- "I kept asking the doctors what the problem was but they kept saying –
  we are doing our best he will become well. I was very anxious."
- "One day I just broke down and asked the doctors what I should do. He said I understand your problems. We cannot do anything for your husband he has HIV. The doctors at NIMHANS told us our status just when he was being discharged."
- "They explained that my husband and I were positive and the children were negative. They counselled us on medicines, how to practice safe sex and home based care."
- "Soon my husband began to feel better. He started to work but he also started smoking and drinking again."
- "For one year he really behaved badly. He kept disappearing and drinking."
- "Finally, I put him in a care centre. He was there for one year before he died."

#### Exercising rights?

 "The house rightly belongs to me and so I went to a lawyer. My motherin-law had willed the house to us. I showed that to the lawyers and they were able to convince the family."

#### HEMA (29) - PROPERTY

One of three children her father is an agriculturist. She was in her first year of college when she was married to a cousin at age 16 despite her protests. When her son was three and daughter just a month old, her husband left her for another woman. Her natal and marital families also rejected her and she was forced to work as a sex worker to make ends meet. She now works for an NGO that works among sex workers and is also trying to get her share of her grandfather's property.

#### Core concern

- "There is about 20 acres that belonged to my grandfather. The price of the land has gone up to Rs. 1,00,000 per acre."
- "My two surviving brothers have taken the stand that I should not get my share because I was given a big dowry at the time of my marriage."
- "My father told them that it would be best to give me a share. It would help me to look after my children."

#### What happened in her life?

- "When my husband left me I worked for while as a maid in a house."
- "A lady who became quite familiar with me said she would find me a job in a big house and took me there. After that day she disappeared."
- "The next day another girl in that house told me I had been sold to that household where we had to entertain men."
- "When we did not oblige we were beaten and not given food."
- "The neighbours took care of my son those days and I took my daughter along."
- "After twenty days I just ran away. After that I tried very hard to get a job."
- "I did not know the language and was new to the city. So when everything failed, I started work as a sex worker. I did this for three years."
- "I joined an NGO that was working with sex workers and educating them about how to prevent HIV/AIDS."

#### **Exercising rights?**

- "While I was doing work I met my husband a couple of times. He was with the other woman. I told that he should be careful. He was positive, so I asked him to use a condom."
- "My neighbours do not know my status. They look after the children well.
   Even if they found out my status it won't matter I can now manage my life."

- "Where I work they know my status and now I have no problems there."
- "Earlier I did have problems with my colleagues. Since, I was finding it
  difficult to function I complained to the office committee. They spoke to my
  colleagues and told them my story of how I reached the situation I now am
  in. Since they were sensitised they have been nice to me. At times I do
  get emotional and guarrel with them."
- "Last year I was asked to sign a paper to start the sale process but I refused to sign because I feel I will not get my due. Now my father has asked me to come to the village during the summer holidays so that the matter can be discussed."
- "I will try to negotiate my claim. I have decided that no matter what I will not let go of my share."

## STELLA (32) - DENIED RIGHT TO PROPERTY

Youngest of eight children. Parents were financially sound but indifferent to the children's well being. A family friend placed her and another sister in an orphanage. She studied to class 10 and trained in nursing. She worked for four years in a Mumbai hospital and for some time as a typist. Her husband was an alcoholic and quarrelsome. For several years they shunted between their two families before seeking refuge in a local care home. She lives in a care home and earns money by making rosaries. Her son and daughter have been placed in an orphanage.

#### Core violation

- "My father and my two brothers, who are regarded as local thugs, sold off a large portion of our property."
- "Only 20 cents out of two and half acres of land remains."
- "A small piece of land was given to my sister and me."
- "When my father was slipping into a coma, my brothers forced him to change the will. We did not get any share."
- · "When I knew that I had HIV/AIDS, I was worried about my children."
- "I asked my husband to get his share of ten cents of land. But they did not give him anything."

#### What happened in her life?

- "When I was working in Mumbai I decided to marry someone. Since, it was an inter-caste marriage my family would not accept him. Once I had a child they reconciled to it."
- "My husband soon became an alcoholic. I knew my husband would not take care of us, so I had to return to my native place. I started going

- to Divine Nagar for meditation hoping that my husband would become better."
- "Usually he was a loving person, but after drinking he used to become very violent."
- "In November of that year, my husband got a slight fever, usually he used to have a cough but I never paid that much attention."
- "When my husband got high fever he was admitted to the hospital. He was there for fifteen days. He had TB and the ESR count was also high."
- "The doctor doubting something got him admitted to the hospital. His blood was taken for an HIV test. When we went the doctor said that my husband had HIV/AIDS."
- "We did not get any counselling before this test. When we went to meet the doctor, he gave a letter and took us to the counsellor. First my husband alone was taken. Then I was also called in."
- "When I went to my in-laws place with my husband they said that their son was fine and that I was making up a story."
- "They also said that I had injected the disease into him. I even showed them the certificate but even then they did not believe it."
- "When I was told that I had AIDS I became totally upset not because of the fear of dying but because of my children. Who would be there for them?
   So I asked my husband to go to his home and try and get his share of the property."
- "When he went there they did not give him anything. When he came back he was totally tired and his condition began to deteriorate."
- "He became sub conscious and abnormal. He used to shout saying that he wanted to see his parents."
- "His brother said that he would come but no one came. Shortly after that my husband died."
- "My mother and I cremated him."

#### **Exercising rights?**

- "When I call his family they say that my children would be getting the property only after my death."
- "I have decided to go to court. I want to get my share of the property from my brothers and my husband's share. This will at least be of use for my children."

 "The gram panchayat<sup>13</sup> has sanctioned my widow pension and a house. But the panchayat member did not do anything. When we approached the court it passed the sanction order for the same month. But till now I have not received anything."

"We have been complaining. We went to the collector's office also."

#### **Key lessons**

Where are the intersections between individual deprivation and societal vulnerability happening? What are the linkages between the experiences and the vulnerability to HIV/AIDS?

The above testimonies reveal that core infringements and deprivations as a girl-child can prove extremely decisive in terms of formative influences. These influences in turn impact the opportunity and capacity of women to cope with the various challenges they face at different times in their lives. These individual experiences not only reflect the manner of discriminatory circumstances that they face but also reveal the potential that each of them has in increasing vulnerability to HIV/AIDS.

Therefore, the respondents have in their sharing focused on the kind of influences that shaped their lives and reflected on the strategic imperatives that need to be addressed to ensure a *more inclusive* and *less discriminatory* environment. In fact, each testimony not only highlighted the respondent's personal travails but also indicated the various linkages that get established as a result of it.

The concerns included hard and entrenched experiences set within difficult contexts of impoverishment and social marginalisation. From experiences of being orphaned, living in dire poverty, lacking the necessary nurturing and care as an adolescent to being denied education and married as a minor were perceived by them as having a bearing on their vulnerability to HIV/AIDS.

## Deal with stigma and discrimination as a continuum of deprivation and gender disparity

In the instance where the respondent (*Maria*) experienced early exploitation as a child, what emerges from her testimony is her feeling of being *constantly undervalued* and her *self-esteem deeply eroded by these* early *experiences* of *discrimination*. Her contention was that despite being educated and even training for a job, she found it very difficult to find a fair and non-discriminatory employer. She shared the same distrust about other health care institutions. It is evident that she is aware of her rights. Despite having fought back at every stage and negotiated with her present employers for a fair remuneration and even challenged the treatment that she got from health care institutions, till date she feels that she has been wronged in many ways and the experience of being positive is only a continuum of this deprivation and discrimination. The sense

#### To address gender exploitation and poverty empower women's collectives

The daily experience of poverty, which created a highly marginalised and disadvantageous milieu for many respondents implied both social and economic deprivation. Nearly half the respondents stated that acute poverty experienced by them during childhood denied them all choices. They were forced to give up education to earn a livelihood, support the family and in many instances, to enable the male siblings to continue their schooling.

The respondent (Sandhya) as a young adult, with no right to expression and the absence of any safety net to ensure a reasonable quality of life, finds herself single-handedly bearing the burden of crisis within the family. These include a host of predicaments such as disease, lack of livelihood and assets and poor services in the context of health or information. Given her impoverishment and the unequal familial role she plays, the cycle of exploitation from childhood to adulthood acts as a structural barrier to HIV/AIDS prevention strategies

When positive women move from being caregivers, to being HIV-infected individuals, to becoming positive themselves, they find themselves in an even more difficult predicament because of the ensuing implications for their children. As a result they are extremely anxious to compromise with the situation and ensure that the interests of their children remain unaffected.

Hence, the concern of women's exploitation needs to be addressed both as an effect and a cause of persistent poverty and lack of empowerment and more critically as a condition that enhances vulnerability to HIV/AIDS. It is evident from the testimonies that in circumstances of acute marginalisation any access to and understanding of rights become realisable and worthy of a struggle only when the women become part of collectives and support groups and exercise the right as part of an association.

## Use confidence-raising strategies to address rights of adolescents and sensitise gatekeepers

The most disturbing experience emerging from the testimony (*Vrinda*) is that the inability to respond to the adolescent's needs tends to snowball into a larger failure and denial of rights. It resulted in her being pulled-out of school and forced to marry. The link between these developments and the quality of her life after becoming positive, with the entire burden of care falling on her, reveals to us

in no uncertain terms, that an effective preventive strategy is not possible without addressing these underlying concerns.

This involves going beyond mere recognition of the fact that adolescents have "real" and specific requirements. It is now imperative that complex partnerships are forged in order to respond to the needs of adolescents. These partnerships would include young people, family, community, service providers and concerned decision-makers. Furthermore, this partnership should seek to facilitate young people to impress upon different stakeholders *their* perceptions about their core needs.

This experience tells us that timely communication and education of all young people and their gatekeepers including parents, teachers to older siblings, is no longer *only a desirable goal* but is an *immediate and an urgent imperative*. Furthermore, these efforts need to focus on young people living in difficult circumstances and in rural areas.

Logically speaking HIV/AIDS provides us an opportunity to address a concern that is long overdue. However to translate this logical formulation into practice is not easy for programme implementers. The testimonies indicate that there are domains, which are not easily or truly accessible to programme implementers. Even if they manage to access the family and community, when the programme implementers try to apply a seemingly rational and logical approach in such an environment, they find themselves dealing with a domain that is highly defensive about protecting the adolescent from any possible violation. Sometimes even inimical decisions are taken by families out of genuine concern for the young person and justified on the basis of safeguarding the adolescent from potential dangers.

The limitation of this approach is evident on the issue of information dissemination. If, the essence of adolescent's rights is their need for information, then this approach tends to be close-ended and often driven by the agenda to prevent 'out-of-bounds' behaviour rather than to empower young people with the depth of information that helps them to exercise choices in the right manner. Furthermore, the family not only perceives some degree of ignorance and being uninformed as natural safeguards but in crisis situations believe that early marriage will diffuse the issue and protect the girl-child from any dangerous incursion.

#### Under these circumstances what lesson can be derived from this testimony?

It is clear that to empower young people, the apprehensions of the gatekeeper need to be addressed. This includes the use of confidence-raising strategies

that enhance the confidence of adolescents and target the gatekeeper's apprehensions. Positive role models of the girl-child must be used to partly demonstrate alternative models of parenting and gate keeping and partly to emphasize the need to develop appropriate life-skills among young people. Because adolescent using *only* the problematic association of HIV/AIDS or other possible experiences of violations could have their pitfalls. No doubt the threat perceptions about the vulnerability to HIV/AIDS helps to achieve a consensus about the need to address their concerns. However the resulting action that gets recommended could be defensive and top-down in approach.

#### Making girl-child's right to education a development goal

With the girl-child's desire to pursue education hindered by biased social norms and attitudes, it is evident that the concern of HIV/AIDS cannot be effectively addressed as an unconnected issue. It is inextricably linked with the larger response related to the girl-child and women's empowerment. In other words, even an essentially public health response has to link up with an expanded response that targets specific development indicators such as education of the girl-child. This is an area that requires multi-sector participation.

Therefore given the enormity of the challenge i.e. to address gender disparity in education what does the testimony *Vrinda* tell us about attitudinal barriers? It tells us very clearly that the fall-outs of the discontinuation of education, are child marriage, underage pregnancy and denial of rights within marriage and abuse and violence by the in-laws. The decision forced upon her by her parent on the grounds, that "having attained puberty" she must not step out of the house reveals the mindset of the adult. When seen from the perspective of the parent, we can assume that the girl-child gets viewed as a "responsibility" that must be quickly passed on through marriage to her "rightful" family.

This area of deep-seated attitudinal bias is a major challenge for institution designing and managing an appropriate response. Is the parent, just a victim of age-old mindset and social norms? Are there new challenges that need to be incorporated? In what way is the altering social environment enhancing the threat perception related to the safety of the girl-child? Is a constant process of dialogue with these and other concerned stakeholders required to rid them of their attitudinal bias and to create a new human equation and relationship?

#### Early marriage a major barrier

Given that the respondents are predominantly from rural areas, the fact that nearly one-third of them were forced into marriage as minors, indicates the extent to

which entrenched societal norms such as early marriage enhances the individual vulnerability of the girl child and impacts the quality of their lives.

In the instances where early marriage took place, the respondents singled this out as the one decision that they would like to undo. The women said that they were extremely unhappy with the decision, and in one instance, where the respondent who was as young as ten years old at the time of her marriage, finally realised that she would have to live with the man, she said she was so petrified that she kept crying. Her mother went with her and managed her household.

Most of the respondents even resented the choice of the intended spouse. They had distinct notions about whom they would have liked to marry. They resented the idea of being forced to marry the type of person that they had all along decided not to. Some had definite plans of pursuing further studies. They were promised that they would be allowed to do so provided they consented to the marriage.

In most cases the women pleaded with the family to not finalize the marriage. They were hoping to at least stall the decision and were willing to make any kind of compromise like discontinuing their studies, staying at home helping the family as long as the parents were prepared to give up the plans of marriage. Apparently none of this worked and one respondent was warned that if she complained too much, the police would arrest her mother and her in-laws. She even contemplated the idea of committing suicide. Apart from the psychological trauma they went through, many of them also experienced adverse health effects. Child bearing happened as early as 14 to 16 years and some with unhappy outcomes. In one instance the infants died and in another developed symptoms like diarrhoea as early as three months and by the age of one and half year was diagnosed as being positive.

Their despair is best described in the following words of one respondent: "I was married at the age of 15, the child was born at 16 and I came to know about my HIV status when I was 18 years old. I felt very bad. I wondered how society would react and discriminate against us and how my family would behave towards me. I did not know anything about HIV. Before marriage I had seen an advertisement on the TV, which showed two human skeletons and AIDS was written in the bottom. I had feared that may be I will also become like that. I felt like committing suicide."

The decision to get a minor girl married is often defended on ground of helplessness, lack of choice and inability to defy dominant norms. Therefore,

unless the basic attitude and perception about the girl-child is challenged it will be difficult to ensure any kind of enduring change in the situation of the girlchild. However, the question that arises is how do we bring about a change in attitudes and perceptions.

## Forge partnership with movements and programmes aimed at addressing gender discrimination

For any programme to *prevent* and *address* the issue of *HIV/AIDS amongst women* it has to strategically make common cause with older and experienced interventions and programmes around women's empowerment. Unless this entire resource, which includes the women's movement, is mobilised and harnessed in support of the fight against HIV/AIDS, it is not going to be possible to impact the environment, which women living with HIV/AIDS are struggling to cope with. They will not only continue to be victimised by inimical decisions such as child marriage but are also going to find themselves waging a very disadvantaged struggle against the terrible stigma and discrimination, within the family and outside.

#### Legal rights and entitlements

The struggle that many women are waging includes the uphill battle against domestic violence and resisting coercive efforts to dispossess them of their share in the property and deny them due entitlements and rights. Since, the repression against women is due not just to the lack of proper instruments of law but because laws are usually circumvented, their effective usage and supportive interpretation are often prevented. So women find themselves dealing as much with concerns in the domain of women's empowerment and rights as in the realm of public health and development.

## Seeking gender-sensitive services - information, counselling to care and support

The actual and potential experience of stigma and discrimination that women face and could face in health care and other institutional settings such as schools or at work place is another major dimension that emerges very strongly out of the testimonies.

The respondents found that one section of the institution actively spearheaded the stigmatisation while others tended to tacitly support it or quietly make whatever amends they could. In many instances the women did come across an exceptional and caring person such as a doctor, sister or counsellor who stood by them.

Very often what was unnerving for them was the 'matter-of-fact tone' doctors used, treating it like any other common disease. All this happened at a moment when the respondents experienced extreme emotional turbulence after they first learnt about their or their spouse's status.

Most respondents found that they were victims of a knee jerk response. Often, people in authority did not know how to handle this situation. In fact, in many instances it was the positive people who guided the process, so that the same treatment was not meted out to others. A classic example given by one respondent was that: "The doctor just said Mrs—you have tested positive like your husband and then just walked off. I was shattered. I started crying. Then the next day she called me and counselled me. I then asked her why she had broken the news to me in that matter and that I could have committed suicide. She apologized and admitted that I should have been counselled prior to being told my status".

In 1999, the respondents experienced unimaginable levels of stigma and discrimination. Looking back at her experience a respondent stated that: "They all knew I was positive as they had put on a sticker on my stomach saying that I was HIV positive. When the doctors saw the sticker they used to back off. However, there was one doctor who was fine. Even, the nurses said that she is having HIV. They asked for Rs.100 to give me an enema. I did not have money. So they then shifted me to another ward. There the doctors were not ready to touch me while doing the check up. When I got the labour pain the doctors had put on five gloves". But with her child then testing negative and being subsequently confirmed as negative everything seemed worthwhile. Much later she joined the network of positive women and now feels empowered enough to look back at her experience with less bitterness. She now helps other positive women to get over their isolation and sense of despair.

But not everyone shares this feeling. Many respondents are extremely bitter at how within a short span of five to even one year, everything in their lives got unmade and often for reasons beyond their control. Many of them are presently struggling to ensure a modicum of stability in their own lives and most importantly, in the lives of their children. For all of them it is important that their experience is not repeated with others.

Some of them have realised that once they were empowered and asserted their rights they were treated differently. They have found that collective bargaining was an important tool and the presence of a network, however nascent, made a difference to people's attitudes towards them. The stigma and discrimination,

they realise, also gets further fuelled by their lack of self-confidence and sense of disempowerment.

This is what makes many of the women constantly relive their experiences of being counselled. It was a defining moment for many women. For some irrevocable damage had been done. So even though they realised that the problem could be managed with counselling they were not in a position to appreciate it.

Sharing this experience one respondent stated that: No one had given me any information on the disease. The only thing that I had heard was that it us a dangerous disease. Something like cancer. My husband has now become a totally weak person. He is psychologically traumatised and not ready to accept anything. If the doctor had explained this to him in a friendlier manner or in a different way the situation would have been much better. But his approach was negative. They were very rude and harsh Now after reading many articles especially those, which come on World AIDS Day, I have understood that it is possible to live a normal life. But I also know that we will be prone to different diseases. Some of them can be cured with proper medication. Now I keep consoling my husband that this is like any other disease and that he can live a decent life. I keep telling him that a life has no guarantee and that other diseases also kill people. But even though he has the ear to listen, he does not have a normal mind that is capable of understanding this".

On many occasions, the respondents found the counsellor more anxious to communicate their version of preventive education rather than help the positive people to cope with the situation at hand. Therefore with respondents often denied pre-test counselling, the post-testing counselling proved to be more of an exercise of telling the test results to the positive people rather than any genuine effort to counsel them.

To illustrate this one respondent stated that, "they just took our blood for the test and told us to come after 15 days. They then took us to the counsellor and gave our records to the counsellor and said that we are having AIDS. They did not even say HIV. The counsellor immediately said that from now onwards you both should stay separately and not like husband and wife. There should not be any sexual contact. But, if you want to have sex then you should use condom. You will live for another five years only and the child will survive only for another four months and in future you should not have any children".

#### Conclusion

The model of vulnerability created by Tarantola (1992)<sup>14</sup> defines vulnerability as a "limitation of the extent to which women are capable of making and effecting free and informed decisions". Within the context of HIV/AIDS, it translates as the lack of power on her part to regulate or minimise the risk of exposure to HIV. Within a population regarded as generally vulnerable, women may be more vulnerable than the others.

This was located at three inter-dependent levels: personal, programmatic and societal<sup>15</sup>. While personal vulnerability focuses on a woman's development or the environment that make her vulnerable, programmatic vulnerability focuses on the impact programmes have in reducing or decreasing a woman's personal vulnerability. Finally, the societal vulnerabilities study the factors that "define and constrain personal and programmatic vulnerability."

The vulnerability model elucidates the critical linkages between programmes that address women's concerns of health and education, societal norms like child marriage and the struggle waged by woman to cope with their vulnerability to HIV/AIDS. *These linkages* call for greater examination by people engaged in the design and implementation of development strategies. The testimonies have shown that programmes need to create strategies that have a multiplier effect. These testimonies have shown that while engaging with the problem of HIV/AIDS a complex set of challenges exist that need to be addressed. The provisions of programmes such as primary education for the girl child *by themselves* do not effectively impact deeply entrenched societal norms.

For instance respondents were able to access schooling and in some cases even studied till the 10<sup>th</sup> standard. However, even this did not in any way empower them to cope with situations like early marriage and their own levels of ignorance on reproductive health contributed to the problem. Reflecting on her life, Vrinda finds, "If I had someone whom I could talk with (about her problems) I would never have gone in search of a friend."

The women inevitably found that the vital linkage between an unsupportive family or community during their early years, the consequent pressures of "finding stability" within marriage, leading to their being affected by HIV/AIDS were not being adequately appreciated.

<sup>14.</sup> AIDS in the World, J Mann, D Tarantola. Cambridge, MA: Harvard University Press, 1992.

<sup>15.</sup> AIDS in the World, J Mann, D Tarantola. Cambridge, MA: Harvard University Press, 1992.

## The National Response to HIV/AIDS: Expectations and Challenges Expectations

The group<sup>16</sup> consisting of people affected by and involved with the concern, activists and professionals stated that combating *stigma and discrimination* should be the *core mandate* of the *response*. It was emphasized that to eliminate stigma and discrimination, the response needed to be multi-pronged and firmly centered on the human rights of PLWHA<sup>17</sup>, supported by a policy framework that was gender-sensitive. Since stigma and discrimination had to be addressed at two levels i.e. the "self" as well as the biased views of the "other", they recommended it was necessary to take two related steps. They were:

- To heal the hurt and humiliation, that PLWHA's individually and collectively internalised, leading to self-stigmatization.
- To address "distress" levels of communities living in high prevalent districts.

Given the developments in Kerala, where children of positive parents faced a vicious reaction from the community and debarred entry into the school, the respondents felt that such emerging forms of stigma and discrimination should be discouraged. The authorities should not allow it to grow as a legitimate mainstream opinion or demand.

However, since the worst and the most distressing impact of stigma and discrimination happened in the health-care setting there was an unanimous demand that the entire process of sensitizing health care providers be changed. It should go beyond knowledge creation and awareness building and target the behavioural change of health care providers.

#### Challenges- Stakeholders Response

Stakeholders drawn from diverse segments such as policy makers, programme implementers, health care providers and representatives of civil society organisations and professional institutions, agreed in principle that stigma and discrimination needed to be addressed in a holistic manner. Although they recognized the concern, not all of them approached it in a similar fashion.

Many stakeholders felt that the situation had changed for the better, with people now less frightened about HIV/AIDS. The people were also not reacting in as

<sup>16.</sup> These suggestions emerged from a series of focus group discussions held in the three States.

<sup>17.</sup> People Living with HIV/AIDS.

violent and extreme a manner as in the past. However, they did accept, that this attitudinal change was happening too slowly and not keeping pace with the growing epidemic. In other words, some vital sections were still in a state of partial denial.

All stakeholders perceived the changing attitude of *health-care providers* as pivotal to any effort to reduce stigma and discrimination. A section of the respondents felt that their attitude had changed for the better. In the last five years, some of the health care providers, in particular doctors of specific departments were being far more cooperative and supportive. Yet, this change was not universal. There were specialists, needed for specific curative care, who tended to be reluctant and evasive. Many were still hostile to positive pregnant women and not entirely ready to treat opportunistic infections.

The decision-makers, which included elected representatives as well as programme managers and administrators viewed stigma and discrimination as a systemic weakness that would get reduced with better management of the problem and rapid strides in the treatment and cure of HIV/AIDS.

An elected representative at the State level was sympathetic about the issue and the plight of vulnerable communities, keen to decriminalize sex work and stressed on the need for a caring society. However, he refused to get into a hard-hitting engagement with the issue of stigma and discrimination. At the local level, the panchayat members were willing to organize awareness-raising meetings and campaigns. However, they were not willing to be active spokespersons on the issue. They feared that if they spoke openly about HIV/AIDS the community would misunderstand them and the small role that they are playing in rural areas would get undermined.

However, across the states programme implementers were experimenting with different ways of improving programme delivery. This included interventions related to health care-delivery, the setting up of departmental mechanisms to track and redress violations, economic empowerment of women and strengthening of multisector partnerships. Without a doubt, these health care initiatives seeking to improve services, access to drugs, treatment of opportunistic infections, integrating HIV/AIDS care into routine activities and entering in to partnerships with private institutions are vital efforts.

They are at the cutting edge of the response. However, they require strong executive will, resources, multi-sector collaborations and a legislative framework to translate the intention into practice. Given these imperatives, it was clear to

everyone that the programmatic effort faces the challenge of going on scale and transforming attitudes and mindsets. These inadequacies were most evident to implementers working at the grassroots level with marginalised communities. The challenge for district administrators was to address both the discrimination and marginalisation and to implement interventions in a manner that protects women's confidentiality, ensures outreach and provides them a safety net to counter the devastating effects of HIV/AIDS.

In the light of these responses, the representatives of civil society organisations emphasized the fact that given the complex linkages between poverty, gender and HIV/AIDS, the major challenge before the national response lay in creating an appropriate address mechanism. This mechanism must go beyond dealing with a single indicator, portfolio and issue and enable women living with HIV/AIDS to benefit from a programme that converges and brings together the different initiatives, schemes, entitlements and programmatic frameworks.

#### **Emerging recommendations**

To strengthen the intervention against stigma and discrimination the following *action points* emerged from the respondents and stakeholders who participated in the research, from members of the networks, women living with HIV/AIDS and all stakeholders on concerns related to awareness building, implementing the principle of GIPA, right to property and other entitlements and rights within health care settings.

All **awareness**-raising interventions must address the concern of stigma and discrimination

- To do this health information must be first given to teachers and government staff and channelled through them to the general public.
- Involvement of informed political leadership is essential on the various issues of HIV/AIDS – its management, social and economic impact.
- Participation and partnerships of positive women's networks in awareness raising programmes on all dimension of HIV/AIDS response including the PPTCT programme is essential to effectively impact women living with HIV/ AIDS and prevent its spread.
- Awareness campaigns must include a referral list of the addresses of the network and help lines.
- Reproductive health information desk in every hospital is required, which must be staffed by women and preferably positive women.

- Information counters on STD, HIV/AIDS must be available in every district hospital staffed by members of the positive networks.
- Nurses in PHCs must be trained to provide information to women on reproductive health queries, HIV/AIDS, opportunistic infections, treatment and care.
- HIV/AIDS education must reach young people through compulsory gender education for both boys and girls in high schools.
- Education must speak on issues related to sexuality and gender discrimination such as marital rape, domestic violence, child abuse, and reproductive rights of woman.
- Information on HIV/AIDS and opportunistic infections must be made available to women through schools and colleges.
- Counselling must be made available in schools and colleges. Teachers within
  the schools must be trained appropriately to ensure continuity of the process
  and there should be qualitative monitoring and feedback on the gaps.
- IEC material in simple language is not available now. Must be in local dialects.
   Must have cartoons, photographs, and graphics to enable people to understand issues easily.

## Implement the GIPA (Greater Involvement of People living With HIV/AIDS) Principle

 PLWHA must be represented at decision-making levels. All official implementing agencies such as SACS, NACO, line ministries and departments must conform to the principle of GIPA and appoint Positive People on decision-making committees and bodies.

#### Property, Legal Entitlements, Affirmative Action, Workplace Policy

- This must include landed property, cash benefits such as Provident Fund, gratuity, pensioner benefits, and insurance claims.
- Speedier judgments of cases involving HIV positive persons must be encouraged.
- Upon death of spouse property should duly devolve on women living with HIV/AIDS
- Though free legal aid is available it needs to be strengthened, at the State and the *taluk* level and especially for women.

- Awareness of legal issues and rights of women on matters concerning property needs to be provided. The positive networks need to be actively made a part of issues of concern to people living with HIV/AIDS.
- All Development Schemes, to enhance livelihood, social security for women must give preference to HIV positive women.
- A workplace policy that guards against discrimination of women living with HIV/AIDS, while safeguarding her rights to due processes and entitlements as an employee must be enforced in the public, private sector and small scale units.

#### Health care services

- Provision of quality health care to women living with HIV/AIDS must be made mandatory for both government and private hospitals.
- Treatment must be made available to PLWHA in all medical departments depending on the nature of the illness and should not be limited to STD or skin departments.
- STD departments in hospitals must have more lady doctors to treat women patients.
- Information on sex, sexuality/medication must be available in the hospitals.
- Medicines for opportunistic infection must be available in all hospitals.
- ARV medicines should not be subject to sales tax. This should be considered especially for women in the third stage and poor women.
- Women from the positive networks must be involved in workshops for medicals and paramedics to create greater interaction and understanding.
- Private labs, nursing homes and hospitals must have provisions for counsellor.
- There should be individual counselling for women living with HIV under the PPTCT Programme rather than the current group counselling that is provided. □

# Key findings: Empirical report

## **Testimonies**

## Discrimination against women

## **Key Frame: CEDAW**

Discrimination Against Women means any distinction, exclusion or restriction made on the basis of sex which has the effect or purpose of impairing or nullifying the recognition, enjoyment or exercise by women irrespective of their marital status, on a basis of equality of men and women, of human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.

## Violation - Dowry demand

Supporting framework: Constitution of India, Dowry Prohibition Act

**Article 21 :** All women have the right to live a life of dignity

**Section 3:** Any person gives or takes dowry he shall be punished with imprisonment ...

VIOLATION - Right to property Supporting Framework: CEDAW

**CEDAW, 16 1h:** All women have the right to ownership, acquisition, management, administration, enjoyment and disposition of property whether free of charge or for a valuable consideration.

## Lakshmi (27)

My grand father who was an agriculturist was very well off but my father struggled a lot because he married my mother without the permission of my grandfather. I have a younger sister and brother. While we were studying our father didn't stay with us. He had problems earning a living here so he went to work in the city as a caterer. Till I was in class 10 he was not here. He visited us at times. That is one thing about which I feel upset. At that time there was no phone facility. We used to write letters to him. If I had to go out I went with my mother but since she rarely went out I used to stay home most of the time.

But after my father went out to work our position started improving. We bought our own land. I finished my 10<sup>th</sup> standard and joined 12<sup>th</sup>. Then my father, mother and brother left for Malaysia for work. My sister and I were left in the care of my uncle and grandmother. I was a very social person, but never got close to anyone. I

concentrated on my studies and scored 80 per cent. I wanted to study chartered accountancy but my father was not comfortable with the idea of me travelling to Namakkal. So I started doing a bachelor's degree in commerce.

I remember how my relatives used to say, "She is a girl why are you spending so much on her studies". My father said both my girls are studying well so I want them to continue their studies and improve their future. So like that I didn't have any problems for three years. After my graduation they started looking for a groom. I said, "I'll marry the person you choose. Don't ask me anything".

My marriage was fixed with a machinist in a local factory. Till my engagement I didn't see him though he had come to my house a few times. I was a bit orthodox on that. Then after my engagement I met him. One day before marriage someone known to my father told him that he knew the family and that if your girl is married there she will have problems in her life. My father became very worried and I said I would not marry him. But my father kept saying "don't you believe me". If I had totally refused they would have agreed to my decision. But when they asked me so much I agreed. On the day of the engagement they had also asked for dowry. My father was upset about this. He told them he would do according to his capability and not to expect anything more. He said he would give 40 *tolas*<sup>18</sup> of gold and Rs. 50,000. But they asked for 50 *tolas* and Rs. 50,000. I felt very bad about all this.

From the day of our marriage the problems started for me. His mood used to change very frequently. But we both liked each other. After our marriage we went to stay close to the place of his work. I conceived a month later and had problems. So in the 7th month he left me at my parent's house. He frequently came to see me. I used to talk very frankly with him. When our daughter was born we were very happy. I was stayed with my mother for one month

Every month he would give some money from his salary for my expenses and the rest to his father. I told him that now we have a girl and we need to save something for her future. Then his father suggested that we buy some land. But I had already sold all my jewels to arrange money for buying a house. But my father in law said 'we can buy a house later. Right now we will buy land." I agreed to give the money but told my husband "the land should be in my name or your name or in our girl's name. It should not be on your father's name." His sister also agreed to give some of her jewels. My father bought those jewels and gave Rs. 1.70 lakhs <sup>19</sup> for it. He had bought it with money that he had kept for me. But finally the land was written

<sup>18.</sup> A tola is equivalent to 10 grams.

<sup>19.</sup> Ten lakhs is equivalent to one million

in my husband's father's name. I had a major fight on this with my husband. I told him "you don't know how to protect yourself." My father had also given money to his father. I felt very bad. It was his hard-earned money that he wanted to save for his son. But now everything is gone. Moreover, my husband nominated his father for the two insurance policies of one and a half lakhs in each of our names. He had also mortgaged these bonds to a bank to buy a fridge and a car. When I asked him why he had nominated his father he said it will get transferred to my name automatically.

My in-laws took care of the agricultural land. Then in the 10<sup>th</sup> month I conceived for the second time. My husband and his mother told me to have an abortion I agreed to it. But I was feeling very upset about it. After four years he even started beating me. Then once I said very strongly, "if you beat me again I would leave this house. I didn't marry you so that you can beat me. Everything has a limit." From that day he reduced beating me. Once after I had conceived for the third time, he hit me and I fell. I was very scared so I went to see my mother and my parents took me to hospital.

When they were getting ready for the operation, the doctor called my father and told him that I was is HIV positive. My father got scared. The doctor then called my husband and spoke to him. He refused to accept it. Since the doctor knew our family she shouted at him. She then said that she couldn't perform the operation and recommended us to another hospital. So we went there and the delivery took place. The child was dead. Everything that was used for me was thrown out later. The doctor asked me, "you are well educated. Where did you study?".The doctor asked me very frankly "did you have a sexual relationship with some one else?" I said I am not like that. The doctor then told me I was HIV positive. I couldn't accept it.

I knew something about HIV through the television and how it spreads. So after I came back home, I was very upset. We both were. We spent Rs. 8500 on doing CD4. I asked my father to treat him for my sake. When my father said, "he should try to take care of himself", I felt very bad. My husband said he would go to his parents. I also agreed to that because I could not live anymore with him. His parents had behaved very badly with my father. When my husband died, I did not go to see him. I did not want my child also to see him like that.

All my relatives were supportive and helping me to recover from the shock. They suggested I work and told me not to think of it as HIV but as diabetes. Like this they gave me strength.

My husband knew one year earlier that he was positive. All the medical reports were kept in his sister's home. I learnt of this after his death. After my husbands death I initially thought we would be able to settle everything through talks. When that failed my father filed a case and we were able to get Rs. 50,000 of the Rs.1.70 lakhs that my father had given them. If at that time I had filed a complaint in a women's police station my case would have been strong. But before I had thought about they took the first step by saying that "our son is no more and my daughter-in-law is asking a share in the property. But she will not be alive for long". The sub inspector and the inspector who were present asked my father-in-law "how can you be sure that your daughter won't be in the same status tomorrow and if you also die then what will you do?' They talked very badly. My in-laws then said, "She is going to live for another two or three years so what is the use of asking for a share in the property. Now the case has gone to court and it will take one or two years to settle".

While my husband was alive and we were separated my father asked for five lakhs. His uncle refused and asked us to give back my *mangalsutra* (chain or thread worn by women as a marital symbol in India), fridge, television, and car. My father became very angry and said "I will also give the HIV virus that your son gave my daughter." Then they agreed to give half my husband's wealth to my daughter and all the insurance money. At this point my sister in law intervened and my father in law refused to give anything. We went to the police but nothing has happened.

My in laws also asked my husband's company for his gratuity but when they were told everything would come to me his mother filed a case saying that after the death of her son neither I nor her husband were giving her any money. The issue was settled out of court and though they said they would give me a share of the one and a half lakhs I have got only Rs. 50,000. Till now his provident fund and Employee's State Insurance money has also not come. My in laws themselves wrote everything and came for my signatures. I said if you give my share I will sign. So till now the problem is going on but I will fight till I get it.

Supporting Framework: Article 21. Constitution of India

All women have a right to privacy and confidentiality

Violation - Right to treatment. Right to access health care.

**Supporting Framework:** 

Article 12. CEDAW

All women have the right to access health care services including those of family planning

Article 14. Constitution of India

All women are entitled to equality before law and shall not be denied equal protection of law

Article 15. Constitution of India

No person shall be discriminated against on grounds of religion, race, caste, sex, place of birth or any one of them.

## Sandhya(35)

My family consisted of my father, mother and five children. My father was a fisherman. We earned our income this was. If one day we did not get fish, we had to starve. My brothers and sisters did not study due to financial problems. My father never gave any importance to education. He used to say that if you work at least you could get a cup of tea for that. But mother's brothers educated me. I studied till the 10<sup>th</sup> standard but did not complete it because I had failed in one subject. My uncle told me to do the supplementary exam for the failed subject but I did not listen. I started working for Kerala *Shastra Sahitya Parishad*<sup>20</sup>. They had an all women's program that was conducted by my friends. I taught in a literacy program for mothers. My father used to scold me when I used to go to the *Parishad*. He used to say, "neither do they do any work on their own and nor they let anyone else do any work". That was his attitude.

During that time my father fell ill and there was no one to look after him. So I had to take on that responsibility. There were a lot of prawn cleaning factories in this area so I went to work in one of them. I did this on my own will. I wanted to make my own money so that I could buy a pair or earrings — I did not have an earring until I was 18 years. All of my friends had. It was my dream to have one. Moreover all my brothers were married and were living on their own so there was no one to look after me financially.

<sup>20.</sup> A cultural centre

Mine was a late marriage; it was at the age of 28 years. This was due to the financial difficulties of my father who was suffering from eye cancer. My brothers got me married off. My eldest brother had bought some land with his dowry. He sold that and got me married. I was not interested in the marriage because the person was not good looking. But my father was not well during that time. He forced me to marry. He said that if I did not get married at that time then I would not ever get married. However my father died five days before my marriage. As this was my father's wish, I had to do it.

My husband studied till the 6<sup>h</sup> standard. My in-laws are very nice people. We have six cents of land. We built a small hut by taking a loan. But after my husband fell sick we weren't able to pay the loan properly. Now I am staying in my husband's house. I have two children who are four and six years old.

My husband knew before our marriage that he had AIDS. When he fell ill after marriage he said that he had HIV before. While going though some papers I also found the certificate of a HIV test done in Tiruvananthapuram. In that the result was positive. So I asked him why he married me even after knowing it. He said that the doctor had said that he had become all right. The fact that my husband was HIV positive had come in the paper but my family did not come to know about it. Even after explaining it to him he still does not know what AIDS is.

When my husband developed diarrhoea he was admitted to the ESI hospital. When it would not stop he was sent to another hospital for the HIV test. The result was not given to us. It was directly sent to the doctor. It was the doctor who called me and said that my husband was HIV positive and hence our ESI facilities would be cancelled. Once it was known in the hospital that we were positive they cut our names from the register and said they don't have the medicines we require and asked us to go to Kottayyam. The doctor there did the check up but did not give us any medicines. They sent us to the ESI at Kaloor for another test and said if the doctor there gives an order we shall be treated at the ESI hospital. It was important for us to be treated at the ESI hospital because then we get our daily wages even if we don't go for work.

But the doctor at Kaloor refused to sanction the treatment and wrote this on a card that was to be given to the local ESI hospital. There they treat us as untouchables. We were kept as museum pieces and shown to others. It is very insulting. They still treat us as untouchables. Since my husband did not go to work for five months he also lost his job. It was while my husband was in hospital that I met people from the network. They explained everything about HIV to me.

We have not reported all this to the officials in my husbands company, as we were scared that this news would be given to others. If that happens then it would affect our children adversely. Our children are negative, but hearing that their parents are positive, others may think that they are also positive and all benefits would be denied to them. They would suffer. The other workers are asking us to give it in writing to the office but when we think about our children we don't want to reveal it to other people. We are also not sure how people in the company will react when they come to know. Our uncle is in the same company. So if he comes to know all this our family will also know. But we need to meet the people in the company. We will not be able to get any benefits without their help.

Since we don't get any medicines from ESI, we buy our medicines from Kottayam. The doctor at ESI does the check-up but he does not give us any medicines. We have to get it from outside. The doctor does not know anything about HIV. Whatever information I get on AIDS (magazines, papers etc) I give to him, thinking that it would help him develop his knowledge. Even he asks me to bring him books on HIV.

I have three brothers. If they had married me off to a good person then all this would not have happened. They should have taken the responsibily.

I think if I had the freedom to make a decision about my life partner then this would not have happened.

Sandhya now lives in her marital home and supports the family doing odd jobs for the network.

#### Freedom from violence

### **Key Framework: CEDAW**

Article 1: Discrimination Against Women means any distinction, exclusion or restriction made on the basis of sex which has the effect or purpose of impairing or nullifying the recognition, enjoyment or exercise by women irrespective of their marital status, on a basis of equality of men and women, of human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.

General Recommendation No. 19: the definition of discrimination includes... violence directed against a woman because she is a woman... It includes acts that inflict physical, mental or sexual harm or suffering, threats of such acts, coercion and other deprivations of liberty.

## Violation - Right to Property Supporting Framework: CEDAW

**Article 16 1h:** All women have the right to ownership, acquisition, management, administration, enjoyment and disposition of property whether free of charge or for a valuable consideration.

Violation – Right to Dignity and Life free of Discrimination

**Supporting Framework: Constitution of India** 

Article 15 (2):No citizen shall be discriminated on grounds of race, religion, caste, sex or place of birth...(no one) shall be subject to any disability, liability restriction

...with regard to access to shops, public restaurants, hotels and places of public entertainment or the use of wells, tanks, bathing ghats,...

## Sindhu (28)

I was one of nine children- three elder sisters, two elder brothers and three younger brothers. My father worked as a *coolie* <sup>21</sup> in a shoe factory. He also had some land. After a while he just stopped working. I was very young and I don't know why he did this. My sisters and I rolled *beedis* at home. There was a school where my brothers studied to class four, five and six. My first sister studied up to class two and my second sister up to 7<sup>th</sup> class. I don't know why I was never sent. I never even thought of asking. But now I wish I had gone. If I had studied I could have got a job that is better than rolling *beedis*.<sup>22</sup>

My elder sisters were married off and my elder brothers married people of their own choice. When I was 20 I was married off in a temple in the clothes I was in to a truck driver from the same place. I didn't want to marry him but my brothers said he earned a lot and that they would look after everything. Even at that time I did not

<sup>21.</sup> Person engaged in physical labour of loading and unloading of heavy goods.

<sup>22.</sup> Local cigarettes made of tendu leaves.

like the look of him, but my brothers forced me. Within a few months of my marriage both of them married people they liked. On the day we were married he had such a bad stomach ache he couldn't even tie the *thali.*<sup>23</sup> He used to constantly suffer from stomach aches and leg pain and had ulcers in his genitalia. The doctors did not do any tests or tell us what the problem was. They just kept giving him medicines. The only thing I was aware of was his alcohol problem.

After the marriage we lived in a part of my elder brother's house. During this time he abandoned me twice when his elder brother asked us to leave the house. He left me on the street and disappeared on both occasions. The second time, I borrowed two rupees from a nearby shop and went back to my family.

My brothers complained to the police but since we could not produce any documents- wedding invitation or photograph they could not file a case or do anything. So I stayed with my elder brother. It was terrible. I had to all the housework and they burnt me with hot tongs if I asked for food. A year later he came back and I decided to go with him because life was unbearable were I was. I told them no matter how he treats me I am going with him. This time he stole the little money that I had and disappeared. When I went and complained to my family they said why have you come back? Go away. For a while I stayed in a friend's house then my elder brother again took me back but said I had to do the housework and obey his wife.

My brothers then managed to find my husband and told me to go with him. He had changed a lot. He was looking thin and tired. He constantly got fever and medicines made no difference. He then tried *ayurvedic* <sup>24</sup> medicines and became well enough to drive again. Then one day he had an accident. The owner was with him. He was carrying Rs. 10, 000. The owner did not want to go to the police station with the money so he gave it to my husband and told him to go home. He again disappeared with the money. When I went back my mother said your brothers have done this to you. Come and stay with me I will look after you till I die. She had cancer.

About eighteen months later when I went with her to the hospital I noticed a strange looking man who kept staring at us. A day later we realized it was my husband. I asked the nurses what the matter was and they said he had HIV/AIDS and that I should also get myself tested. When my husband tested positive I did not know what it meant. It was the ward boys who told me not to touch him or

<sup>23.</sup> Chain or thread worn by women as a symbol of marriage.

<sup>24.</sup> A traditional system of medicine practised in India.

take the vessels home because he had that illness. For a month I cared for both of them- mother and husband. Then one day he fell at my feet and asked me to return to him and said "I need you to look after me". He also promised not to leave me again.

I took a house near my brother and cared for him. We had no money apart from the little I earned from rolling *beedis*. No one came to see us. He also developed TB and became so sick that I had to take him to the TB hospital. I used to beg at the bus stand to buy him medicines. Then the doctors told us that there was nothing more they could do for him and asked us to leave. I then had to work and look after him. It was very difficult. So I sold my chain and got him admitted in a nursing home. He started to get well and the doctors asked for Rs. 200 to test him. We did not have that money so we left. We stayed in a hut and I begged to feed ourselves.

It was all so depressing I wished I could die but then if I died who would look after him. I asked my brother for money, told him he was very ill and looks like he is going to die. He gave me some money, which my husband took and disappeared again. He drank a lot and because of the medicines he had a reaction. I took him back to the TB hospital where he died three days later. The staff there told me not to take the plate and other vessels back and said if you do sterilize them or you will get the same illness. None of our relatives came when he expired. The hospital arranged for the hearse and I did the last rites myself. His family is now accusing me of killing him. After he died we also learnt that he had married two other women some distance away and that when he disappeared he used to go to them.

When I went back to her mother's house that night she told me to stay with her. She died a year later. The family treats me very badly. My father says women should marry and go away. Sons will care for us and perform our last rites so they can stay in this house. Once the social worker at the hospital spoke to my elder brother and scolded him for the way he and the others were treating me. He twisted the whole thing and told everyone that I had sent someone to beat him up. He beat me up after that. Since I am widowed I am isolated and made to wear widow's clothes. My sister- in-law even pulled the chain I was wearing saying it was not befitting for a widow to wear one. One day a social worker came by and I told her all my problems. She arranged for me to get 10 kilograms of rice a month. All are there to receive it but they still don't feed me saying rice alone will not help.

About this time at the suggestion of my niece who has studied up to class ten, I got myself tested. I was counselled before and after testing. When my family got to know they told me to leave the house. They have also told everyone in the village and I am completely isolated. I am not allowed to use the village well. If I need water to bathe they pour it for me from a distance. I live in a corner of my family house. I earn some money rolling beedis and painting pots. I have also been doing self-disclosure counselling at the hospital. They say they will pay me conveyance but I have not received anything so far. But I continue to do it because I want to help others like me. The social worker in the hospital gave me some vessels to cook and eat in. Things have become a little better in the hospital after the social worker spoke to some of them.

My sisters have meanwhile filed a case for a share in the family property. My brothers are saying we have no right since we were married off and it is only if our father so desires. But this is our grandfather's property and we know we have a right to it. The case has been in court for the last three years.

Now my younger brother is trying to get me out of this house. He is the only one staying here with my father. For many years now the vessels of the local temple have been kept in the house. Now he is saying that this house is like a temple and we should all move out. I know he is doing it just to get me out. I quarrelled and have refused to leave. Last time they told me to leave and threw my things out I threatened to complain to the police. Now there is a police station in my village and I will certainly complain if they do it again. At least they leave me alone after that.

#### Maria (28)

My mother died when I was two years old and my father, who was blind died when I was six. My stepsister from his earlier marriage, she is about 30 years older than me took me to a convent and left me there till I was 18. I have four sisters and two brothers but she did not tell me this till I was 18 because she was afraid I would go to them and then she would have no one to care for her. She has no children.

Life was hard. All day long I had to clean windows in the three-storey school building for which I got one rupee a day. The Rs. 30 I earned went towards the fees for the night school. I was miserable. I felt a loss of love and family life and used to curse myself for being born. The nuns were quite cruel. They would oil our backs and hit us with a stick if we did not study and once I had to eat the food I

had thrown into the dustbin as punishment for wasting food. To this day I can't leave any food on my plate. The nun hit me with a slipper once because I spoke to the gardener. I used to also fight on behalf of the other children so the nuns did not like me. I was in the convent from the age of 2 till 18 and was like a slave to the nuns. Sometimes I thought I would run away. But I didn't want to end up as a prostitute. I was also afraid of my stepsister.

On the plus side I got an education. And all this has made me strong. I can adjust anywhere and face any hardship. And despite it all when I look back on my life I feel I have done quite well and am proud of it.

The principal was awfully mean. Years later after I tested positive I went to see her. Told her I was ill that I had cancer. She said no it is HIV and added that she had told the nuns to pray for me. I was shocked. I then learnt that her sister who worked as a nurse in the hospital where I had been tested had told her. I felt very bad and wrote a letter telling her she had no right to break my confidentiality and tell everyone. After all she had known me as a child. I think she felt bad after that. She still writes to me.

After school I did a two- year ANC course. Even during training I got no stipend because I was a 'trainee' and had to make do with the tips I got from patients. When I started working in a private hospital I was given just Rs. 150. Since this was much less than what others were getting and I was doing the same amount as them I asked the director who said it was because I had 'no experience'. I refused to be exploited in this manner and just left and got married.

At this time I was going around with the person who I married. He was the manager of a hotel. We knew each other for six months. We talked about everything and even of HIV because it was something I was scared of. During our training we were shown a case. He was kept in a glass room ... just skin and bones. I thought Lord I should never get this disease. When I tested positive my first thought was of this person.

About two years after I was married, my husband got a deep cut on his right hand. When we were having it dressed the lights went off. There were two syringes in the tray, one clean and another that had been used. The nurse mistakenly used the dirty one. Six months later he started getting rashes and fever. He was first tested for malaria and when that came negative he was tested thrice for HIV the same day.

He was then admitted in hospital. My two-year-old daughter was tested and so was I. My status was revealed to me in the hospital corridor where I was playing

with my child. The doctor just said Mrs—you have tested positive like your husband and then just walked off. I was shattered. I started crying. Then the next day she called me and counselled me. I then asked her why she had broken the news to me in that matter and that I could have committed suicide. She apologized and admitted that I should have been counselled prior to being told my status.

A year later my husband died. He was shocked, when he was tested positive. He never really recovered after that. No one helped me during this period. My sister used to come every week and wash our clothes. My in-laws came to know of his status through the parish priest who told my sister-in-law. Even at the mass for my husband he kept repeating that he had "an incurable disease" so the whole town came to know. I was furious. I fired him and told him he had no right to reveal the status to my sister in law or others. His duty was to tell others to help us instead he was doing this. I also told him I could take him to court for violating my confidentiality. He apologized. Initially my mother-in-law did not like me. She used to complain about me to my husband and when he died she accused me of giving the illness to her son. I pointed out that if I had the disease first I would have died first. After that she started appreciating me and she became much nicer. She is now dead.

I then went back to the hospital I had tested in for a job. The doctor there offered my Rs. 200 and in addition to helping in the clinic I had to do household work for her. I quarrelled with her and told her she was taking advantage of my situation knowing fully well that I was a trained ANC. She got upset and suggested I go to an NGO were there were lot of positive people.

I took up her suggestion, went there, and got a job. Initially they were only paying me Rs.1, 500. I took up the issue with the director. Told them I was working very hard and that I could not manage on the amount I was getting. They explained that it was because I did not have a master's degree in social work. But they agreed to give me an increment of Rs. 500 every six months. I am glad I took up the issue. It made a lot of difference to my life. I have also learnt a lot from the work I do here. It has given me a lot of confidence to fight for my rights and now I can speak anywhere on matters of sex and sexuality.

I was once invited to a doctor's meeting by the SACS. I agreed to go on condition my confidentiality was maintained. They agreed to do so but before I got there they had revealed my status to everyone. So when I went in I found every one looking at me in a peculiar way. Later one of the doctors asked me if I had asked for confidentiality. When I said "yes" she said, "These people make rules for us

but don't adhere themselves." I was angry. I told off the doctor concerned and said that I would have revealed my status if I wanted it known. He tried to explain it away saying it was a case of ego hassles and that the NGO advisor had problems with the NGO I was working with. I just told them I did not want to have anything to do with them and left.

At one time there was a person in my life. We had met on the bus and since he was a sort of fixer with political connections I thought I could use him to get work done for the NGO. He knew I was positive but wanted to have sexual relations. When I refused he got violent, tore my clothes and kicked me. I went to the police station and filed a complaint. Since he was influential the cops tried to stall by telling me to call my sister. I said if my sister has to come then so has his sister. I will not let you bully me just because he is influential. The police then sorted out the problem and told us to go our separate way.

I also have property problems with my in-laws. My husband's family has a huge house that is in the hands of my sister-in-law. Of the six children in the family only three are surviving. When I asked for my share she asked me to build a house in the marshy end of the plot. My first instinct was to tell her to keep the land. But now I have decided to wait and watch till they divide the land. I have decided to tell them I don't want the land and to give the equivalent in money to my daughter.

When I look back on my life I find there was so much violence both mental and physical and that I have had to fight whether it was in boarding school or in work situations. And after I became positive it has all become worse. The stigma and discrimination people living with HIV/AIDS face is unbelievable – from society, doctors, employers and family. Everything becomes that much more difficult. But I have also seen from my own life that people's attitudes can be changed.

# Access to basic rights including the right to life accentuating vulnerability of the girl child

## Key framework: CEDAW. Supporting Framework: Child Rights Convention

**Article 12. (1)** State parties shall take all appropriate measures to eliminate discrimination against women in the field of health care...

**CRC 3 (2).** State parties undertake to ensure the child such protection and care as is necessary for his/her well -being...

**CRC 6.** Every child has the inherent right to life...

**CRC 24.** The right of the child to the enjoyment of the highest attainable standard of health

# Violation: Right to Information on sexual and reproductive health

## Supporting Framework: General Recommendation 24 on Health

State parties to ensure without discrimination the right to sexual health information, education and services for all women and girls... In particular.. should ensure the rights of female and male adolescents to sexual and reproductive health education by properly trained personnel in specially designed programmes that respect their privacy and confidentiality.

## Vrinda (24)

My family consisted of my parents, my brother and me. My brother is now 28 years old and elder to me. My mother's condition was such that she used to alternate between attacks of depression and euphoria so we had to do all the housework on our own. My father, who worked as a gardener was always depressed and tensed. As a result we were never sure when my father was in a good mood. Since my mother was a mentally ill, I couldn't share my secrets with my mother, whether about purchasing anything or my personal problems. Unlike other girls who share their secrets with their mother, I just couldn't do that.

I got my 1st period during my 7th standard vacation. Since I didn't have an elder sister, I didn't even know what the real problem was. I thought that I had some dangerous and contagious disease and offered prayers in temples. But the next month when my periods started again, I was forced out of fear to tell my father. He didn't say anything. He took me to his mother, who explained everything to me. She told me that, this was a normal thing for girls and that now I had become a mature girl.

Then gradually I started showing signs of maturity. A few of my friends who knew about all this and had their periods asked me whether I had got my periods. They also asked me how my mother had reacted to my first periods and what she had

got me as a gift and also about the things that I had used during my periods. But I had nothing to tell them, I felt very sad.

Since I did not have a mother to look after me I didn't even know how to fold a cloth into a napkin. Every month my dress used to get stained. Even on matters of hygiene and cleanliness I did not know what to do.

I was very interested in learning. But my education was only up to the 10<sup>th</sup> standard. This happened because of an incident in my life. I used to be very open with my father but I could do that only to a certain level. I needed somebody with whom I could share all my secrets. So I chose a friend, in this case a friend who was male. Our society never accepts a relationship between a boy and a girl. All the people started giving it the name of an affair. But for me he was only a friend. He used to listen to all my family problems and console me. More than a good friend he was always a good listener.

When I was in the 6<sup>th</sup> standard my father got into the government service. He also wanted me to get married to a government servant. But after listening to a lot of rumours about my friend he wanted to marry me off. All these problems affected my studies. Also the relationship between my father and me got spoilt because of the different rumours about me in the community. My father started hating me. He stopped my education and didn't want me to go out of the house.

I wanted to go for higher studies. I had wanted to become a teacher or a nurse since childhood. This was my dream. But my father didn't wait for any good proposals; he fixed my marriage with an auto driver. I always hated drivers, but I was forced by my family to get married to him. If I had a mother or some one to advise me or someone who I could talk with, I would never have gone in search of a friend. I also pleaded with my father not to get me married at that age. But my father was of the view that girls only required primary education. He didn't listen to me and was more tense because of the rumours of my affair.

I was married in 1997 at the age of 17. At that time I had joined a homeopathy pharmacy. I have been working there for the last 9 years. My husband and his family had a loving nature. We were close to each other. My husband loves me but now he is ill. After marriage we decided not to have children for a year. But after one year when we tried and I couldn't concieve we approached a doctor. He said that my husband's semen count was low. My husband took medicines and

then I got pregnant. During this time, some sort of a swelling was seen on my husband's stomach. He was operated and the lesion was taken for a biopsy. First they told us that this was due to tuberculosis (TB), but the doctor also doubted about some other disease. He asked my husband whether he had an extra marital affair. I was not with my husband during all this.

It was actually my employer who told me that my husband had a serious disease and that he also doubted that my husband had an extra marital affair. This was two years after the marriage. Then he developed fungus on his tongue and diarrhoea. About this time we came across a magazine with a medical column, in which the doctor described all these symptoms as that of HIV. After reading that we went to see a doctor, I asked my husband not to reveal any of his doubts and only talk of his symptoms. But when we went there to my surprise he explained to the doctor everything, which shocked even me. He said that he had an affair for over 6 months. He also told the doctor about losing weight and other symptoms. From the very moment that my husband knew that he had AIDS he became totally weak mentally and physically. He started getting fearful thoughts and started revealing a totally different behaviour. But I had to take all this lightly because if I too started to get weak then who would be there to support my husband and give him mental strength.

No one had given me any information on the disease. The only thing that I had heard was that it was a dangerous disease. Something like cancer. My husband has now become a totally weak person. He is psychologically traumatised and not ready to accept anything. If the doctors had explained this to him in a friendlier manner or in a different way the situation would have been much better. But their approach was negative. They were very rude and harsh. They told us that medicine were available only at the Kottayam medical hospital for this.

Before we used to think that a person with HIV would die within a year. But now after reading many articles especially those which come on World AIDS Day, I have understood that we can live a normal life and we need to have medicines. But I also know that we will be prone to different diseases. Some of them can be cured with proper medication. Now I keep consoling my husband that this is like any other disease and that he can live a decent life. I keep telling him that a life has no guarantee and that other diseases also kill people. But even though he has the ear to listen, he does not have a normal mind that is capable of understanding this.

About a year and a half after my husband was tested positive I decided to get myself tested though the doctor at the Kottayam Hospital had said that I needn't

do a test since it was too early for me to get AIDS. He didn't give me any information either. He only said that there are a lot of medicines and that most of them are costly. He said that it would not be possible to prescribe any of the medicines right now since I won't be able to spend on it.

My family life has been shattered because I feel that I have no hope. Now we don't have any symptoms of AIDS. But the first mental shock that we got, we are not able to recover from it. The doctor has prescribed (Anti Retro Virals) ARV for about six months as a rate of Rs. 3,500. He didn't even explain the real affects or the need of ARV. I am not sure what more we will have to face. First the doctor had said that my husband need not take any costly medicines for the next ten years. But looking at his mental state, he prescribed ARV. After this my husband put on weight, there was no other benefit. But now we know that in the later stage when the symptoms would begin we will have to spend on expensive medications. If we had known about all this earlier we could have mentally prepared ourselves and could have earned properly for the medicines to be used. Due to my husband's condition he can't go for work. At present the whole family runs on my salary.

Now his parents know. But at first we used to hide it from them. Whenever we used to go for consultation we used to hide it from my husband's parents. But people who saw us there used to come and tell our parents. First they didn't know that it was AIDS. They thought that I was trying to spoil their son's life. They used to shout and abuse me a lot. But one day when I was unable to bear all this I told my uncle. My uncle then went and told our parents. From then onwards they have respect for me and they love me a lot.

I have told my father that this is a mental disease. He and my brother are giving me the money for the medicines. My brother knows all about this and is still a bachelor. He says that if he gets married he may not be able to support me. The doctor in the dispensary where I work does not know that I have AIDS. I don't know what his reaction would be if he came to know. Maybe I will have to quit my job.

My marriage is the one incident that affected my life. It was against my will. Perhaps it was my fate but if my father had agreed with me when I was trying to explain, this would not have happened.

**Supporting Framework: CEDAW** 

**Article 16 1h:** All women have the right to ownership, acquisition, management, administration, enjoyment and disposition of property whether free of charge or for a valuable consideration.

## Stella (32)

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My family consists of my parents and my eight siblings. I am the youngest. I have three brothers and we were financially sound. My father and brothers used to take all decisions according to their own will. They were not interested in getting me and my sisters married. My father said the family income would go down. My elder brother had married before my father's death. Now he has no contacts with us. One of them runs a bakery in partnership with another person. The other brother is a farmer. Another brother is at home. He lost one of his fingers in an accident. So he can't work. However he gambles a lot and though he has a wife and child he does not have any connection with them. His wife's relatives look after the child.

A large portion of our property was sold off by my father and my brothers. Now only 20 cents <sup>17</sup> remain. There was a little land in me and my elder sister's name. But that was also forcefully taken back from us by my brothers. We did not get anything. My three brothers have also got my fathers will.

For almost 11 years I was staying and studying in an orphanage under the convent. Though we were financially sound my father did not take any interest or care for us. Most of the time our father was away on business matters. So I and my elder sister were taken to the orphanage by a person, who knew the sisters in the convent. I continued my studies in the orphanage. After that I continued there as a person who took care of needy people there.

Soon after I finished my 10<sup>th</sup> class I wanted to join a teachers training course. At that time our financial condition was not that bad. But my father got angry. He almost came to hit me and disagreed with my decision. So I wrote a letter to the sisters at the orphanage. They asked me to return to the orphanage. My father used to give my brother money to squander away on gambling, but he didn't have money for my education. There were around 80 children in the hostel. I used to cook for them and take tuitions. With that money I joined typing and short hand

classes and passed them in both Malyalam and English. After my training my brother took me to his place. From there I went to Bombay to my sister's place. There I joined a hospital and worked there for almost four and a half years.

During my job in Bombay I met my husband. He was at that time working in a tyre shop. He was a Hindu (Nair) while I was a Christian. At that time I was 24 years old and he was 29. He had studied up to the 6 <sup>th</sup> class. My sister accepted this situation at first but when we decided to get married, my sister did not agree with it. So I decided to marry against my sister's will. Due to this I couldn't stay with my sister anymore. I worked in the hospital doing both night and day shifts.

Then I decided to have a register marriage in 1993. I didn't go home after that but waited for them to come to Bombay. But they neither saw me nor did they talk with me. Later my brother came and told me that things like this are common in a place like Bombay and that going with a person for a month or two is no big thing. He also said that if I lived according to their wishes then they would give me part of the property and also conduct my marriage. But I did not agree with them. At first all of them were very sad because I married a Hindu. After five or six months my sister came and took me to her house and my marriage was conducted in a church.

Soon after the marriage we rented a house. After some days we went to my husband's house. We spent time here and there. After one year during the time of my delivery, my parents came to see me. They understood my feelings and then everything became alright.

For about five or six months after marriage he had no problems. Then he became an alcoholic. Things started becoming difficult. I knew my husband would not take care of us, so I had to return to my native place. I started going to Divine Nagar for meditation hoping that my husband would become better. There was some change in him. Usually he was a loving person, but after drinking he used to become very violent. He always used to give his salary to me. In between as my husband could not get a good job, he went back to his father's house and was living there. After a while my family asked us to come back home and stay with them. I gave birth to our second child and during that time my father died.

In November of that year, my husband got a slight fever. Usually he used to have a cough but I never paid that much attention. When my husband got high fever he was admitted to the hospital. He was there for fifteen days. He had TB and the ESR count was also high. The doctor doubting something got him admitted to the hospital. His blood was taken for an HIV test and we were asked to come

back after ten days. When we went back the doctor said that my husband had AIDS. We did not get any counselling before this test. When we went to meet the doctor, he gave a letter and took us to the counsellor. First my husband was taken in. Then I was also called in.

The counsellor told me he had AIDS. I said that there is no way that could have happened. I never asked what my husband had said. He asked me whether there was any sort of extra marital affair. I said that nothing of that sort had happened. The counsellor then explained everything. He said that there was a place that people like us could go and stay. He said that we could educate our children there. When I went back home I told my sister about my husband. At that time she was pregnant and she was very afraid that it would spread. My test was not done at that time.

As the counsellor had told me that we would not live for long, I took him to his house to meet his relations. After some days his condition became a bit better. His father, mother, brother and wife were there. They said they did not like our staying there in that house. It was mainly because my husband used to drink. Their property was divided and we thought of building a house in our ten cents. At first his father had agreed. But later he changed his words. We left the house. After about 14 days my husband's condition worsened. He could not even drink water. So I wrote a letter to his father explaining about my husband's condition. I told him he had HIV and that there is no medication for it.

When I went to my in- laws place with my husband they said that their son was alright and that I was making up a story. They also said that I had injected the disease into him. I even showed them the certificate but even then they did not believe it. For some months his condition was such that he would be alright for one week and then the very next week he would get hospitalised again. He was not able to eat anything. He was given all sorts of medicines but his condition did not improve. As I said before my in laws did not like me. My mother- in-law was more against me than my father-in-law. They were indifferent to my children also. My in-laws were very well off.

When he fell ill at my in-laws place they took him to the doctor. The doctor asked them to conduct an HIV test. They got the result and showed it to the doctor. The doctor told them about his condition. Even then they did not tell me anything. They said that it was only a growth and that it would be treated in Tiruvnanthapuram. Before they used to say bad things about my father and my family but now they have started saying that my family should take care of him.

But I said that it would not be possible as I did not have any money for treatment. The little money that I had was used up by now. So they said that they would help me financially and then asked me to take him for treatment. I told a sister there about my husband and she advised me and my children to undergo the test. When I was told that I had AIDS I became totally upset not because of the fear of dying but because of my children. Who would be there for them? So I asked my husband to go home and try and get his share of the property. When he went there they did not give him anything. There was some dispute because when he came back he was totally tired and his condition began to deteriorate. He became delirious and abnormal. He used to shout saying that he wanted to see his parents. We phoned up his place. His brother said that he would come but no one came. Shortly after that my husband died. I called up my mother and let her know. My mother and I cremated him.

After the funeral my children and I continued staying here. My son later joined another orphanage. My daughter was with me. I thought that my in-laws would at least call me up. When I did not receive their call, I wrote a letter to them. After receiving the letter my husband's brother called me up in a drunken state and scolded me a lot. I also wrote to my husband's uncle. They told me that his father had died in March. Otherwise I would never have known. My children have been tested. But they are ok.

Now I stay here at this mission and make chains with beads for chanting. Earlier, my sister used to send me money every 2 -3 months. Now that has also stopped. I also work as a nurse now. When patients come I look after them and give injections. I don't get anything for this. I do all this for free. I haven't done anything about my husband's property yet. When I call his family they say that my children would be getting the property only after my death. So I have decided to go to court.

I want to get my share of the property from my brothers and my husband's share. This will at least be of use to my children. Once when my sister was about to file a case for our share, our brother attacked my sisters' husband with a knife. During this time my brother also forcefully got the property in his name from my father. The *gram panchayat* has sanctioned my widow pension and a house. But the *panchayat* member did not do anything. When we approached the court it passed the sanction order for the same month. But till now I have not received anything. We have been complaining. But nobody is bothered. We went to the collector's office also. When the order was made the collector didn't have any money in his fund. Thus we have been denied this privilege also.

**Supporting framework: CEDAW** 

**Article 16:** Women have the right to freely choose a spouse and to enter into marriage only with their free and full consent.

## Violation - Right to employment without discrimination

**Supporting framework: CEDAW** 

Article 11, 1 b: Women have the right to employment opportunities including the same criteria for selection in matters of employment

#### **Constitution of India**

**Article 15, 2:** No citizen shall be discriminated on grounds of race, religion, caste, sex or place of birth...(no one) shall be subject to any disability, liability restriction with regard to access to shops, public restaurants, hotels and places of public entertainment or the use of wells, tanks, bathing ghats,....

## Vidya (27)

Besides my parents there are three children in my family. I am the eldest. I have a younger brother and sister. At the time of my 9th class final exams my mother was hospitalised. Being the eldest I had to do the household work and study simultaneously. Somehow I finished my 9th class then I joined the nursing class and started working. For a while I worked in an a eye hospital. My father had a small photo-frame shop but after he fell down he stopped working.

My friends and relatives told me about tailoring classes. I wanted to learn tailoring. But when I was a child I had an operation in my leg so I cannot sit for long hours on the tailoring machine. I asked the doctor he said that after some time it would give problems. But I learnt to make - dolls, basket, embroidery etc from a friend.

My mother who had undergone surgery for a blood clot in the brain was scared that she would die and wanted to see me married. At the age of 19 I was married to a boy who was working in the central government. I didn't want to marry him and even said that I am not that old and cried. But I was not that bold the way I am now as I was brought up like that. They didn't allow me to go out. So I could not argue with them. I thought people would think that why does a 10<sup>th</sup> educated girl not understand her mother's situation. So I agreed to the marriage.

Before the marriage my parents went to see the boy's house. They inquired about him in the neighbourhood and the office. All was fine. However, on the day of the marriage he told me had a drinking habit. I didn't like that. I felt I was cheated because I had been told that the boy had no bad habits. He also had fever on the day of the marriage. We thought it was normal fever and the doctor gave tablets and he was fine.

After that I had problems all the time. Whenever I didn't feel well I used to go to mother and take rest there because at my in-laws I had to do all the work. I was never allowed to go out alone. After the marriage friends used to call us for lunch but he never took me there. Even when I wanted to go to the temple my mother-in-law didn't allow me. They never allowed me to talk with others. I felt as if I was living in a jail. I had my food and saw TV. Initially we used to go for a walk but afterwards that also stopped.

I lived like this for one and a half years. Then I conceived. I felt very happy. After five months I went to my mother's home. He came and saw me frequently. I had a baby girl by caesarean. At this time my husband again had some allergy. We showed my husband to the doctor who prescribed some ointment and he was fine. When I went back to my marital home I noticed that I had boils in the urinary tract. I had a fear of HIV. I had read about it in the hospital. I thought my husband is a nice man he wouldn't have gone in the wrong way. So I didn't doubt him.

Then again he had problems and was admitted in the hospital and had loose motions. He was there for one week but he was not fine. So we took him to a bigger hospital. There his test was done and the result was told to my sister-in-law. She went and fought with my mother saying that her brother had got infected because of me. Then my mother came to me and said he got infected because of you. The next day when I went to the hospital my sister-in-law was crying. She told me that he had HIV.

It came as a shock to me. I went to the doctor and asked how this had happened. I can't believe this. Though I know it could not be cured, I asked the doctor to cure him. The doctor asked me are you breast -feeding the child?" I said 'yes'. He told me to stop and to get my blood tested. He said to give blood and then go home. The doctor didn't give any reasons. The doctors didn't came near me and other patients wondered why they were doing so. When we brought my husband back home he started behaving abnormally. We came back in a car. After reaching home he refused to enter the home and sat in the staircase.

Everyone was watching us. We couldn't say anything. He refused to sleep and started saying "I have to go to office, get ready". I couldn't calm him. The doctor came and gave him a sleeping tablet. A family friend was also present. The doctor told him everything. He was my husbands colleague. But he didn't say anything outside. Many friends came to see him but he never said anything. My husband used to sleep for long hours due to the tablet. So we stopped the tablet. His status started becoming worse. He used to urinate in bed and suddenly one day he couldn't breathe and he died the same day. His status was known in '97 and he died the same year. After his death I stayed there for 3 months.

I used to leave my child with my mother as I had to go out for work. I went through many problems and my mother-in-law also started creating problems for me. Then my child started having health problems. My sister-in-law's relative is a doctor in a hospital. They recommended me there. I went to see the doctor and he said that the child can be tested at the age of one and a half years but we will check you. I tested positive. They told me to have healthy food and be confident. After talking to them my confidence increased and I started having my treatment there.

My child also tested positive. I was devastated. She was very healthy and active. After my husband's death I tried for his job. I even got a medically fit certificate from the doctor. But even then the employer refused and wrote that I was medically unfit. By then my in-laws' torture increased. My mother-in-law asked me to give his job to my sister-in-law. I talked about this to the general manager. He said we couldn't do that as this job was given on compassionate grounds to the widow. But my in-laws didn't believe it. As his service was for a short time the pension is also less.

I didn't get the job because the general manager said that as I was HIV positive I could not be employed. He had sent my file to Delhi writing that I am HIV. Then they sent a letter, which said that the pension money is enough for my child and me. I went and said this to the doctor. He said we could go to the consumer court. But I thought that everyone would come to know and this would spoil my sister's life. My brother was also not married at that time. People would start thinking wrong about my family. They would not understand the situation and would discriminate us. There will be problems in society. So I dropped the idea of trying for the job.

After my husband's death we couldn't pay the rent, as there were a lot of expenses after his death so I was told to vacate the house. Then I started living with my mother. I stopped thinking about work and concentrated on my child. She started

having loose motion and a breathing problem. She started getting boils on her. Then one day her status was very serious. We took her to the hospital but she died.

People treat us badly once they come to know. It has happened to me once. I had gone to the hospital for an eye check up. The doctors gave eye drops to everyone, but when my turn came they told me to put it myself. They could have worn gloves and treated me. When they do something like this, people stare and start asking questions. When I said "I don't have anybody, so you must do it", they just put my case sheet at the end of the bundle and told me to wait, adding, "anyways we are giving you treatment free of cost". Our position has become like this.

## Mridula (25)

We are five children - three girls and two boys. I am the last and the pet in my family. Even as a child I had health problems. I used to go to a doctor who gave me injections and tablets to reduce the pain. When I was 13 years the joints in the hand and legs started swelling. I was taken to Trichy where we were told that I had a hole in my heart. From the age of 15 I have had low blood pressure for which I take medicines.

Occasionally I get pain. I am not supposed to wash clothes or lift heavy weights. If I do all that I get pain. My family does not allow me to do work. But at times I do some work on my own. I studied up to 9th class because after attaining puberty in class 9, they did not send me to school as it is a village. So the teacher came to my house and I passed the 10th. I wanted to study more. But I discontinued after that because there were no facilities. When my people wanted me to get married the doctor said "If she gets married and becomes pregnant it will be dangerous for her life. Let her be at home and continue her studies, otherwise send her to me, I will look after her". But if I was not married, the people in the village would talk. So they got the permission of the doctor and I got married. But now all of them feel differently about it. They say we have spoiled her life by stopping her studies.

One week before the 10<sup>th</sup> standard results I was married to a relative. He was a widower with two daughters. So to look after them I was married to him. He knew about my health problems. He was a tailor. I was happy with the marriage. He was not very old. At that time I was 19 years old. Earlier when I was at home I wanted to go for tailoring classes but I could go only for three months because I got my joint pains and I could not continue. When I went to the doctor, he said that I should not continue tailoring.

Life after marriage was difficult. My husband was affectionate but I had some difficulty with the children. The younger one was a small child. The elder one was in upper Kindergarten. She used to talk badly and she did so even after my husband's death. My father-in-law was also there. Before my marriage I thought I would be able to handle it. And I had agreed to it. The elder one knew all the details but the younger does not know anything. And though I was 19 at the time of marriage I knew nothing about sexual and reproductive matters.

We were married in 1997 and in 2002 he came to know of his status. Six months before his death, he told me he was positive. At that time we had been married for six years. He had known that he was positive for a year. He had a swelling in the neck and he was down with fever frequently. Before that he was perfectly all right. When the swelling continued we visited the doctor. The doctor told us to go to Perambalur to get the test done and then go to Tambaram hospital for the medicines. When he went to the hospital for the first time he took me with him. He gave his blood for testing. After that he used to go himself, he did not say anything to me about the report.

During the first visit itself the doctor told him to do an HIV test. I know the nurses there. After two days, I went to the hospital and asked the nurses. They told me the result. I did not tell him I knew. I was waiting to hear about it from him. But he did not tell me for a long time. He used to go to Tambaram to get medicines every month. When I asked him he said he used to go for TB treatment. One day, by mistake, he kept the prescription slip before me. I saw the prescription. Then I asked him "why did not you tell me about this?" He said, "I did not want to give you a shock, with all your health problems". My husband did not say anything about his condition to me but he used to tell others. That is where I think I was deprived of my right. He did not have any consideration for his life. I was very much affected by that. He did not understand me. He has so many contacts (with other women) I tried to stop that. He said, "I will be like that. You cannot stop me." He never gave me the right of a wife.

At the time of his death only my neighbours knew he was HIV positive. I was also not aware that I would be affected if he was. Six months before his death, he told me to get my blood tested, but I ignored it. It was only when the counsellor visited my house after my husband's death and asked me to go and get myself checked up that I had it done. When they told me that I had HIV/AIDS, I was not shocked. By that time I had already seen my husband die. Now I know a lot more about HIV/AIDS through things I see on the TV and through the counsellor at the hospital.

After my husband's death I came back to my parents' place. The children are with their grandfather. The younger child wants to stay with me but my in- laws don't want to send her. The children have not been tested. But I don't think that they have been affected.

Now my family says "We have spoiled her studies and her life". They are saying this all the time. I was not worried about marriage but had I continued my studies, I would have had a comfortable life. I could have found work according to the level of my education. Initially when my husband was alive I went for computer studies for three months. This was through the free services of the government. I finished a three month course and they asked me to join for the six months course but they told to me pay, Rs. 200 first. So I did not go. My husband stopped me by saying, "What are you going to do after studying this?" Now I want to study and do some work. I have told my parents, I would like to continue but the family is in a bad state. I do not want to trouble them. Because of shortage of rain, our paddy fields are dry.

Education is essential and I do want to study. But I don't feel that this was a violation of my right. When my parents said that my brother must continue his studies I did not think anything. The atmosphere was like that. I do not think anybody is responsible for my situation. I was not healthy from childhood. There was nobody to guide us. Neither my parents nor my brothers could have guided me because they also are not educated. They themselves do not know. Some other educated people could have told me. I saw a lot in the books about HIV but I was not aware of how long a person with HIV can live.

I used to read newspapers and watch TV every day. Now I go to the shop and read the news papers. My family and neighbours know that I am positive. But they are all helpful. When I went to a doctor in Trichy my parents came with me to find out the truth. The Doctor told them about my being HIV positive. He thought that I would have told them already. He said if you had told me that you had not told your parents I would not have revealed your status to them. I told him, there is nothing wrong one day they must know about it.

I now stay at home and make baskets and do other odd jobs. It was taught to me by my neighbour. I am also part of a self-help group and we learn to make a lot of handicrafts, which are sold by an NGO in the city.

Miridula has now actively joined a network at the district level and helps affected women by providing them moral support.

## Burden of care. Women's traditional care responsibilities

### Key frame: CEDAW

**Article 11:** Right to same employment opportunities. Right to social security in case of retirement, unemployment, sickness...

Prohibition of dismissal on grounds of pregnancy or of maternity leave...

**Article 12:** State parties shall ensure to women access to health care services.

**Article 13:** Ensure to Women - Right to family benefits, Right to bank loans...

**Article 14:** State Parties shall ensure to rural women right to organise into self - help groups and cooperatives...

# Violation - Right to Confidentiality

**Supporting Framework: Constitution of India** 

**Article 21:** All citizens have a right to privacy and confidentiality.

Violation - Right to access health care, treatment, and medicines

**Supporting Framework:** 

## **CEDAW**

**Article 12:** All women have the right to access health care services including those of family planning.

#### **Constitution of India**

**Article 14:** All women are entitled to equality before law and shall not be denied equal protection of law.

**Article 15:** No person shall be discriminated against on grounds of religion, race, caste, sex, place of birth or any of them.

#### Saraswati (35)

I used to work as a maid during my childhood. We were four daughters. I studied till the 8<sup>h</sup> standard. I had to stop my studies due to financial constraints. My sisters used to take tuitions so they studied till graduation. There were free government schools but I did not go. I had the desire to learn but I could not go. I did not feel confident to study. Moreover my family used to run on the income that I used to bring from household work. I had to look after my younger sister. My elder sister asked me to study but my parents wanted me to go for work so that I would bring some money home. I am the third child in the family. My younger sister did her pre-degree and after that did nursing.

I got married at the age of 27 to a person who worked as a *coolie*. I had two children. When my younger child was four months old he was hospitalised for six

months. When he tested positive they told us the result and pushed us out of the hospital. Actually the doctors didn't ask us to go but the nurses made a big issue of my child's status and forced us out. This was a government hospital under the medical college. The people in the hospital gathered to see the child with 'AIDS' in ward no. 4. We had to leave from there to avoid the humiliation. I was about to commit suicide with my child. But my younger sister came and took me home. So I left with my child. I got the medicines that had been prescribed from outside since they had already thrown us out of the hospital. We had to mortgage our house to pay for the child's treatment. After that we never took him to a doctor again. Whenever he fell sick we used to give the same medicines that the doctor in the hospital prescribed the first time. He died when he was 1  $\frac{3}{4}$  years old. I don't know when my house owner is going to throw us out of the house. We haven't paid their money. I get only Rs. 750 per month and a travel allowance of Rs. 150 which is a total of Rs. 900. We have four meetings in a month and 4-5 days of work. All other days I sit at home.

After our child tested positive my husband and I underwent a test. At the lab they said that there is nothing to fear about. They asked us to eat good food so that we can recover. I have heard about AIDS before from newspapers. What we have heard is that this usually occurs in sex workers. Moreover a person near my house had died of AIDS.

It is almost three years since we learnt of our status. After about two years my husband and I started developing different diseases. My husband can no longer work and is taking medicines for TB at home. Both of us need medicines, so we require a lot of money. Our daily food we can adjust anyhow. But what do we do about medicines? I also have a child to take care of. My daughter is seven years old and in the 2<sup>nd</sup> standard.

When we go to the hospital they say they have no medicines. Once when I enquired at KSACS they said that they have already given a fund of one and a half lakhs to the hospital for medicines the previous week. But when we again asked at the hospital they said that they have not received it. What are we to do for all this? The people in the hospital are also very rude. Whenever I ask for free medicines one of them asks me to spend the money I spend to travel up to there for medicines.

Even in my own house I am isolated to a certain extent. My younger sister is a nurse so she has no problem with me. But my two elder sisters isolate me to a certain extent. They are asking me to contribute for my sister's marriage. But I have nothing for my own family. From where will I give?

Now I am doing field work for an NGO that works among sex workers. When the staff there came to know of my status there were problems but these have been resolved. The money that I get from doing the work is something big for me. I have a lot of problems doing this work but I can't do anything else in the project since I am educated only till the 8th standard.

In my husband's family there are 11 children. We haven't let them know because they will isolate me as my family has isolated my husband. They all say that I contracted it from my husband. My husband is also not financially sound. He didn't get anything from the family because in his family only girls get the property. He has only what he earned from his job.

# Violation – Right to Information, proper counselling, and rights to their reproductive choices

### **Supporting Framework - CEDAW**

Article **10 h:** Women are entitled to specific educational information to help to ensure the health and well –being of families, including information and advice on family planning

Article 16, 1e: Women have the rights to decide freely and responsibly on the number and spacing of their children and access to information, education and means to enable them to exercise these rights.

## **General Recommendation No 15 –** Avoidance of discrimination against women in national strategies for the prevention of HIV/AIDS

States must intensify efforts in disseminating information to increase public awareness of the risk of HIV/AIDS infection and HIV/AIDS, especially in women and children, and of its effects on them.

#### Supporting Framework: General Recommendation No. 24 - Women and Health

State parties to ensure without discrimination the right to sexual health information, education and services for all women and girls... In particular .. should ensure the rights of female and male adolescents to sexual and reproductive health education by properly trained personnel in specially designed programmes that respect their privacy and confidentiality

## Parvati (22)

I am an only child. My father died with I was 5 years old. When I was in the 6<sup>th</sup> class I attained puberty. From that day onwards my mother did not let me out of the house on my own. When I was in 8<sup>th</sup> class she said you are not a boy there is no need to pursue further studies. Actually, till 8<sup>th</sup> class I had free education in a

government school. When I went to 9th class I had to shift to another school. My mother was very annoyed since she had to spend money she stopped my education.

I was then 14 years. After that she saw a boy and settled the alliance against my will and wish. I told her I was not ready for marriage and that as she wished I said I would stop my studies but I will not get married. But she insisted and said, "I am not feeling well nowadays then who will take care of you". I was married off under a lot of pressure. I even told my uncle that I was too young. But he said that if you complain then they would arrest your in-laws and your mother. I was so uncomfortable with the whole idea I even thought of committing suicide. But then I agreed for the sake of my mother. I was in my childhood and I didn't like the boys' family members.

My first child was born when I was 16. From the age of three months she had the problem of diarrhoea. When she was 2 1/2 years old she had severe pain in the urinary tract so we took her to a private hospital. But they sent us to the government hospital and asked that all three of us get blood tests done. There they did not tell us anything. They just took our blood for the test and told us to come after 15 days. They then took us to the counsellor and gave our records to the counsellor and said that we are having 'AIDS'. They did not even say HIV. They said that from now onwards you both should stay separately and not like husband and wife. There should not be any sexual contact. Even then if you want to have sex then you should use condom. You will live for another five years only and the child will survive only for another four months and that in future we should not have any children. This happened in 1999.

I felt so bad that it could happen to me. My mother married me at a tender age when I should have studied further. I was married at the age of 15, the child was born when I was 16 and I came to know about HIV when I was 18 years old. I felt very bad. I thought how this society would react and discriminate against us and how my family would behave towards me. I did not know anything about HIV. Before marriage I had seen an advertisement on the TV which showed two human skeletons and AIDS was written in the bottom. I had a fear that may be I will also become like that. I felt like committing suicide.

My in-laws used to torture me a lot and when I spoke to the counseller, she said if you have any problem or your husband leaves you then we have an ashram where you can go and stay. I thought it was a good idea and left my child with my mother-in-law.

As time passed the breast milk started solidifying which lead to severe pain. People at the ashram there said "Let anything happen but you first go and bring your child". When I went back and asked for the child they said "you left saying you don't need the child, why have you come back. And you went out with somebody should I provide witnesses?" I did not know what to say so I just left that place and went to the police station and registered a complaint about the tortures and asked the police to help me in bringing the child back to me. So my in -laws gave me my child back but said "don't come to us in future. You acquired the infection. Our son will not do such wrong things. He is innocent". They also told my parents 'you know what disease your daughter is carrying?" They did not say that the problem was with their son. They said that, "your daughter has HIV/AIDS. Our son does not have any disease". Like this they accused me for all the problems. I took those things on myself, as for me my husband is important.

In that one week we went first to *mama*'s<sup>25</sup> place. There when mosquitoes used to bite us and then sit on them they thought that even they will get infected. So they told us to leave their house. So we went to my cousin's house. They didn't offer us food or even a mat so we slept on the floor. In the morning they gave us coffee, Rs. 50 and told us to leave. Even though my cousin is in the police department and well educated they thought they would get infected.

This was in the year 1999. At this time my mother sold her land and rented a house. We shifted there. Then my husband again started drinking and beating me. After we shifted there my child passed away. My husband insisted on taking the dead body to my in-laws house. There, no one came near the dead body because they feared infection. I did not have money to do the rituals. Then my mother gave me Rs. 1,000 and I took the body for cremation. Everyone was laughing at me. They said that I should not conceive again.

When I conceived again the doctor told me that I should not have this baby. They advised me to abort the child. I had the belief and confidence that I could give birth to this baby. But whenever the doctor saw me they told me to abort the child. I told them that there are ways to protect the foetus and anyhow I have the right to decide whether to abort or not and there is no need for them to decide on behalf of me. Your work is to give counselling the rest you leave it to me. I went to the Government hospital and said that I want to give birth to this baby. So they referred me to a doctor who referred me to another hospital where they gave me tablets. They told me to take tablets from 8th to 10th month and said that we have to do an operation to take the baby out.

<sup>25.</sup> Mother's younger brother.

When they took me to the operation theatre I wondered why this was happening to me. I had not done any thing wrong in my life. The hospital people took signatures from everyone and said now you all are responsible for whatever happens. That night I had a normal delivery. They all knew I was positive as they had put a sticker on my stomach saying that I was HIV positive. When the doctors saw the sticker they used to back off. Even the nurses when they came to give enema kept saying she is having HIV.

They asked me for Rs. 100 to give an enema. I did not have money. So they then shifted me to another ward. There the doctors were not ready to touch me while doing the check up. There was only one doctor who was fine. When I got the labour pain the doctors had put on five gloves. The child tested negative and I was very happy. When the child was 1 ½ years old I had another test done and even that was negative. Then afterwards I went to a private hospital. There also it tested negative. I was really very happy.

Nowadays I go to the network so I get a lot of support. Now I have all the information. If I had not come here I would have died. Now my life has changed. People are now talking to me. After this child people have accepted me. Earlier I used to have lot of pimples on my face. Now since I look fine people say that may be they had given a wrong result. People say that you must have had that disease. I did not breast feed my child. He is now 4 years old. My husband is working as an electrician and I do small odd jobs for people.

## Pushpa (25)

I was the last of four sisters. My father, who was a cook died early but before that three of my sisters were married. I was sent to school but I never really went because I was just not interested in studying. I was also sent to tuition classes but even that I did not do properly. I have just learnt to sign my name. I just had a terrible fear, which I cannot even explain to you. About three years after my father died I was married. They came and asked for my hand. We were told that he was in the garment trade earning Rs. 3,000 and that he had a house of his own. But I did not like the look of him. I quarrelled with my mother and refused to marry him. I wanted to spend a few more years with my mother. A year later the same family came again with their proposal. This time my mother argued that she was growing old and that she wanted to see me married before she died.

There was a lot of pressure from his family. They said all we want is your daughter. You don't have to spend a lot on the marriage. A simple temple wedding will do. My mother borrowed Rs. 15,000 and gave it to the boy and I was married in a

temple. Then I was taken to the city were his two sisters lived. He had no parents and his sisters had taken care of him since he was five years old. The first night ceremony was performed there. He had ulcers and sores in his genitalia. I told my mother about it and said I did not want to be with him. She told me to adjust myself to the situation and suggested that I could go back to him after three months.

So I went to live for a while with my elder sister, who was also living in the same city. I was feeling terribly depressed because I was forced into this marriage and kept weeping all the time. Seeing my situation a well to do family in the neighbourhood asked me to work in their house as a maid. At that time they asked me why I was crying all the time. I told them that he stayed home all day and refused to go to work and was not even feeding me. They offered me Rs.100 and shelter. They also took my husband to hospital for treatment. There he was given some pills and he was cured of the ulcers.

After that I went back to him and soon I was pregnant but all the while I was anxious because no one had told me what the problem with him was. Even the hospital did not tell me. Subsequently I had a baby girl but all along his problem kept recurring. We used to stay with his sister who did not look after us. When I spoke to his sister about this and the fact that his problem was recurring, his sister said, "Since your marriage there have been problems between both of you. Why don't you just leave the house?" I quarrelled with her and told her "you are together in this. You lied to my family and got me into this situation". I was so depressed after that encounter that I went to my sister's home and told her what had happened. She gave me Rs. 100 after which I went to some of my other relatives. They all gave me small amounts of money that I used to take my husband to the TB hospital because he was coughing a great deal and I was pretty sure it was TB. My second child was then one and a half years old.

During this time if I asked him why he did not work, he would become very violent. It was at this point that he was tested. An NGO that is working with positive people, came to know of my situation and started to help me out. The counsellor there told me that he was positive and explained in detail what it meant. I had absolutely no money at that time and what is worse I had to carry the two children with me. It was a doctor who came to my help. He provided food for all of us but my husband would eat all of it and not give any even to the children. The children would cry from hunger but what could I do, I was so hungry and weak that I was unable to do anything.

After my husband tested positive I was tested three times before the counsellor and doctor at the clinic told me I was positive. I asked them why they had tested me thrice. They explained that now days it was done that way.

After hearing that my husband was positive, I felt terribly anxious and wondered how society would react and how I would bring up the children. I took his papers to various doctors and pleaded with them to save him. I said even if he just sits in a corner it was okay, I would work and take care of him. But they all told me he was in the last stages and there was nothing that could be done. I was so depressed hearing all this that one day I poured kerosene on myself and tried to commit suicide. Some neighbours saw what I was doing and they said they would inform the police. So I decided against it.

A few days later he died. I had no money for the last rites. The hospital took the body to our village. There I put a towel next to it and begged for money. I performed the last rites with the money that people put on that. Even when this family had asked for my hand in marriage, I had not liked him. They cheated on me and got me married to him. After his death, people in the village advised me to work in three or four houses and take care of the children. I started to do this but I was so depressed I often thought of suicide. I couldn't sleep at nights and my bones and joints ached with all the work.

After starting to work I have become more confident and have been able to speak out. As long as I was in my mother's house, I had three full meals but after getting married, I never had my fill. Now when I am tired and lie down, my daughter sits near my head and asks me what is wrong. The other, sits at my feet and tells me she is hungry and asks me to go to work. It is because of them that I work. They have given me the courage to live and work and support them. I will also educate them well. That is all I can do. I would never want them to be like me.

#### Rita (44)

I was married off when I was ten years old, though I did not want to be married. My parents forced me into it. We were nine children and I was the eldest. My parents said it is only after you are married, that we can think of the others. Both my parents were illiterate, but I was sent to school. I studied up to the 4th class. I was so young I did not know what marriage meant. It was like a game to me. My aunt (mother's sister), spoke to me on how I should behave once I was married.

Though I was married at ten it was only three years later, a year after I had reached puberty, that we had our first night. Till then I stayed with my parents. He

was 24 and I was afraid to go near him. I used to weep all the time and it was my mother who served him his meals and did other things for him. Seeing me crying all the time, my aunt, who lived next door, used to keep telling me on how I should behave with him. She explained what would happen on the first night. What she used to say made me very depressed. I wonder if this was all there was to life...get married, have children and then death. What was worse, I was already married so I had no choice but to bear it.

My in-laws treated me well. For 12 years I had no children. Finally I spoke to my parents and my father took me to an *ayurvedic* hospital where they did blood tests of both of us. They told us that my husband had a problem and therefore, I could not have children. They also told us to come back in fifteen days if we wanted to be treated for it. But we did not go back and after sometime he died. He suddenly got very high fever and a bad cough. One day he vomited blood and expired before anything could be done. Even before he was cremated, his mother spoke of how he used to womanise even in the days before he was married to me. She kept saying that it was because he used to frequent such places that he died early. It was only then that I learnt of this side of his character.

After his death, I stayed with my in-laws for sometime and they looked after me very well. But since I had no children and I was not feeling comfortable there, I returned to my mother's house. I was then 20 years old. There I went to my school and got my certificate and applied for a job as an *ayah* in a hospital. Those days, we used to stay in a thatched hut, one-day it caught fire, and my certificate was destroyed. After that, I was not able to get a fresh certificate because the number was lost. Since then, I have only been able to do house work. During this time, my *mama* used to keep coming to the house and we became quite familiar with each other. One day, we were alone and we had intimate relations. I told my mother what had happened and also that I wished to marry him. Unfortunately, neither she nor our other relatives wanted me to marry him because he was already married with three children. His wife was also very much against it but he kept saying that he would be able to look after both of us well. After all I was so young. We got married.

He was a building contractor and for a while, he did look after all of us very well. But then he started to get into debt and now, he is not able to support us as well as he used to. I now have two children- a son and a daughter. Both were born of caesarean section. When I was pregnant with the second child I had a bad cough and one of the stitches from the first operation came off. I was in hospital for one

and a half months and he looked after me. Even now, he would have, but his children from his first wife have grown up and he has spent a lot on their education. He also lost his business and after paying off his debts, he has very little. Moreover, he has grown old and infirm, so he gives me very little. He rarely comes to this house. He spends more and more time with his first wife, who lives in the only house he now possesses. For all these reasons that I have to work.

I found out I was positive about a year and a half ago, after I started working with this NGO. I used to have white patches on my hands and genitalia, so one day I showed it to a skin doctor who comes to this clinic. He treated me and very soon, I was cured. But I had doubts in my mind after seeing others who come here, because some of them had the kind of skin patches I used to have. So I spoke to the doctor and got myself tested. Before testing me they told me everything about HIV/AIDS and again two days later before they disclosed the result. Despite the counselling, I was terribly depressed for three or four days. I couldn't think straight and was not able to take any decisions.

During this time, my husband turned up and I told him of my status. I also asked him to get himself tested. He just laughed and said, "You are alright, I am alright and my first wife is also alright, so how can such an illness come to you." While we were talking about this, my son who was sleeping in the same room heard everything. He asked me, "Are you also positive". I said, "Yes I am. I have been tested and found positive, but don't disclose this to anyone." Actually my husband, keeps getting fever and infections, which make me think it is due to HIV, but he insists it is because of old age. Because of the counselling, I insist we use condoms but he does not like it and this is one reason why he rarely comes to this house.

One thing I am sure of after all I have been through is that I would never want my children to have the kind of problems I have had. I will make both of them study well and after that I will make them work. It is only after they are independent that I will allow them to get married. My son must be 25 before he marries and he must take care of his wife. But it is only if he obeys me, that I will look after his interests. If not, he can go where he wants and then as far as I am concerned I don't have a son. I am saying this, because both my husbands turned out to be womanisers. I found out about my second husband soon after I got married. He has separate houses for the two families though the children do go between the two houses. But the wives don't interact in any way.

As for my daughter, she matured a month ago and what information she needs at this age I have told her. When she reaches the appropriate age to be told of HIV/AIDS I will tell her. But these days, they are taught this in science and if they find out it is okay, but I will not tell them. My dream is to educate them and get them married well, before I die. Only my husband and son know of my status, no one else. Even when I want to discuss it, we go outside.

Now I am quite independent. I work as a sweeper and earn Rs. 600. When I am ill, I get treatment and medicines, because this NGO works with positive people. If this place is closed, I go to two other clinics but they are not aware of my status. ARV medicines are costly. No NGO can give it to us. The Government must reduce the cost and some NGOs should distribute them to us or give it to one doctor to give it to us. Even if I don't get it, let those who come after me get it, but this is something that must be done.

In the old days, people did not know of HIV/AIDS, but it is not like that now. If testing were done in my area, you would find about 50 positive people. When I see people around me and the illness they have, I think they must be positive. It is just that no one talks about it openly, for fear of discrimination and being thrown out of their homes. Women have rights and there are even laws to protect us, but there is no one to enforce them. At present, no one knows of my status, so everyone treats me well, but if people found out about my status I would move away, because no one would want to have anything to do with my children or me and we would be treated badly.

#### Access to health care and treatment

#### **Key frame: CEDAW**

**Article 1:** Discrimination Against Women means any distinction, exclusion or restriction made on the basis of sex, which has the effect or purpose of impairing or nullifying...

**Article 12:** State Parties shall ensure to women access to health care services, including those related to family planning

Article 14 (2) (b): State Parties... shall ensure to rural women the access to adequate health care facilities, including information, counselling and services in family planning.

## Violation – Right to information, proper counselling, and rights to their reproductive choices

#### Supporting framework - CEDAW

Article 10 h: Women are entitled to specific educational information to help to ensure the health and well –being of families, including information and advice on family planning

Article **16**, **1e**: Women have the rights to decide freely and responsibly on the number and spacing of their children and access to information, education

and means to enable them to exercise these rights.

### **General Recommendation No 15 –** Avoidance of discrimination against women in national strategies for the prevention of HIV/AIDS

States must intensify efforts in disseminating information to increase public awareness of the risk of HIV/AIDS infection and HIV/AIDS, especially in women and children, and of its effects on them.

#### Supporting Framework : General Recommendation No. 24 – Women and Health

State parties to ensure without discrimination the right to sexual health information, education and services for all women and girls... In particular .. should ensure the rights of female and male adolescents to sexual and reproductive health education by properly trained personnel in specially designed programmes that respect their privacy and confidentiality.

#### Arti (26)

My father is a tailor and my mother works as a *coolie* in the forest. I have one sister and one brother. After doing her 12<sup>th</sup> class, my sister learnt typing and computers. Now she is looking after the accounts in my father's shop. My brother works in a shop that rents out utensils.

I studied till 10th class. When I failed in two subjects in 10,th my father who has a lot of affection for me, arranged for tuition and I passed. Then I left school because I didn't want to study any more. He even got two or three jobs for me. But that didn't suit me as I had to travel by bus, which created health problems. So I used to go with my mother to work in the forest. For one day we got Rs. 25 each.

At that time, my father used to stitch blouses for Rs. 15. He arranged for me to go to a tailoring institute but I could not go. There was not much income through it. Though ours was a small village, it had 8 tailoring shops. Then my marriage was fixed with my consent. I liked the man. I was 21.

For four years I was happy. We were four people all together. My mother-in-law, brother-in-law, husband and myself. But it was a small house and facilities were poor. So after two years we started living separately. Within a year of marriage our son was born. We were living happily for one year. I conceived again. At that time my first child was only two years and I did not have any knowledge of copper- T and other measures. I aborted that child because we didn't want the second child immediately.

During the pregnancy of my second child, the hospital took a test in the seventh month. They found I was positive so they told my husband, that I should go to another hospital. I went to the doctor who had handled the delivery of my first child. He referred us to another hospital. When we went there for the delivery we did not disclose our status, because we feared rejection and the hatred that would follow.

My husband and I were referred to a nature therapist by my brother-in-law. He had heard about the person from many workers in the mill. We took his medicine for about a year. He put us on a special diet and he used to visit our house regularly and give us the medicines. We spent nearly Rs. 2 lakhs on the treatment for both of us.

I had lost my second child also within a year of his birth. He was also positive. At first my son was fine. One day he developed fever and started vomiting. We took him to the hospital and kept him there for 22 days. He had symptoms of epileptic fits also, so they gave him an injection and after 22 days he was discharged. He was fine for a week and after that he again developed dysentery. He died the same night. We had not revealed his status. But after his death we thought that it was better to reveal my elder son's status so that he could get proper treatment. The doctor provided him with good care even after the status was known. But the fever did not stop and he was admitted to the government hospital for pneumonia.

Though the doctors provided treatment, there was some problem when one doctor at the paediatric ward, questioned why an 'STD case' was being kept in that ward. She also said, that it was better to take the child home because his condition was such that it was better to take him home and treat him there. Previously

when he was admitted, the doctors used to treat him well. I feel that if right treatment had been provided on time, he would have lived longer. We were scared to show him in any hospital, because he would be refused treatment. When my son was serious, the doctor was refusing to admit him. But the network members helped me. They got all the gloves and things like that and gave them to the doctor and asked her to admit my son. The doctors and nurses used to ask me questions like how my husband was affected. I was able to get treatment for him because we fought for it.

It has been two years since I have been separated from my husband. We separated after the delivery of my second child, as he said he could not afford my treatment. We meet sometimes. He comes and gives me money for my expenses and stays for two days and then he leaves. During the time we were getting treatment from the nature therapist, his brother was paying for our treatment. His brother also paid for my son's medical expenses recently. At that time when I was undergoing *siddha* treatment some misunderstandings crept up between us and I decided not to continue. We blamed each other for getting affected.

I am now staying with my father. I help out at home. We have told people in our village that I keep unwell and so I have come to my father's place. My family is very supportive of me. I am keen that what has happened with me should not happen to my sister or brother. If my parents had been educated then I might have known. But in the case of my sister, I am willing to reveal my status so that they (sister and the boy) undergo a test before marrying. I will request the boy and my sister to provide an 'AIDS' free certificate.

I heard about HIV through advertisements after marriage. All of them said that it was a dreaded disease. After marriage also I thought it was a dreaded disease. I have not noticed HIV related advertisements in the newspaper or the TV. If I had known about HIV I would have thought of testing before I got married. I thought it was caused through wrong behaviour.

#### Violation - Right to education

Supporting framework - CEDAW

**Article 10:** Women are entitled to opportunities ...for access to studies and for achievement of diplomas in educational establishments of all categories in rural as well as in urban areas. This equality shall be ensured in pre-school, general, technical, professional and higher technical education as well as in all types of vocational training.

#### Violation - Right to confidentiality

Supporting framework: Constitution of India

Article 21: All citizens have a right to privacy and confidentiality

#### Bhagyashree (27)

My father was in the armed forces. Mother died when I was five. I have one elder sister and brother and one younger brother. I have studied till the 10 <sup>th</sup> standard. I had wanted to study further but my father did not allow, as he could not afford to educate all of us. He chose to educate my elder brother only. He has studied up to B. Com. If I had been given the opportunity, I would have also studied further. My mother was also not there when I matured. So I went and asked my neighbours who told me about periods. I was 11 years old so I did not feel anything like fear. It happened very suddenly to me. I was playing and some people surrounded me and then my neighbour called me and told me what to do.

Initially I was staying with my uncle. When my father married again, I did not like my new mother. So at the age of 15, I left my home and went to live with my brother. I met this boy next door. We fell in love and married after a year. I was 16 years of age at that time. His father was a doctor and the mother worked with the son in a mill. Since I was not able to conceive, my father-in-law advised me to go to CMC Vellore to do tests. I was told there would not be any problems. I had a child after 5 years of marriage.

When my son was three months old, my husband bought another woman and he said that she was his wife. We were married with the approval of both our families in a formal way. I don't know whether his marriage is registered, but I do have a photograph of his marriage to her. When he refused to leave her, I returned to my father's house and filed a police complaint. The case is now in court and being decided. Though an order of maintenance has been given by the court I have refused to accept it. My father-in-law and I are on talking terms. He often takes care of my son's need and gives him money.

Two months ago I had a urinary problem and visited the doctor. She advised me to go for blood tests. She did not tell me what these tests were. This doctor is from the same caste as my father-in-law. When the results of the tests became known to her, she informed my father-in-law, who called me and told me I was positive.

When I heard that I was HIV, I wanted to die. I felt that I had not done anything wrong. I had not been unfaithful. After my husband I have had no interest in sex. So for me to get affected, he must have been with someone before or when he was with me. When I was told of how it happens, I remembered how my father- inlaw had told me not to breast feed my child after the delivery. At that time I asked him why he told me it was because of jaundice. I was wondering why he told me that. It was because he had known that his son was positive and wanted to prevent my child from becoming positive. He used to also tell me to stay away from people who had cough and cold, saying that I would also catch it. I came to know recently that my father in law had been told about my husband and my status when I was pregnant. At that time the doctor had not told me anything. He used to speak to my father-in-law only. I also remember that when I was pregnant I did not see my son immediately after delivery. I was able to see him only after three days. I am not sure what medicines they gave him. After that no medicines have been given. I was given some medicines during pregnancy but I do not know for what.

My father-in-law is trying to blackmail me. They had been saying that if I agreed to withdraw the case they would pay me. I refused because I want him to be punished for what he has done to me. So I will not agree to withdraw. Now my father-in-law is saying that my status will be revealed. I have told him that if my status comes out his son's status will also be revealed because I will take him to court. I do not know whether my son is positive. I intend to get him tested.

I fear that if some friends or any one come to know that I am HIV positive they will start behaving indecently with me and discriminate against me. They will say that since she went in the wrong way she got infected. When I go to the hospital, that doctor looks at me in a strange manner. So I don't feel like going there. When they know that I am HIV positive they look very 'cheaply' at me. They did this when I went for my blood test. I won't go to that hospital again.

#### Meenakshi (27)

I come from a family of four. I have an elder sister who is married. My father is a *pujari* <sup>1</sup> in a temple and my mother works as an *ayah* <sup>2</sup> in a school. The people in our village are mainly doing agriculture related work. My parents educated me till 10<sup>th</sup> class. I failed in one paper but then I wrote it again and I passed. Though my parents wanted me to continue my education I was interested in marriage at that time. I had failed twice in the 6<sup>th</sup> class and then again in the 10<sup>th</sup> standard. I managed to pass with great difficulty. I felt guilty that my parents would have to take a loan to educate me and then suppose I failed. My education was not free. Though it was a government school my yearly expense was about Rs. 3000. I went for tailoring classes. They bought me a tailoring machine and I used to stitch. Then for two years I worked in a coffee blending shop where I used to look after the accounts and the sales. When I was 20 I was married to a truck driver. My husband was 24 years at that time. He used to often go to Delhi for about ten days. He had studied only till the 6<sup>th</sup> standard.

The same year, 1999 I gave birth to a baby girl. For two years I was very happy with my in-laws and my husband. There were no problems. After that I again conceived and when I went for a test in the third month the hospital people said that everything is fine. Three months after that my husband had severe pain. At first we went to the temple. But after that we took him to hospital. There they tested his blood. Then they took him to a room and asked him something. He was saying that 'I never did this. I didn't go in the wrong way. I am not like that.'

As my due date was nearing I did not go with him. Only my father went with him. I was staying with my mother. On the fourth day I went to the hospital. He had been there three days and he said that he did not want to stay anymore. While he was in hospital my sister's husband had come and said that near their village there was a mountain wih a lot of herbs and things would be fine in one month. Since I was pregnant I was not able to give him full concentration. My sister took full care of him. They used to call me up and say it is not HIV and even came and saw me in between. Then suddenly one day, when I was told that in another two days I would have a normal delivery, he took ill and had slight paralysis. The doctor in the hospital said that it was difficult to save him.

I was tested the day after my husband was tested. They told me I was pregnant and since my husband was infected I should get tested myself. They did not say anything before the test but when the result came they told me I was infected and gave me some tablets. Before that nothing was told to me. My status was

revealed to my uncle first. I was not aware that they should not do that. He went out and told people. But I don't care. I wanted to show that I can take care of my children.

We then left for our village. Within five minutes of getting there my husband died. Three days later my son was born. At that time we went to the nearby hospital but the people there said that they will not look after my delivery. Then one sister said you wait here because you will deliver within 10 minutes. My uncle said we should go to another hospital but I said that I will not leave this place and I know that I will have a safe delivery here. Then we paid Rs. 1000 for one day. For 3 or 4 days I did not go out of my room. Only one nurse said, "that I will look after you". Earlier in the government hospital they had given me a tablet and told me to take it just before my delivery. But I did not take it because I thought it would stop the pain of delivery. The doctors said that if I took the tablet it would be good for my child. But I decided that whatever happens I would not have the tablet. I thought that I will live for some time only. So I was feeling uncomfortable.

Since the death of my husband I have been living with my parents. I help with the agriculture work. My mother-in-law still comes to meet me. My daughter who is 4 years old goes to school. My son is a year old. My father looks after him when I go out for work.

The problem I am facing is of employment. I need some proper work so that I can protect my children. When employers come to know that I am a widow they don't consider me. If I say my husband is dead and I am also HIV positive then no one will give me work. When we enter the village people say 'oh my god she is coming'. They consider us as a bad omen. Even if I go with a positive mind they think negatively. I had gone to the collector's office also. But they did not do anything. The government has a responsibility to provide us with information. If I had known about HIV long ago, before and after marriage, I could have done something about it. I would have known enough to do a test. But I can't blame anyone. Even my parents did not know about the disease.

#### Violation - Right to be free of violence

**Supporting Framework: CEDAW** 

**Article 1:** Discrimination Against Women means any distinction, exclusion or restriction made on the basis of sex which has the effect or purpose of impairing or nullifying the recognition, enjoyment or exercise by women irrespective of their marital status, on a basis of equality of men and women, of human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.

**General Recommendation No. 19:** The definition of discrimination includes... violence directed against a woman because she is a woman... It includes acts that inflict physical, mental or sexual harm or suffering, threats of such acts, coercion and other deprivations of liberty.

#### Violation - Right to property

**Supporting Framework: CEDAW** 

**Article 16 1h:** All women have the right to ownership, acquisition, management, administration, enjoyment and disposition of property whether free of charge or for a valuable consideration.

#### Shobha (38)

I was one of eight children – two elder sisters, three elder brothers and one younger brother. Both my parents were agricultural workers. All of us went to school; I studied till second PUC. There was a school in the village and our father insisted we all study. We had a nice childhood. I matured at age 14 and was married at 25. I worked for several years in an *ayurvedic* shop doing labelling and bottling. I agreed to marry the person I did. He was 29 years old and owned a pan shop in Mumbai. My dowry was Rs. 50,000 and ten *sovereigns* ¹of gold. This was three years ago.

A few days after the marriage we went to Mumbai. We shared a small space with his elder brother and his family. What I noticed was that he was always suspicious of me. I couldn't sit anywhere or talk to anyone even his younger brother. He would rant and rave if he saw me doing anything like that. It was all very depressing. He earned Rs. 500 a day. He always came around midnight and usually he was drunk. He would force me to have sex and would get violent if I refused.

When I was seven months pregnant I went back to my mother's house, as is the custom. When my blood was tested at five months it was negative. But when it was tested in the ninth month the doctor told me there was some problem with my blood and that I should tell my husband to come. I became suspicious because I was repeatedly told that there was something wrong with my blood. Then I saw the prescription and immediately understood that it was HIV. I had read about it and what I knew from what I had read was that I had got it from my husband. I was shattered. I felt terrible and also very anxious. I wondered why I had got married when I was so happy being single. I kept crying all the time and found it difficult to even eat or sleep after seeing the baby.

It was terrible. I also suffered a lot of discrimination in the government hospital. The sweepers and ward boys wore extra gloves when they had to do anything for me and kept staring at me. Even the doctors and nurses from other departments came and looked at me. They talked in English and I knew it was because of my status. My case file also had HIV written on it and I was kept in a separate room. I think something must be done and doctors must be educated so that people like me can be saved from such stigma.

When I was tested at the time of my delivery it was done without any counselling and the result was told to my brother without my consent. This was in a private hospital. He in turn told my family. They all hid the result from me. The hospital also told me to go to a government hospital after my status became known so my parents took me there. After a long labour I had a caesarean section. When my husband came for the delivery the doctor spoke to him for a long time. When I saw him I told him to get his blood tested but he refused and just left the city. He did not even take leave of me and I have not seen him since. It was only after I went back home that my family talked to me about my status. Now I know that the doctor broke my confidentiality at that time. But at that time I did not know about such things as confidentiality. It was only last year when I tested at KMC hospital that the doctors counselled me and spoke to me and sent me to this NGO which is helping me with my case.

When three months had passed my family asked them to come and take me back. They said, "She is not good for us, we don't want her." I also wrote several letters to my husband but there was no response. My two brothers also went to him in Mumbai and asked for an explanation. They said all was well at the time of the marriage why are you doing this? My husband told them they wouldn't take me back and do what you want. My parents also went and spoke to his parents. They mentioned my status and told them their son was responsible. And also

that he had refused to come back and be tested. They told my parents we know exactly what is wrong with our son and we have got the right medicines for him. He is going to be okay.

So I have been staying with my parents. I help my mother with the housework and look after my son. I am well cared for. But my sister who is separated lives with us. She constantly taunts me saying we can't keep feeding you though it is my parents who run the house. She earns by rolling *beedis*. Now I want to go back to work and earn for my child and myself. Two months ago I filed a case in the police station for desertion and the court for maintenance. I want to teach him a lesson. It is because of him that I have this illness which has no cure. I am also angry at the way in which he and his family were treating me and accusing me of making him ill. They are telling everyone that I got their son ill and that I am of loose character. But it was my elder sister who first openly talked to me in this regard. The family then met and discussed the issue and after that I filed the case. Now I don't want to go back to him no matter what hardships I may have to face here. My family also does not want me to go back but I am afraid he will ask me to come back. Once when I called him before filing the case he said, "You have given me enough problems in my life" and banged the phone down.

#### **Violation - Right to education**

#### **Supporting Framework: CEDAW**

Women are entitled to opportunities ... for access to studies and for achievement of diplomas in educational establishments of all categories in rural as well as in urban areas. This equality shall be ensured in pre-school, general, technical, professional and higher technical education as well as in all types of vocational training.

#### Renu (36)

There were six children in my family- four sisters and two brothers. I have studied up to 5 <sup>th</sup> class . I wanted to study but I was married off at the age of 12 three months after I reached puberty. After I was married for a while we lived comfortably with my in-laws. Then one day my husband and his father quarrelled. I don't know what it was about but that very day we returned to my mothers' house. For one year my husband did not work. My father looked after us well.

Then he got a job in a liquor shop. He used to give me all his earnings, and I would manage the household. My first delivery was of twins but both died. I was then 14. For three years after that I had no children then three children – two girls and one

boy - were born. Later we learnt that there was a woman in a nearby sweet shop with whom he had an affair.

Fourteen years later he fell ill and was diagnosed as having TB. One day he vomited blood and had to be hospitalised. It was then that he was tested and found positive. I was tested at the same time. The doctor told me I was not positive but asked me to test again after three months but I did not do it then. I took the reports and went to my in-laws with whom we had no contacts. His father said that it is not possible for my son to get such an illness and that it was because of me that he had got it. I pointed out that I was well and argued that it was his son who was ill. He then came to the hospital with some others and left some money.

I also told my uncle about my husband and he went to Kerala and got medicines. Rs. 15,000 was spent on it. It was he who revealed my husband's status to the family and others. When my mother found out about our status she told us to eat separately. She also told every one else not to touch our clothes. If we were eating and the children wanted a bit she would tell them not to eat from our plate. But my in-laws were okay. They treated us well.

After my husband's death my brother and I moved to another town. There he worked in a liquor shop and I had a small business selling snacks to those who came there for a drink. With the money I got I was able to take care of the children. Then suddenly my brother left his job after a quarrel with the son of the shop's owner. So we had to return to our parents' house. My father was an alcoholic. He used to gamble and drink and had mortgaged all our property and lost it all. Now we have one house that has also been mortgaged. One day I asked him why he was behaving in this fashion. He got angry and left the house. He went around telling every one that my mother and I had thrown him out of the house. He has not returned since.

Since things were very bad in the house I went and saw my in-laws who gave me my husband's share of the property, which comprises of two shops. My father in law's willed it to my mother-in-law and after her it goes to my son. The shops bring in a rent of Rs. 850. Of this, Rs. 500 goes to the bank in my first daughter's name as per the will. I get only Rs. 350 in hand. My father wants me to sell the shops and give him the money. I have refused and told him it is my husband's property. My mother and brother are also angry with this. They tell me to go and die somewhere else.

My in- laws are also upset with me for two reasons. One is that I got my husband's job for my brother. My brother-in-law is angry with this because he wanted the job.

My mother-in-law is annoyed because when I first asked her for help she refused. It was my elder brother-in-law who read the will and gave me my share. My mother in-law won't give me even a glass of water.

Now I am maintaining the family but with great difficulty. I sell flowers. My brother who is staying with us refuses to work. He watches television and drinks though he knows how to drive a tempo. He wants me to sell the house and buy him a tempo. He keeps quarrelling all the time. I even took a loan of Rs. 3000 and gave it to him to do business but he drank it all up in a week. He has only returned Rs. 700 and refuses to return the rest.

Here my neighbours ask me why I bother to look after the household. My mother does not look after us, my brother is a drunkard and my father has said he will return to the house when I die. My neighbours suggest I go away and live by myself. I don't have the courage to do so. Also when I was in trouble my parents cared for me. It won't be right for me to go away. If I go it will be only if I am assured some security. Till then I will stay here and maintain this household. My daughter is going to reach maturity soon. I don't want to leave her alone and go to work. This society is not good. I want her to study well. I often have to go away for melas<sup>26</sup>, jathas<sup>27</sup> and weddings. If we move away she would be on her own. It is for these reasons that my sister is bringing up my second daughter. My son is playful and difficult. I am trying to put him into a hostel because I want him to study well. My sister- in- law has suggested I go and work in the city. I have not taken a decision on this but will do so after this wedding season is over and I have made some arrangements for my son.

Now my mother is making things very difficult for me. She tells me to drink poison and die. In front of others she says "what are you giving us?" and "what you do is not sufficient". It upsets her when the neighbours are kind to me and give me leftovers. I know they won't look after my children if I die. I have to look after them and also take decisions regarding my life. Even when I am sick my mother does not bother to feed me. Since I tested positive five years ago my bones ache. I get medicines from the government hospital but for small things I get it from the village itself. Earlier the doctors were very helpful but once they took photographs of me in a self-help group without my permission. I did not like that and told them so. They haven't helped me to find a job either despite all my pleadings. So I don't go there anymore. Only my family and in-laws know. I am afraid of being discriminated by society. Since I am a widow, men look at me strangely. One

<sup>26.</sup> Local fairs.

<sup>27.</sup> Folk theatre.

man asked me why I did not re-marry. I told him I had children. I fear of how they would look at me if they knew my status.

#### **Property and inheritance**

**Key frame: CEDAW** 

Article 15: State parties to accord to women in civil matters a legal capacity equal to men and the same opportunities to exercise that capacity. They shall give women equal rights to conclude contracts and to administer property.

**Article 16:** State parties shall ... ensure women same rights for both spouses in respect of the ownership, acquisition, management, administration, enjoyment and disposition of property whether free of charge or for valuable consideration.

#### Meena (35)

There were 7 children in my family - four boy and three girls we were very poor so my sisters and I went to the government schools and studied till 8th class After that I had to stop because the high school was some distance away. Even among my brothers only two were sent to study. The other two worked as farm labour. I was married at 18. Since he was working as a driver I initially refused to marry him but my father and brothers said that we are very poor people we can't get you a doctor

or lawyer as you want. You have also reached 18 years so you have to marry this man because he is okay in every way for you. He had two elder brothers and one sister.

The first five years we lived very well. At this point my husband's family decided to move out of their parent's home and go their separate ways. It was a collective decision and we felt it was the right time to do so because we were all doing well. About five months after we moved out my husband started to fall sick. Each time I took him to a family doctor who gave him some medicines. For a while he would be all right then he would fall sick again. This went on for a year. I became very anxious. Since he was not working I was finding it very difficult to feed the family-I had two daughters by then and even had to send them to school. There were times I had no money even to take my husband to the doctor. I would borrow from here and there but felt terribly embarrassed to keep asking people again and again.

Finally, I admitted him in hospital. They treated him for this and that and it all cost a great deal. The doctors would not say what really was wrong with him. About six months later he felt well enough to go back to work. For a while things were better than he had an accident and was badly injured in the leg. After that he was not able to work. I had no one to whom I could even speak about my problems. Neither my family nor my in-laws supported me or even asked me what the matter

was. I was very troubled. So once when we were going to National Institute of Mental Health and Neurological Sciences (NIMHANS) for counselling, we took my sister- in- law with us and introduced her to the doctor. He then explained our status to her. She went and informed the others in the family. Before they came to know this they kept asking me why I had taken him to a hospital so far away. What are you doing to our brother? You are trying to kill him. I couldn't take this blaming all the time so I took my sister- in -law to NIMHANS. After that their attitudes changed. They gave money when needed.

One day he developed high fever and became unconscious. I rushed him to NIMHANS. For six months he remained in a coma. I struggled between the hospital and home. I kept asking the doctors what the problem was but they kept saying - we are doing our best he will become well. I was very anxious. I also found it strange that they spoke so kindly to me which they did not do with other patients. One day I just broke down and asked the doctors what I should do. He said I understand your problems. We cannot do anything for your husband he has HIV. The doctors at NIMHANS told us our status just when he was being discharged. They explained that my husband and I were positive and the children were negative. They counselled us on treatment, prevention, safe sex and home-based care. But I did not really understand what it all meant but decided to do what they were saying because it must be a serious illness. My husband and I decided to abstain.I did not understand what it meant. I was illiterate. The hospital gave him medicines and the doctors offered to get me a job with an NGO that was working with positive people. I was illiterate and had no experience of working outside the house. I did not know what to do. The doctors at NIMHANS forced me to give it a go. They said we will help you. So I joined the NGO and have been there ever since.

Since my husband was feeling better he started to work but he also started smoking and drinking again. Before that day I had not heard of HIV/AIDS. When we asked for clarifications on the virus the doctor said you wouldn't understand it all at this time but as you go along you will. It is because of the nature of this disease that we first took care of your future needs like job, free medication for your husband etc. My husband did understood the problem but he followed the doctor's advice on prevention/ safe sex and home care only for a short while. After that he went back to his old habits like smoking and drinking. If I insisted on condom use he turned violent. He used to accuse me of being a sex worker and of how the blame for the situation we were in was being attributed to him. Sometimes if I did not agree to have sexual contact he would sleep in the office and not come home.

For one year he really behaved badly. He kept disappearing and drinking. Finally I put him in a care centre. He was there for one year before he died. I was in the field when he died. The whole burden of the family fell on me and I had to take loans to survive. I have still to pay off these loans. The NGO I am working with is very supportive. They sent me for training and I did quite well. I stopped doing the tailoring that I used to do at home. After a while when I started to fall ill and found it difficult to do field work, I was given a softer job profile. If I have a problem it is about getting leave for treatment. Once I had to go to a dentist. He kept telling me to come later. I know it was because of my status. Finally I asked the NGO to help. They gave me a letter to the head of the department. They did treat me but kept asking how I had become positive. I refused to reveal anything to them.

But I was having a lot of problems. The money I earned just sufficed for my daughters and me; there was nothing left for any extras. The children used to go to the same school and since the teacher knew our situation they were given various concessions. One of our relatives had their child in the same school. It is they who disclosed our status to the school. The principal called me and asked me if I was also positive. When I said yes she asked me to get the children tested. They were then in the 8 and 6 the class. I took the report and showed it to the principal so they were allowed to stay on. It was when they asked me to get it done again the next year that I lost my temper and asked why they were asking for it again and again. Despite all my explanations they refused to take them back so I had to move them to another neighbourhood school but they have just not adjusted there. It was because of the other parents that she refused to take them back because earlier on her own she had taken them despite knowing my status.

The other issue I am struggling with is that of property. When our joint family broke up we had paid Rs. 75,000 to the four others and it was decided that after my mother-in-law the house would come to us. Unfortunately we have no papers to prove that we paid this amount. No one told us, not even our friends and neighbours that we should have some proof of this. Even while my husband was alive we tried to get what is due to us but failed. After he died with the help of my NGO I went to some lawyers who agreed to take on my case and asked me to produce whatever papers I may have. They then spoke to my brothers-in-law. Initially they denied they had received Rs. 75, 000 but after the lawyers spoke to them they gave in.

But it was also found that Rs. 40, 000 was due as unpaid tax. My in-laws said they would not pay it off. When I think of what my families have done to me I get very angry. How am I with my small salary going to pay off Rs. 40,000? I am very

anxious and I am also angry with my husband for not providing for us. Initially when I asked them for the property they did not agree at all. Then I revealed my status and asked them what would happen to my children. My sister-in-law who has two boys said she would marry my girls to her boys. I refused and quarrelled with them. Told them to keep their house and told them I would bring up my children on my own. The house rightly belongs to me and so I went to a lawyer. Now I am desperate to pay off the tax arrears and get the property but I just don't have the Rs. 40,000. I fear it could revert to them.

I know crises will keep happening in my life as has happened with the children's school or the dentist. I worry about who will help me. Medicines are also expensive as is the children's education. I never studied. My dream is to educate my girls.

#### Hema (29)

I grew up in a village. I have three brothers and my father is an agriculturalist. We were all sent to school and it was when I was in first year of college that I was married. I did not want to marry. At that time I did not know of such things as the legal age for marriage but since I wanted to study more I did protest. My parents argued that from the day I was born they had decided to marry me to this person who is my father's sister's son and that they had promised to allow me to continue my studies. I reached puberty at age 11 and was married at the age of 16. My husband had completed his graduation in Commerce and was doing agricultural work with his father and brother when we got married. I soon became pregnant so I had to do my course through correspondence. There was a gap of one year after which I went back to college. During my third year I became pregnant again and with that I discontinued my studies.

For two or three years we did well. Initially he exported tiles as a business venture but because of huge losses he wound that up. We then moved to Bangalore and he started a hotel. That also did not succeed. I was very angry with him because he had gone through all the money we had brought with us. We often quarrelled about this. One day I asked him how we were going to survive and bring up our children- one boy and one girl. He shouted at me and left the house. Till we came to the city and even for a while after that we had a good relationship. But once his business ventures started doing badly there was a lot of tension between us and we were always fighting about money.

About this time my husband left me for another woman. He used to work in a hotel and he left me for the receptionist there. At the time he left me he had got a job at a local club. For two years he did not come home. I informed both the families and they searched for him. Then I lodged a complaint with the police and filed an FIR<sup>28</sup>. Subsequently another police station informed me that they had found my husband. When I went to the station to meet him he said "I don't know this woman she is lying?" By then he was married to the receptionist. My eldest son was three years old and the younger girl just a month. I couldn't understand what I should do. I quarrelled with my family. Asked them why they had married me to him when I did not want to. Now what am I to do? My father suggested I return home and said I will care for you but my brothers objected said we don't want our married women to return home they have to manage where ever they are. They said people will talk and it would not be good for the family reputation so stay where you are. So I decided I would manage on my own.

Actually, there is about 20 acres that belonged to my grandfather. The price of the land has gone up to Rs. 10 lakhs per acre and the family has been talking about selling it. My two surviving brothers have taken the stand that I should not get my share because I was given a big dowry at the time of my marriage though they have agreed that my demised brother's children who have been brought up by my parents should be given a share. My father has told them that it would be best to give me a share, which could go towards the upkeep of my children because I will not let go of it. Last year I was asked to sign a paper to start the sale process but I refused to sign because I feel I will not get my due. Now my father has asked me to go to the village during the summer holidays and that the family will then discuss the issue. I will try to negotiate again. Earlier, I was a little worried about this but I have been assured by an NGO that they will help me to get legal help and my due share. I have also decided that no matter what I will not let go of my share.

When my husband left me I worked for while as a maid in a house. A lady who became quite familiar with me said she would find me a job in a big house and took me there. After that day she disappeared. The next day another girl in that house told me I had been sold to that household where we had to entertain men. When we did not oblige we were beaten and not given food. The neighbours took care of my son those days and I took my daughter along. After twenty days I just ran away. After that I tried very hard to get a job but I did not know the language and was new to the city. So when everything failed, I started work as a sex worker. I did this for three years.

<sup>28.</sup> First Information Report.

Once when I was not well some NGOs who were working in the field wanted to take me to a doctor. I said rather than taking me to a doctor please help me to find a job. So the NGO suggested I ask their organization for a job. The people there said I should get myself tested before they would give me a job. I went to a government hospital and got it all done. I tested positive and was given both pre and post-test counselling. I took the reports and showed it to the NGO. They scolded me then said there was no job now and to come back after a month. Two months went this way. Then I went and quarrelled with them. Why did you make me test myself I was fine? Now you are also not giving me a job after promising to do so. Now what should I do? Where should I go? I felt very depressed and just left. I went back to the hospital to the counsellor who gave me a lot of support. She suggested I bring my husband along for testing. I managed to persuade him to do so and he also tested positive. The first time I heard of HIV was after I started to do sex work. Some NGOs used to come to the field and speak to us about STD and HIV/AIDS. They used flip charts and other material to explain the symptoms of the disease and how we could protect ourselves from it.

Meanwhile I got a job with another NGO doing fieldwork like distributing condoms and talking to sex workers. I felt I should be working with my kind of women who need to be protected so I have been working there for five years. I work in particular with new entrants to sex work. I get a salary of Rs.1,500 and lunch, breakfast and medical benefits. I do go home once a year to both my marital and natal families but get no support from either. I go because my younger child is with my parents. None of them are helping me because when I got married my father gave Rs. 4 lakh in dowry, 40 sovereigns of gold and some land. It was a grand marriage. As long as my in-laws were there everything was all right but after their demise I have got no support because I have six sisters-in-law and two brothers-in-law. They are all well settled. During their parents' life time the property was divided and my husband's share was Rs. 5 lakh and some land. However he used to gamble at the races and lost everything.

Only my father knows my status. He learnt of it a year ago when I became very sick and was bed ridden. I also told my father to take care of my children in case anything went wrong. He said as long as I am alive they will be cared for but I can give no guarantees for your brothers. At that time the NGOs told him with my consent. But he did not know that I worked as a sex worker.

My son is now in 5<sup>th</sup> class and my daughter in the 3 <sup>rd</sup> class. The NGO has helped me to put my son in hostel. He has been there for two years. I don't want to get a

divorce because then they won't have a father and this is especially important because I am in this field.

My in-laws are all well settled and they are ashamed of the way their brother has behaved. They are also afraid I will ask them for financial help. Even when they see me in Bangalore they don't acknowledge me. While I was doing fieldwork I met my husband a couple of times. He was with other women. I asked him why he was going around with others when he was positive and said that he should use a condom. He said I don't need any advice from you I can take care of myself. I fear he is not using condoms. After that he would come to the house off and on and ask for money. I used to scold him and tell him that it is he who should be earning and giving me money.

My neighbours do not know my status. They look after the children well. Even if they found out my status it won't matter I can now manage my life. Where I work they know my status and now I have no problems there. Earlier I did have problems with my colleagues during fieldwork. They told the women we were reaching out to of my status and asked them not to accept condoms from me or interact with me. They warned them against me say I will sell them. Since I was finding it difficult to function I complained to the office committee. They spoke to my colleagues and told them my story of how I reached the situation I now am in. Since they were sensitised they have been nice to me. At times I do get emotional and quarrel with them.

Many of the women who have come into this field it is not by choice but because of various problems in their life. They don't get correct or adequate information regarding HIV and other issues. Society has no respect for them. Even our childrenare treated badly and not cared for and it gets worse if the parents are positive. People are so suspicious of us. Once when I was going home after getting my salary the police picked me up from a bus I was going home in and took me to the police station on the grounds that I had been soliciting. It was only after the NGO came and gave them proof that I had only my salary with me (they actually had to show the salary register with my signature) that they left me off. Sometimes the police who are supposed to protect us also abuse and use us. If they see us on the road, they hit us, arrest us and put us in remand homes without reason. They asked for commission and if we give it we are let off otherwise we are put behind bars for some reason or the other. Sex workers have no freedom and it becomes terrible if they are positive. Something must be done for them. They have a right to live with dignity.

#### Violation - Right to marry of own choice

Supporting framework: CEDAW

**Article 16W** omen have the right to freely choose a spouse and to enter into marriage only with their free and full consent.

#### Padma (23)

We are three brothers and sisters. My father was an account agent in a bank. My mother was a housewife and had studied till 6 <sup>th</sup> class. We were a very happy family and our father wanted to educate us. After the 12<sup>th</sup> I was doing a diploma in health and nutrition but I couldn't complete it. My sister has graduated in Commerce. My younger brother did "corporate training" after the 12<sup>th</sup> and is working now.

After a sudden accident my father developed health problems. He also started worrying about our future and started thinking about our marriage. My sister was married and after 7 months I was also married. I was 21 years at that time but I did not want to marry. My husband was working as a lorry driver at that time.

When my husband came to know that he had HIV he was very shocked. The treatment was given in a big hospital. I consoled him. He said that if there had been some other women in your place she would have fought and left me by now. But you are taking good care of me. I said that from now onwards you should not be like this. Then when I asked the doctor about having a child she explained that when I am five months pregnant I should go for a check up and then take the medicine in the seventh month. Then I will have to go for a check up 10 days before the delivery and get admitted in the hospital two days before. Through a caesarean operation the child could be protected. I explained all this to my husband. I also told him he need not work as a driver and start a small shop with a PCO<sup>29</sup> so that it will not be stressful and he would be able to take care of his health. Though he agreed he was not at all interested in that.

He had told me earlier "I had relationships with other women and I had done the test." But at that time he did not give the detailed information. May be he would have if I had asked him. After his death his cousin told me that he had gone with him while he did the HIV test but then just left it like that. When I asked him why he had said that it is TB, he said "your husband had taken a promise from me that

<sup>29.</sup> Public Call Office

I would not tell anyone he had gone out with his friend and had relationships with other women". He also said that, he was never interested in the marriage but due to pressure from my relatives he had to take the decision but he never expected that this would happen.

I came to know of my status in 2001 when I was five months pregnant. When I conceived I thought I would talk to a doctor. So every month I went for a check up. In the fifth month they did a urine and blood test. Then next day they asked me to do another test which would cost Rs.400. But it cost me Rs. 900.

But they didn't tell me anything. They just asked for money for another test. The next day they gave the papers to a lady and told me to ask everything from Madam. Even there they didn't say anything. When I saw the paper it was written HIV positive. I thought there is some problem. So I went alone to the doctor. The doctor said that you have a problem in the blood so bring your husband for a test. I sent my mother home and went to see my husband. First I thought I will not tell it to anyone but then I told my husband.

My brother-in-law and the two of us went to the hospital. We didn't know anything about the disease. At that that time there was no counselling. So the doctor called my husband and talked to him. After some time he called me and explained how I could protect my child from the infection. Both of us were given counselling separately. I don't know what he was told. I was told that I can give birth to a child and that I can have sexual relations. I was also told everything about HIV. Though

I was shocked I was clear about the disease. She told me everything but I was not able to concentrate as I was thinking that how will I tell it to my parents? How am I going to live?

My husband was very upset when he came to know. I had to persuade him to come out. He refused but then I consoled him and made him come out of the house. He remained at home for two days. When the office people called and asked about his absence I said he has taken leave and that he will not come from now. That evening his friend came and asked him to go for a walk. He locked the house from outside and went. At 10:30 he forced me to drink milk. When we were sleeping I had a severe stomach ache and I tried to wake him up. He told me to sleep so I called out to my mother-in-law. He slapped me for that. The next day he didn't wake up. He was dead.

I then came to know that he had taken poison and had even given me some. When the neighbours took me to hospital the doctors said her condition is bad so

take her to the government hospital. I was taken there and given treatment. After that the post-mortem was done. He had even left a suicide note that due to this disease we are committing suicide. This letter came into my brothers-in-law hand. So my father didn't know about that. Afterwards when police came for investigation my in-laws told me to say that due to inability to pay back the loans we decided to commit suicide. I said the same and then I stayed in the hospital for two days. My father came to know and he was shocked. He was then given counselling.

After that I was admitted in the general hospital. The doctor said that the case was complicated because I had gone into labour in the seventh month itself and that only one life could be saved. My father said, "You could save any one of them".

A few months back the tenants in my house refused to vacate. My husband owned it. So I had to lodge a complaint in the police station saying that the tenants had not paid two months rent. When police went to investigate they said if my husband's mother tells them to vacate they will do so. They also said that they have an agreement with my mother-in-law, which says that "we will not be asked to vacate for five years and we have even given an advance of Rs. 10,000." The police asked for the papers but they did not have any.

Since I could not afford a lawyer and did not want to undergo a long court procedure I decided to approach the *panchayat*. I spoke to the MLA and a *panchayat* meeting was called and it was decided that the tenant should pay. He also agreed to do so but later refused. So I again went to the MLA who said your mother- in-law is creating problems and suggested I approach this case according to the rules. I went to the *panchayat* office and found out the procedure then went to the police station with my relatives. The inspector called my mother in law for interrogation. She said "I will not give anything to her till I die". He also told her I was positive and needed the money for treatment to which she did not reply. Since my mother- inlaw will not abide by the *panchayat*'s decision I have decided to approach the court. I have been to a lawyer and he has said that he will take the case to court as a violation of rights and not say that it is a HIV case.

#### **Ganga (22)**

I am one of four children - three sisters and one brother. Our father works in a private factory. Our childhood was a happy one. We all studied with a lot of support from the family. I completed my 10 <sup>th</sup> standard. I matured at 12 and was

married at 16. I did not want to get married because I wanted to continue my studies but there was a lot of pressure from my relatives. He belonged to my family and every one said he was a good boy and that I should marry him. Earlier there was a boy my father was very keen I should marry but his family got a bigger dowry from another family and he married there. As a challenge to that family my father said he would marry me the same year and into a good family. To prove this I was married to this boy. My consent was never sought in this regard. I was 16 and he was 29. Also in conservative families like mine, a girl's opinion is not really asked in such matters.

After the marriage this family really cared for me for a year. During this period he had no job. After that his father died and he got his job on compassionate grounds as a linesman in the Karnataka Electricity Board. And since he had to travel some distance for the job he was given quarters close by and we moved there. Initially everything was okay. The families used to keep coming and going and when I became pregnant I returned to my mother's house for the delivery.

During this period my husband was alone. He had a huge number of friends. He took a loan of Rs. 30,000 that he squandered on drinks. He also roamed around a lot. Often it was difficult to get him on the telephone. No one knew where he was. When the baby was five months I returned to him. I noticed that he was drinking a lot and he always come home drunk. When the baby was eight months

old I came to know of my husband's status. I learnt of it from my father. He said every one was talking about it and asked me if it was so. I refused to believe him and told him my husband was a good man and this was not true.

I then spoke to my brother- in-law about it. I said everyone was talking like this and what should I do? He had also heard rumours so to make certain that it was true my brother-in-law and I then decided on a strategy. We decided his brother would tell him that he needed blood and since he did not want to take it from just anyone would he oblige. He would also say that that the doctor had asked for a test before accepting the blood. We decided that if he readily agreed it meant he did not have a problem. Looking back I recall that my husband said nothing when his brother asked him to donate blood. He just went to the lab and gave his blood. The report tested positive but my brother-in-law did not tell me the result for a long time.

Some of his friends had found out and told his family. Once in laws came to know of his status their whole attitude to both of us changed dramatically. They spoke to us strangely and gave us no support. Earlier they used to come to our house

and eat with us. Now they came less often and even if they did, they cooked their own food and refused to eat our food. They would not even touch the water we give them. They were also not nice to my daughter and I was treated badly. When they came they cleaned the kitchen and I was not allowed to enter the kitchen. I had to wash the clothes and vessels outside.

When we went there I had to do everything for my husband and daughter and we had to stay in a small room. If they give food well and good otherwise we had to go hungry. They kept a separate set of plates and glasses in the room for us. Even in an emergency if the baby needed water or something I had to take the glasses they had kept for us. Otherwise they would scold and abuse me. My sister-in-law would speak badly and ask me why we had come and if my child took any eatable from theirs they would scold and shout at her.

My child and I were also tested after counselling and I was found positive but the child is negative. When we returned to our house for about five months after that no one came from his family to see us. But my parents supported us a great deal. We were sent rations and fruits. They came at least twice a week to see us. They were also looking after my daughter. They had taken her while we were in hospital. He was very upset because no one from his family had anything to do with us.

On rakhi<sup>30</sup> day he was sure they would come but they did not. The rakhi was sent by post to him by his sisters. This was the first time they had done such a thing. He became very depressed and would hardly speak. He said he had been rejected and discarded by his family and friends because of his status. One day he said he wanted to go and see his mother. I suggested he speak to her on the telephone. I don't know what transpired but when he returned several hours later he was absolutely drunk. I had a bad headache that day and was lying down. He told me he did not want anything and would sleep for a while. He then went and shut the door from inside. At dinnertime I knocked several times but there was no response so I had dinner on my own. I then asked a neighbour to come and wake him up. He said let him sleep it off. There was no electricity and I was up all night. Usually when he goes to bed without dinner he wakes up around three but that night he did not do so. At five in the morning I called the neighbour again. He said that since this was a government house we could not break down the door and that we would have to call the section officer and divisional officer. We called them on the telephone. I also called both our families. The section officer came with the police. They peeped through the window and told me he had committed suicide.

<sup>30.</sup> Festival.

My mother-in-law insisted that the last rites must be performed in the village. I did not want to do that but under pressure the body was buried there. I stayed in that house for four days but no one spoke to me or supported me. People just stood and stared at me. My sister-in-law and mother-in-law taunted me. They said his elder brother had died after I had come into the family and now he was dead. If I had satisfied him he would have never gone out. During this time I was exhausted. They did not give me proper food and water. They also told other family members that I should not be allowed into the house. My child was with me, if she asked for food I had to go and stand near the door with a plate, and when they gave it was with taunts and abuses. My father said that since I was so young I should not be put through the ceremonies signifying widowhood but they insisted that it be done. After that I went to my mother's house.

A few days later I went with my brother to my in-laws. There they all screamed at me and said who asked you to come here. My brother and I spoke to some of our relatives in the village and we got the *panchayat* together the same evening. The *panchayat* leaders told his family that she is the daughter-in-law and she must stay in her husband's house. My mother-in-law told them that she could not keep me in the house because I had this illness and both my child and I must go because all the other children play here. Moreover, no one would marry my younger brother if I stayed there. The *panchayat* was also told that I could take whatever money was due to my husband from his employer and take care of my daughter. We will not keep her in this house. The *panchayat* also agreed to this and so I left for my mother's house. My family and I did our best to ensure my right to stay in my husband's house but unfortunately the *panchayat* did not stand by me.

Some months ago one of the three LIC<sup>31</sup> policies that my husband had taken matured. It was of Rs. 2 lakhs and 90,000. I used Rs. 90,000 to pay back debts and the rest I invested in me and my daughter's name. I have been told that Rs. two to three lakhs would come to me. My in-laws thought nothing would come to me. They went to the LIC office and said the money should be given to them. They sent a lawyer notice claiming that they had a share in it. They were told only the nominee would get it. Till the first policy came no one at LIC knew of his status. When the second policy was due the doctor there said that we had to get a certificate from the hospital where he was taken after the accident. The doctor who filled the form in the Bangalore hospital had written HIV across it. When we asked if it could be changed the doctor said that if LIC does an inquiry they would find out so I can't change it. The policies are for one year, eight months and one

<sup>31.</sup> Life Insurance Corporation of India.

year nine months. The earlier one was for three years two months. I am now trying to get this and am talking to the people concerned about how best to get it.

No one respects me in my village. How will I live in such a society? How will my daughter get admission in school? If I go to any function people stare at me. When I go and sit with others to eat they move away. I feel very depressed. If at this young age it is like this for me I wonder what it will be like for my child. Won't people look at her with suspicion for having parents like this? I have no one to all. It appears there is no space in thi ssociety for people like me.

My husband deceived me. He did not tell me his status. If he had told me, I would have lived my life. After all I was negative and I could have brought up my daughter.  $\Box$ 

# Coping with stigma and discrimination: Searching for a collective response.

The seven focus group discussions (FGD) conducted in the three States of Kerala, Karnataka and Tamil Nadu - consisted of individuals affected by the concern and others involved with it in their professional capacities as medical practitioners, project managers, representatives of NGOs and lawyers.

How did the groups respond?

Each group responded differently to the issue of stigma and discrimination. The differences can be broadly characterised in two ways.

The response of some of the groups in Kerala and even Tamil Nadu overtly influenced by specific developments and concerns were more cohesive. They strongly identified the dominant challenges that needed to be overcome and felt that existing responses were somewhere falling short of their expectations.

The rest of the groups were more eclectic and less unified in their perceptions about what constituted an act of stigma and discrimination and even had different opinions about what caused it and hence provided a range of correctives.

However across the groups there was a feeling that health-care providers, which, included those at government hospitals were stigmatising positive persons.

Hence the *two major challenges that* the respondents attempted to address were:

- How the issue of stigma and discrimination could be framed in a manner that takes it beyond an individual grievance and make it a broader concern that not only affects the individual but the very quality of response to effectively control HIV/ AIDS.
- Recommend solutions that would help to address this complex problem.
   It was clear to all concerned that legislation to prevent blatant acts of stigma and discrimination could give everyone including the government the authority to curb discriminatory practices. However, it was also realized, that such legislation could only deal with representative acts of violation. It cannot cope with large-scale denial

or prejudice or even organized backlash. Therefore, what was of immediate and day-to-day concern was the "hostile" and "evasive" attitude of doctors, health care workers, employers, teachers, principals and the community that mattered to people affected by HIV/AIDS.

#### The major needs and solutions that they identified were:

#### Deal with the collective memory of pain and humiliation

In dealing with these challenges they emphasized the fact that unless the *collective hurt is healed* neither the framing of the issue nor the proposed solutions can advance beyond a point. Given the powerful collective memory around the painful and humiliating experiences of the past, it is difficult for many of them to bury the past and confront the problem in its present form.

Unless this *collective memory is addressed*, and the *dignity and confidence of the positive persons restored*, it will be difficult to motivate them to be open about their status and extend help to everyone concerned to shape an effective response to HIV/AIDS.

For instance, in many of the groups the discussion inevitably began with a **sharing of** what constituted some of the **difficult experiences** that people living with HIV/AIDS had experienced. This meant that although, the stigma and discrimination against people affected by HIV/AIDS have over the years, changed-in form and practice, given the collective memory focussing on some of the more painful and humiliating experiences that they have gone through, for many it is difficult to recognise or feel hopeful about the small breakthroughs and changes that have taken place.

They remembered some terrible happenings like "just taking the person in a car and abandoning her somewhere and letting her die". *They are not able to forget the fact that the family was often extremely inhuman.* There were instances when women faced total isolation, were not allowed to come out of the room or even meet their children. In another instance a doctor in a Public Health Centre (PHC) broke the rules of confidentiality and in a very irresponsible manner informed the father about the status of his son. The father in a state of mild drunkenness informed the entire village and took the extreme step of throwing them - son, daughter-in-law and grandchild-out of the house. Such breach of confidentiality, which continues to happen in rural areas, was seen as devastating for positive people and inimical to an effective programmatic response to the problem.

But it was the attitude of health-care providers that has left a bitter trail and destroyed

their sense of confidence and trust in people. They found that if they kept their status secret they had no problem in accessing treatment for the different opportunistic infections. Once they disclosed their status either voluntarily or because of an investigative process, they found the attitude of the health careproviders changed. They were not willing to provide even diagnostic consultations.

More often than not they were intent on referring the affected people to another practitioner and as far as possible to another institution. It was this **professional evasion**, they stated, that was "**hurting**" **them most** because this often happened at very critical moments when they were going through extreme pain and suffering.

"I took all the results and went again to the doctor but this time I decided to tell him that I am positive. The moment he learnt about it he did not bother to see anything else on the file, he did not want to see the test results. Then suddenly after talking with two other doctors, he told me don't worry go and meet some other doctor. We struggled so much to arrange for money and get the tests done and they did not say anything about the results."

#### Prevent social exclusion of people living with HIV/AIDS

In Kerala the discriminatory treatment meted out to the two children, Bency and Benson evoked great anxiety among the respondents. The key concern of the group was how do you ensure that social exclusion does not take place? How do you ensure that a child who is positive is not denied admission or thrown out of a school? How do all the concerned people deal with the growing bias against people living with HIV/AIDS and the spoken and unspoken prejudice of the school authorities and the community?

In the case of such blatant acts of discrimination, what was worrisome to the respondents was the fact that such incidents were happening in a state with high literacy and a high awareness about HIV/AIDS. What was compounding the situation was the fact that the State Government was finding it difficult to use existing remedies to address the situation. They felt, that if a more specific legislation gets enacted to forbid such violations, it would no doubt help to challenge such unacceptable practices but would not necessarily guarantee the elimination of the backlash contributing to the stigma and discrimination. Given the fact that a more serious battle had to be waged against systems managed by insensitive and uncaring service providers fuelled by an intolerant community, it was clear to the respondents that no single solution would help to overcome the situation.

Explaining this one respondent stated that, "The school authorities hesitate about admitting children who are positive. They have a feeling that if HIV positive children study in a school, every other child may become positive. They look at such children with hatred. In such conditions when the parents approached the Deputy Education Officer (DEO) and the Collector it was of no use. In a school where there are 2000 children and their parents complaint against a positive child the teacher takes recourse to the easiest solution and throws the child out of school".

In such contexts, it was believed that the solutions had to be both broad and specific and as far as possible the response has to be unified and multi-level. Firstly, create as far as possible a widespread understanding of the concern, spread awareness about the routes of transmission and the management of the condition after getting infected by HIV to prevent misconceptions and reduce prejudices against people living with HIV/AIDS.

More specifically, **sensitise critical** and key sections **of people** working in different institutional settings and **ensure** that **these individuals act as an interface between the professionals, service providers and the people living with HIV/AIDS**. Finally, prevail upon the government to ensure that the administrative actions taken by concerned departments are reinforced by effective and enforceable policy directives.

#### Deal with the high level of distress among communities living with HIV/AIDS

At Nammakal, the group which, consisted of representatives from many stakeholders from an elected representative of a panchayat to doctor, counsellor, lab technician, educational administrator, truck driver to people living with HIV/AIDS, the discussion focused on how the on-going programme needs to address the distress levels of people living with HIV/AIDS and tackle the growing problem of stigma and discrimination faced by truck drivers and others associated with the industry.

Given the magnitude of the problem of stigma and discrimination, the group identified the need to address the *high level of distress* among the *people affected by and living with HIV/AIDS* as the leading concern of the district. With the prevalence of HIV/AIDS having gone beyond truck drivers to the general population to include large sections of pregnant women, the respondents singled out the issue of stigma and discrimination as the most serious concern. The recognition of this concern coupled with the perception that there was an abysmal lack of coping mechanisms

and strategies resulted in respondents stating that in a population of 15 lakhs there are hardly "three to four counsellors".

At the core of this inadequate response to HIV/AIDS, the group stated, was the weak and ineffective programmatic interventions in critical areas such as counselling and sensitisation of service-providers. This in turn has had an adverse impact on the readiness and willingness of everyone who needs to cope with and manage the predicament.

With people living with and affected by HIV/AIDS experiencing extreme depression, acute social withdrawal and some even having taken recourse to suicide the group strongly argued that counselling services of high standards and wide outreach was needed.

A counsellor agreed that, since "revealing the result is the most crucial act" and one that can make a great difference to the positive persons, they need to be provided with "long hours of counselling". They felt that unless this was done effectively there is the danger that when individuals "come to know that they are positive the first thing that comes to their mind is suicide. In fact, it is very difficult to take patients for testing. They are not ready to go. They think let the disease remain with us itself".

This fear of HIV/AIDS was far worse, in the rural areas, stated an elected representative of a *panchayat*, "I have come across HIV cases. They feel very scared that they will die very soon. That fear should go out of their hearts...."

#### Change methods of sensitisation, strengthen services

There was a feeling that given the state of distress, the programme has to go beyond its routine patterns and the so-called tested and tried preventive methods that it has been using thus far. The *responsibility of counselling* should go beyond just counsellors. It *should be part of* the *job profile* of the entire gamut *of health care* and other service providers working in different health care and social settings from doctors, nurses, para-medic, health-administrators to social workers, teachers etc.

Moreover, the content of awareness and sensitization should also be changed and it should deal not only with the clinical aspects of HIV/AIDS, but also with the human interest and development aspects of the issue. In the case of doctors, the sensitisation should succeed in motivating them and involving them "emotionally"

with the problem. Only such an all-round and concerted response to the problem would enable the people living with HIV/AIDS to fight again the overwhelming fear of stigma and discrimination.

In terms of services, the strengthening of pre and post-test counselling and the *principle of confidentiality, is vital*. In HIV/AIDS what matters most, according to the respondents is "how you tell them about their status". They stated that, therefore it was necessary to be flexible about how this gets handled as it may "change from case to case". But none of this, they said should go against the principle of confidentiality. They also felt that it was even more vital to adhere to this principle when it came to women. If the women maintain that the husbands transmitted the virus then the situation is still manageable but if a woman is positive and the man is negative, the situation becomes even worse if confidentiality is breached. She has to be allowed the right to decide the manner in which she will inform her family.

It is therefore necessary for a *close partnership* with and *involvement of people living with HIV/AIDS*. Integrating their experiences and their participation would help the counsellor to "see, hear, feel and realize" the concerns of people living with and affected by HIV/AIDS. More importantly, it would also ensure that HIV/AIDS is not reduced to an issue of numbers but would become a lived experience, which is being dealt with on a day-to-day basis by Positive people

#### Inclusion of positive persons as spokespersons against stigma and discrimination

It was stressed that what the situation demanded was a qualitative scaling up of preventive strategies and the inclusion of positive people as key spokespersons with large-scale awareness campaigns and the sensitisation of decision makers and professionals to the issue. The bias and prejudice against HIV/AIDS can only be removed if the issue is "normalized" and given a human face.

#### Educate the family about HIV/AIDS

The doctors felt that the family has to be taken into confidence if the person infected by HIV/AIDS had to be taken care of and treated. In the absence of the family support and consent the doctors often find themselves being accused of suppressing information and acting against the interest of the individual. Over the years they have found that families were far more co-operative and in many instances even proved a source of strength to the positive person. Therefore it was necessary

to allow a certain degree of flexibility as far as maintaining confidentiality is concerned.

#### Enhance awareness in the rural areas B

Alongside informing women about HIV/AIDS, they should also be educated about their rights and given the space to express their views and share their concerns.

Remove negative associations such as HIV/AIDS being termed as a "deadly" disease. Make all efforts to target the youth and educate them using official interventions like National Social Service and Nehru Yuva Kendra.

# Addressing the concern of gender and HIV/AIDS: Response of key stakeholders

#### Introduction

In one-to-one interviews a cross section of stakeholders from Karnataka, Tamil Nadu and Kerala shared their experience of dealing with this concern. Drawn from diverse segments they included- *policy and decision makers* involved with the issue in their political capacity as elected representatives, minister in the Government or as administrative heads managing and administering an AIDS prevention programme. *Medical and health-care professionals*, serving as doctors, nurses and counsellors and numerous *key individuals representing civil society organisations* and initiatives also provided critical inputs.

### Factors influencing the perceptions of the stakeholders

The interviewees explored their own professional engagement with the problem while broadly reviewing the quality of response that different stakeholders had mounted thus far. At the outset, it must be stated that since many of the respondents have had a fairly long association with the concern, one or two tracing it back to 1987 and others from the mid -90's to 1999, their view of the present scenario is to a large extent influenced by the extreme and violent reactions that prevailed in the past. They all shared the view that though in terms of human rights standards, the response is far less phobic than in the past, given the present scope and magnitude of the problem, attitudinal change are evolving very slowly and not keeping pace with the rapidly growing pandemic.

To be more precise, there are *two overarching factors* that have *shaped their perception of the concern*. For one, many respondents agree that *HIV/AIDS* can *no longer* be treated as an *exclusive problem* of the so-called "*high risk*" group as it has filtered to the general population. And as a corollary there is growing recognition of the fact that there are different challenges that are making people vulnerable to HIV/AIDS. Some are behavioural and manifest in high- risk lifestyles

and others are more circumstantial and have linkages with experiences such as poverty, gender inequity and migratory practices. More vitally it could also be traced to outdated belief systems and unworkable social norms.

For another, given the long-term association with the problem **most respondents** had a more inclusive approach, tended to be less judgmental and were aware of the vulnerabilities that women living with HIV/AIDS were experiencing. The problem is no longer being viewed from a moral lens and there is to an extent a more down-to-earth and pragmatic approach.

### **Contributing factors**

The *two specific initiatives* and interventions that have contributed to this more inclusive perspective are:

- The *networks* of PLWHA in Karnataka and Tamil Nadu that have helped to a significant extent in *normalising the problem* and demonstrating that there is life after HIV/AIDS. This has to an extent had a positive impact on people coping with the problem.
- The feeling among managers and service providers of greater confidence about the ability to manage the problem. This is because of specific interventions including safety of blood banks and prevention of mother-to-child transmission, which have been done on a programmatic scale to contain the problem and intercept the cycle of transmission.

# Does this imply that the respondents are denying or ignoring the prevalence of stigma and discrimination?

On the contrary, far from denying the problem or being defensive about it a significant section of respondents have recognised it as a programmatic impediment and tried to locate the specific areas and extent to which stigma and discrimination continues to persist. And some of the persisting stigma and discrimination has in fact been traced back to inequitable socio-economic structures and patriarchal norms. There is also a quiet and firm acceptance of the fact that unless stigma and discrimination is addressed in a holistic manner, the response to the epidemic would prove to be ineffective. Yet, at another level they are ambiguous and tentative about the more subtle forms of discrimination that continue to exist and are unable to explain the deep-rooted "fears" and prejudices that continue to prevail among doctors, nurses, health workers, communities and even families despite large scale awareness campaigns.

### Feedback from health care and medical professionals

The respondents included senior medical professionals including: Superintendents and Deputy Superintendents of leading medical colleges and hospitals, health educators, specialists in cardiology and HIV/AIDS, social workers, nurses and counsellors.

# What is their perception about their professional track record in addressing concern of stigma and discrimination against PLWHA?

### Stigma and discrimination within health care settings has reduced

It is widely believed that the situation has changed since 1997 and that overt and even blatant display of stigma and discrimination is much reduced in the hospital and health care setting.

A counsellor at a Mangalore Hospital spoke of how, "In 1997 there were cases of treatment being stopped midway and patients discharged if they tested positive and I have even heard of how when an HIV/AIDS person died or was discharged all the bedding were burnt. Now this doesn't happen".

While agreeing with this, a senior cardiologist in Bangalore pointed out how, "Every country has gone through this kind of phobia. Even in America initially there was a problem. Over the years everybody learns, often from other doctors. I have seen that the attitudes that prevailed among my colleagues, ten years ago has changed".

A medical consultant who started an infection control unit at a leading hospital did however feel that since the hospital is a speciality institution doctors were so specialised that they did not have the time to keep abreast of all medical developments in areas like HIV/AIDS. So what she used to do was to take responsibility for a patient suffering from a clinical complication due to HIV/AIDS and explain what the patient required to the concerned doctor. "They trusted me so I would call up any doctor and demand that they attend to these patients.... But now the situation has changed.... It is partly because the disease has gained greater acceptance. .... I do not have a special ward for them anymore. What is important is that doctors have started accepting the fact that HIV patients can be treated and their quality of life improved".

Even more categorical was a counsellor working in a leading hospital in Mangalore who said, "I admit that at that time (1998-99) there was a lot of stigma and discrimination but it is not so bad now".

Hospital administrators, be it in Chennai or Mysore felt that whatever stigma and discrimination took place, happened in the past and was practised at all levels by the paramedics, nurses and doctors. They "would refer the case elsewhere and wash their hands off the whole things". But now the situation they claim is a lot different. "Everybody" they state "is co-operative and nobody has a problem in treating these patients".

### Persisting fear and prejudice

Extended interactions with the respondents did however reveal that though stigma and discrimination is not as stark and intolerant as in the past, it does not necessarily imply that health care workers or medical professionals have got over either their apprehensions and fears or their professional reluctance to deal with people living with HIV/AIDS.

Observations across the three States vis-à-vis these concerns were "Acceptability is not 100 per cent ...I hate the judgmental attitude towards the disease. Everyone across the board - physician, nurses, technicians and paramedics - have this attitude towards HIV/AIDS patients. When they hear it is HIV/AIDS they are not willing to help. I do not see this attitude towards cancer patients. I see it only towards HIV/AIDS people. That has not changed regardless of the exposure, education and knowledge of HIV/AIDS". It was also observed that while a poor seeking financial help for expensive treatment such as by-pass surgery or cancer would be able to find a donor "An HIV/AIDS patient, even a child finds it difficult to get a donor."

### Lack of motivation and professionalism

It is also clear from the counsellors that while doctors working in some departments have got over the fear and are able to deal with the issue in an empathetic manner, many of the doctors from other departments are not sufficiently motivated to deal with the concern in a professional and need-based manner.

A counsellor remarked how, "We have to go to them several times. Sometimes they oblige and at other times they say that it is not convenient". It has also been observed that HIV/AIDS patients find that doctors are not willing to perform surgery on them. Many a time when they reveal their status the doctor hesitates to handle them". She added that counsellors have to try and convince them "saying that it is not a big problem" and at times they even have to put pressure from bodies like State AIDS Control Organisation.

The doctor-in- charge of VCTC in Perambalore, GH, admitted that they faced similar problems. "At present the reaction of the medical community is more of reluctance than fear" he said, adding that there is a high level of discrimination being practised by some of the medical practitioners. Most surgeons demand an HIV test and once the status is known as positive they refuse and discharge the patient on some reason or condition".

Talking about the current forms of stigma and discrimination and the systemic problems that prevail, a doctor from Kerala admitted that, "in the case of HIV positive pregnant women doctors are hostile and the private hospitals immediately sent them women to government hospitals saying that requisite facilities is not available with them".

Even more inconsistent, he stated, was the treatment of opportunistic infections. With around 70 per cent of patients turning to private health care providers, there is no standardisation of service. The problem with the government set-up, he said, "is that awareness about the management of HIV/AIDS is only available in the medical colleges. So, only they can tackle the situation... Most other doctors are not ready to treat opportunistic infection... Maybe, they are afraid", he said.

The counsellors also felt that hospitals were not always supportive of poor patients. "Despite working in a hospital setting, they often refer these poor patients to NGOs who even provide free medicines to them"

# Feedback from policy makers, elected representatives, programme mangers and administrators

### **Broad observations**

The understanding that emerges across the board - from policy makers to administrators-is that stigma and discrimination against people living with HIV/ AIDS are symptoms of an inadequate and nascent response to the many facets of this concern.

It was also pointed out that the experience of managing diseases like TB and leprosy has shown that as medical science progressed stigma and discrimination got considerably reduced. Today, HIV/AIDS is facing a similar challenge and what is required is a scaling up of response with the focus on programme delivery and what they were aspiring to get done.

### **Project officials**

### Enhancing services and pubic-private partnerships

It is in the light of this perspective that a Project Director in Karnataka stated that they intended to fight stigma by providing services and entering into a partnership with both government and private hospitals so as to ensure the supply of drugs, provision of testing, counselling and treatment of MTCT for all people living with HIV/AIDS. More importantly she believed, that they needed to go beyond just creating awareness and use a communication approach that would help people to internalise the issue. So the main challenge lay in expanding services, strengthening outreach and developing meaningful communication strategies. The assumption all round is that stigma and discrimination breeds in an environment that is unsupportive and ineffective. So coping with stigma and discrimination is being viewed as a part of the larger programmatic process of learning to deal effectively with the problem.

### Strengthening interventions and legal responses

Expanding on the same assumption, the Project Director of Tamil Nadu identified specific interventions that are being undertaken by the State AIDS Control Society to counter the stigma and discrimination faced by people living with HIV/AIDS. This included more immediate interventions such as setting up of VCTC in every district and more sustained interventions such as improving the treatment for opportunistic infections and motivating the hospital administration to integrate HIV/AIDS treatment and care into the routine activities of the hospital. Meanwhile, many practical interventions, he stated, were being undertaken to ensure a minimum scale of response. This includes measures such as strengthening special government hospitals and encouraging a few private hospitals to treat HIV/AIDS persons

As far as on-going human rights violations were concerned, although a State like Tamil Nadu stated that they had set up an administrative unit such as a legal cell to receive these complaints, render legal help and advice and spread awareness about the rights of Positive people, it appears to be a nascent effort aimed at containing such misdeeds through legal education and awareness building.

It was also noted that given the changing nature of the epidemic viz. becoming more rural and affecting more women, was creating new challenges for the administration of the Programme. Recognising the concerns of gender inequality and poverty, it was felt that in the case of rural women a supportive legislative framework, economic empowerment and partnership with the key departments of the government and NGOS were essential to address "deep rooted social problems".

### Encouraging self regulation

The Kerala Project Director stressed the fact that stigmatising of people living with HIV/AIDS as one of the major concern of the State. One view was that much of the stigma was an outcome of "excessive awareness" or backlash. Informed sections of the community such as doctors were practising stigma and discrimination. Although the government could use mechanisms such as withdrawing the license of doctors to do MTP, it was realised that such measures were not be sustainable and more importantly they would not bring about the necessary change in attitudes and mindset. In fact what is being seen as more effective is to encourage self-regulation or professional regulation. The recent incident of discrimination against the two children orphaned by HIV/AIDS was seen as an "aberration", largely aggravated by the unwarranted media coverage.

### **District administrators**

### Need to strengthen awareness programmes

Responding to these growing challenges, the District Collector, Perambalore talked about the early efforts that were being made in rural areas to address both discrimination and marginalisation being experienced by women. Some of the women who had been affected by HIV/AIDS and even widowed had been identified, encouraged to form collectives, given assistance to buy dairy animals and link up with milk processing enterprises to sell their milk. Such self-help groups, he said, would be formed in every village.

This focus on women, he stated, was essential because they had enough evidence to show that a lot of them in the age group of 18- 22 were positive and pregnant. The district, he added, presently lacked the capacity to implement an MTCT programme but would soon initiate one.

However, he admitted, that in the rural areas it was imperative to launch a major information campaign to counter the extreme fear that HIV/AIDS was evoking. The campaign, he said should go beyond the message of how to protect oneself from HIV/AIDS and include messages that addresses stigma and discrimination. And when it comes to rural women, he felt the campaign, should particularly impress on the fact that these women should not be judged from a moral point of view

because, "For the poor village women there is no question of morality". In fact, the fear of stigma among them was so strong that the administration was taking care not to reveal the status of women.

According to the Collector of Nammakal, where the HIV/AIDS has filtered down to the general population, "Fear and stigma continues to persist and doctors were "still afraid of treating of PLWHA". He was convinced of the need to strengthen awareness programmes in the district with the presence and support of PLWHA.

### Need for greater support from stakeholders

More specifically, the Collector spoke of the lack of support from the frontline departments such as the medical department, which he described as "extremely worrisome". Because in such high prevalence areas the district administration requires far greater support from the different stakeholders, than what is being currently demonstrated. It was felt that elected representatives and NGOS need to educate and mobilise the people and the Government needs to scale up the response, persuade doctors at the primary health centres to come forward and cope with the problem, set up treatment centres at the *Taluk*<sup>1</sup> hospitals and care homes for children living with and affected by HIV/AIDS.

### Policy makers and elected representatives

### Need support of a caring society

Recognising the multiple vulnerabilities that individuals living with HIV/AIDS were experiencing, a former Minister of Health and Family Welfare admitted that when he saw people who are living with HIV/AIDS his "first reaction" was that they "needed help". He also realised that they were totally marginalised, belonged to poorer sections of society and had difficulty in earning a livelihood. While lorry and truck drivers were separated from their family, in the case of sex workers they faced the terrible burden of a highly repressive law enforcement system because the police believed in "chasing the sex workers out and beating them." Given these physical limitations he felt it was essential to have a caring society because only then will they be able to access treatment or deal with the problem.

However none of the measures that he listed clearly articulated the role that political representatives should play. He admitted that there was a lot of stigma but was not willing to directly engage with the issue. Many of the measures he recommended were those that were already part of the programmatic focus of the AIDS prevention programme.

The priorities as he saw them were:

- Educating vulnerable sections of society.
- Convincing sex workers of the need to insist on their clients using condoms.
- Involving NGOs in providing care to the more vulnerable groups.
- Launching of a massive awareness campaign by the Government.
- Strengthening of access to treatment as also the focus on interventions such as the prevention of mother to child transmission.

### Lack of defined role for elected representatives

This lack of a clearly defined role for political representatives became most evident when it came to elected representatives at the *panchayat* and state level. Commenting on this the district administrator stated that the elected representatives such as *panchayat* president "hear what we tell them but when they go back to the village none of this gets reflected in the implementation".

Agreeing with this a *panchayat* leader stated that 'we cannot talk much about HIV/ AIDS because people will think otherwise. When anybody comes to the village to spread awareness, we help them to organise meeting. We invite them to talk to the people because if we talk to them it will not be taken properly by the people". What is significant is that awareness about HIV/AIDS is associated with knowing the routes of transmission and being able to impress on the people that it is a 'killer disease for which there is no cure".

At the State level although the political representative had been exposed to fairly systematic sensitisation about HIV/AIDS, was appreciative of the initiative and even felt that knowing about the problem and the world scenario had made a difference to his commitment to the issue, on the question of stigma he was not prepared to accept the fact that government hospitals could refuse treatment to people with HIV/AIDS.

He insisted that the women should demand treatment and if refused seek their intervention. As a political representative he felt that he could demand explanation from the concerned officials. It was clear that unless this experience of stigma and discrimination in settings like hospitals are properly documented and recorded, it would not be possible to get the sustained engagement of the political representatives.

### Feedback from representatives of civil society organisations

Representatives of organisations providing varied kinds of support services in areas such as counselling care and support, legal aid and HIV/AIDS education, strongly reinforce the attitudinal barriers and constraints faced by different section of people living with HIV/AIDS.

### Healing the hurt is vital

It was widely believed that while some of the more blatant forms of stigma and discrimination has come down the heart-rending experiences of people who have undergone extreme cruelty and discrimination "continues to haunt people even today". Therefore the process of "healing" this "hurt" is as important as eliminating and preventing all forms of stigma and discrimination.

### Legislative and programmatic framework required

Given the complex link between poverty, gender and HIV/AIDS, civil society organisations realise that HIV/AIDS cannot be addressed as a single issue and that a legislative and programmatic framework is required to address stigma and discrimination. One view was that stigma was persisting because health care professionals and the hospitals have not overcome the "fear of infection". This bias has in turn been communicated in "many ways to the family".

### > Insensitive disclosure of status

In the health care setting, stigma often begins soon *as the testing* is done and the doctor shares the diagnosis with the affected individuals. Often the status is disclosed in such an insensitive manner and their dignity so undermined that even, the family members get influenced by this approach and develop an unreasonable fear of HIV/AIDS.

#### Women stigmatised twice over

In the case of the women, she often bears the brunt of the stigma and burden of care when her husband becomes positive. She goes through the process of stigma twice over and what compounds the problem is that when she has to deal with her HIV/AIDS both stigma and discrimination virtually converge into a vicious cycle of violations and unimaginable indignity.

### > Violation of migrant worker rights

Marginal groups such as migrant workers-women and men-who often live together in close proximity find that the testing centres never maintain the confidentiality of the results. The news spreads so fast that they have tested positive that within a

few hours they just vanish from the place. They fear that the stigma from the community can be so severe and even life threatening that they tend to run away. This kind of violations by the laboratories is neither in the interest of the programme nor of the individual.

The fear of stigma from the community is indeed so strong that when the women and men fall ill, they request the organisations to give in writing that they are suffering TB. Apparently TB is viewed as less contagious than HIV/AIDS.

### > Improved hospital responses

As far as the stigma in the hospitals settings were concerned, they admitted, that some change had occurred in government hospitals. Food, for instance is now served in a more humane fashion. Five years ago, they were so fearful that they would throw the plate into the room. However, many organisations felt that in many instances, the forms of stigma and discrimination have changed and it is not so much at the level of "isolating" people, but is often at the very difficult level of being judgmental.

### Collectives unable to impact mindset

Organisations working as support groups for sex workers felt very strongly about these forms of discrimination. They said that they were often treated so badly, even humiliated that they have decided to bring such misdeeds to the notice of hospital authorities. In one instance the Dean of the hospital called all the departments and announced in their presence that if they were not willing to treat women properly, they should leave the hospitals. However all this does not change the mindset of medical professionals and women professionals were far more discriminating than even their male counterparts.

Legal redress is not an easy route to set right infringements and gender discrimination. Even mechanisms such as the family court, which, has been used to file petitions to guarantee women's right to the matrimonial home is not always responsive to the women living with HIV/AIDS. There are no special provisions for women living with HIV/AIDS. The judiciary does not understand the specificity of being HIV/AIDS. Given the fear of stigma and discrimination and the possible lack of understanding of HIV/AIDS by the judiciary, the legal battles get fought on the grounds of gender discrimination and their status as a Positive person is generally not revealed.

### **Annexures**

#### **Annexures**

### Literature survey

### **HIV** awareness

Twenty years into the epidemic it is becoming increasingly clear that awareness levels of transmission routes of the HIV virus and preventive methods continue to be low and at best lopsided, in India.

### NACO's Behaviour Surveillance Survey - 2001 1 noted that:

- 76 per cent of respondents across the country had heard of HIV/AIDS and the common modes of transmission — sexual contact, blood transfusion and needle sharing.
- Less than one in four were aware that HIV/AIDS cannot be transmitted through mosquito bites or by sharing a meal with an infected person.
- Less than a third of all respondents (32.1 per cent) had heard of STDs, in the entire country and awareness of the linkage between STD and HIV was just 20.7 per cent.
- Over 75 per cent of respondents were aware that condom use can prevent transmission and 57 per cent were aware that having one faithful, uninfected partner can prevent transmission.
- But awareness of the benefits of condom use was uneven. 80 per cent of urban men were aware of its protective value as compared to 43 per cent of rural women.
- Awareness regarding other modes of transmission mother-to-child and breast-feeding was found to be abysmally low. Only 20.1 per cent of rural women in Bihar, 20.6 per cent in Gujarat and 23.6 per cent in Uttar Pradesh were aware of this mode of transmission.
- Similarly, only half of all respondents (54.4 per cent) were aware that the virus could be transmitted through breast-feeding. Again, the rural urban divide is evident with only 18.6 per cent of rural women in Gujarat, 19.4 per cent in Bihar, 20.2 per cent in UP and 22.4 per cent in West Bengal aware of this mode of transmission.

<sup>&</sup>lt;sup>1</sup> National Baseline High Risk and Bridge Population Behavioural Surveillance Survey, Ministry of Health and Family Welfare, NACO, 2002

Low awareness levels among women in general and rural women in particular, was also noted by the *Charca project* <sup>2</sup> conducted by the Karnataka Mahila Samakhya in Bellary district, 2002. And what is even more alarming is that, across the board half of those who knew about AIDS thought it was curable. So even if they are aware they don't take it seriously, believing they can be cured. The Study also found that:

- Only 34 per cent of rural women had heard about the virus as compared to 57 per cent of urban women.
- Unmarried females were better informed than their married counterparts because married women have to discontinue their education as a result of which their sources of information get limited.
- Women respondents over the age of 25 had no knowledge about AIDS and when asked if their spouses could transmit HIV, only 39 per cent were aware as against 56 per cent of the unmarried females.
- Only 29 per cent were aware of protection methods and of them, only a third were aware of condoms.
- In FGDs, only 10 per cent of women's groups were aware that condoms could protect them from the virus, as compared to 70 per cent of men.
- Similarly, 40 per cent of men said that single partner sex improved protection, as compared to only three per cent of women.

But there is evidence, that consistent prevention efforts can make a difference. In Gujarat, about three fourths of the sex workers said they had used condoms the last time they had sex with a commercial or casual partner and 66 per cent of sex workers, 77 per cent of their clients and 52 per cent of injecting drug users said they consistently used condoms.

The Unifem supported "Gender Dimensions of HIV/AIDS: Community based studies", <sup>3</sup> conducted in Pune, Chennai, Guwahati and Delhi in 2001, also found awareness levels to be abysmally low across all social groups and with many not being aware of what the virus did to a person.

 In Guwahati 98.5 per cent said that they had little or no knowledge of HIV/ AIDS.

Charca project, Karnataka Mahila Samakhya, Bellary District, 2002.
 Gender Dimension of HIV/AIDS: Community Based Studies, ISST, Stree Adhar Kendra, Initiatives: Women in Development. UNIFEM.2000.

- In Chennai, women said they gained more information about the virus only after they were affected.
- At a Delhi FGD, men said they did not know the difference between HIV and AIDS, while young boys who had heard of HIV/AIDS from television and billboards were ill informed and unaware of opportunistic infections due to HIV/AIDS.
- In Pune, women did not have even elementary knowledge about reproductive health issues, contraceptives or safe sex practices. Responses were also mixed vis-à-vis contraceptives.
- In Pune, 16 of the 35 respondents had not heard of contraceptive devices.
- In Delhi, married women had heard about condoms but none of their husbands used them. They said that men were not "cooperative" about condom use.
- Women said that if they were pregnant or sterilised, it was impossible to suggest condom use because condoms are only seen as a contraceptive device and not as an HIV preventive method.
- Many of the respondents learnt of the protective aspect of condoms, only
  after they were infected and men who were positive said they found it difficult
  to initiate condom use because they had not used it earlier and did not want
  to make their wives suspicious.
- Sex workers in the northeast said use of condoms was almost nil, while in Chennai they said it was difficult to convince men to use them.

### Access to health care

Though the health sector has been hugely enhanced since independence in terms of doctors, nurses and infrastructure, there has been no marked improvement in the health status of the people. And nowhere is this more obvious, than in maternal health programs. Seven out of every hundred children die during their first year and five out of every 1,000 women die of causes related to pregnancy and child birth as against one in 4,000 in developed countries.

A **National Family Health Survey** (1998-99), notes that the number of mothers who received natal checkups in 1992-93 ranged from 31 per cent in Bihar to 94 per cent in Tamil Nadu. Similarly, the number of women who gave birth in a medical institution ranged from 11 per cent in Rajasthan and Uttar Pradesh, to a high of 88 per cent in Kerala. This differential use of services has been

attributed to numerous factors, ranging from availability, distance, cost and quality of services to urban-rural residence, the woman's work status, her status relative to men, religion, caste and caste as also the economic status of her household and community development.

In "Indian Women: Their health and economic productivity", M. Chatterjee points out that in India, the situation is further complicated by "women's perception of illness, which is affected by women's cultural conditioning to tolerate suffering, which varies considerably from across regions of India, resulting in the perceived need for health services being small, even when the actual need is great." He adds that pregnancy and child birth is traditionally considered a natural state of being for a woman, rather than one that requires attention and care resulting in a "lay health culture", that is an "intervening factor between the presence of a morbidity condition and its corresponding treatment."

Given this scenario, the plight of women who believe they may be infected with an STD becomes doubly difficult. As *Gender and HIV/AIDS- UNAIDS Technical Update*, 1998 <sup>4</sup> points out, women oriented health services generally do not focus on STD related services that carry greater stigma than integrated services. Existing STD clinics are generally not suited for women, because women are shy to consult male doctors in such matters and many clinics do not have lady doctors.

And even if they do circumvent these barriers, HIV infected people, both men and women, are invariably left to cope with discrimination in health service settings. Respondents to the UNIFEM supported *Community-Based Studies on Gender* <sup>5</sup> conducted in Delhi, Pune, Chennai and Guwahati, spoke of how medical staff refused to touch them and gave oral medicines rather than injections. Of being tested without consent and being discharged from hospital before treatment was complete, because they did not want to keep them and of being denied counseling. A sex worker in Chennai recounted, how she was not attended to during labour and of having to cut her own umbilical cord.

<sup>4.</sup> Gender dimension of HIV/AIDS: Community based studies, ISST, Stree Adhar Kendra, Initiatives: Women in development. UNIFEM 2000.

<sup>5.</sup> National consultation on women living with HIV/AIDS, Chennai, March 2002.

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#### Violence

While a lot more research would be needed to understand the precise interaction between violence and HIV/AIDS, there is ample evidence that violence and/or the very fear of violence is contributing to the vulnerability of women to the virus by affecting their expectations in relationships and their ability to negotiate safe sex. What is worse, is that apart from making women vulnerable to infection, a woman testing positive is also at risk of violence, intimidation and even abandonment by her friends, family and community. Dr. Shalini Bharat in *HIV/AIDS related discrimination, stigmatisation and denial in India, 1999, TISS,* documents the case of Mary, a 25-year-old who spoke of how when her husband died, "nobody from the neighbourhood came...I sat with the dead body the whole night. Nobody came to the crematorium". And there are countless other instances.

And violence against women is only growing. There was a 74 per cent increase in incidents of violence between 1980 and 90 with rape, molestation and torture by husband and relatives registering the highest growth. In fact the *National Crime Records Bureau* reported in 1995, that the growth rate of crimes against women would be higher than the population growth rate by 2010.

A Karnataka centric study quoted in *Violence against women and HIV/AIDS;* **Setting the agenda, WHO-Geneva, Oct 2000** noted that:

- 34.1 per cent of respondents had been subjected to marital violence.
- 29 per cent said their husbands had hit them.
- 12 per cent said they were forced to have sex when they did not want to.

Many women also spoke of how their husband's alcohol use and the ensuing violence were major hurdles to negotiating sex and the way in which sex occurs.

Similarly, the Charca study *HIV/AIDS* and the challenge to women's empowerment found that:

- Women's control on decisions affecting their sexual safety is exacerbated by alcoholism and violence, with 44 per cent of FGDs reporting the prevalence of alcohol induced violence, which often takes the form of mental and physical harassment.
- A high prevalence of sexual violence with half of the female and 20 per cent of male FGDs reporting in the affirmative. Significantly, more than two thirds of the females above 25 years of age reported the prevalence of sexual abuse.

A multi-site study of domestic violence conducted by the *International Center for Research on Women (ICRW)* between 1997 and 1999 reported that:

- One out of four respondents had experienced slapping, kicking, hitting, threat
  or use of a weapon or forced sex in the 12 months preceding the survey.
- Women living in rural areas and urban slums reported higher rates, than those living in urban, non-slum areas.
- Nearly 15 per cent of all the women in the survey reported one or more incidents of forced sex during the twelve months, before the survey period.
- The prevalence of psychological violence was higher than physical violence across all strata and regions. The highest incidence was reported in Thiruvanthapuram, where 69 per cent of women experienced some form of psychological violence — mostly infidelity, followed by Nagpur (59 per cent) and Lucknow (56 per cent).

When asked what precipitated the violence, women spoke of lapses in domestic responsibilities-cooking, attending to children, in-laws and household as the key factors followed by sexual control, infidelity of husband, accusations of unfaithfulness by husbands and dissatisfaction over dowry amount.

The **Gender Dimension of HIV: Community Based Studies** meanwhile noted that:

- Respondents of all economic and social groups spoke of how they had no choice in spouse selection or the age and time of marriage.
- Of being forced into marriage even when they did not approve of the man.
- In Delhi, married and single women regardless of educational status lacked the options or the power to decide about their lives leaving them no space to negotiate safe sex or chose their spouses.
- In Guwahati, 50 per cent of respondents said that their first sexual encounter had taken place at the age of 13-14 years.

### **Concerns of the network**

# Women living with HIV/AIDS

**Issues and Concerns** 

Positive Women Network

# Some points of concern

- Stigma and discrimination.
- Violence.
- · Livelihood and property.
- · Security.
- · Health care.
- · Information.
- Support systems.
- Negotiating capacity.

### Lack of access to information

- On factors to be considered in modes of transmission.
- On their Reproductive Rights
- On Treatment and Care
- On MTCT preventive and follow up information

# Stigma and Discrimination

- Family
  - Post HIV Unbearable, Brutal In Laws
  - Painful humiliating- Natal homes
  - Driven to destitution
- Property issues
  - Denial of right to property from natal home and from spouses
  - Short life span of women with HIV/AIDS, as an argument to deny property rights

# Stigma and Discrimination

- Insurance Denial of Claims
  - To widows
  - Once HIV status of widows is known
- Community Reluctance
  - To rent property
  - To allow use of community property
  - To perform last rites

# Stigma and Discrimination

- Health Care Settings
  - No pre test or post test counseling
  - Judgmental, insensitive counseling, leading women to end their life
  - False test results of women affect woman's life
  - Lack of sensitivity amongst doctors. Affected women asked to treat themselves in hospital settings
  - Admission only to STD departments regardless of ailment
  - Treatment trials without informed consent
  - Abusive language by health care providers
  - Abortion as a solution to pregnancy for HIV/AIDS affected women

## Stigma and Discrimination

- Health Care Settings
  - Encouragement of Siddha trials has led to proliferation of quacks. Consequent side effects that affect women.
  - Media and Government support for these trials have complicated advocacy and action efforts.

# **Work Place Settings**

- Sexual Abuse at Work Place.
- Women projected as public face of HIV by NGOs without their consent.
- HIV status of women revealed at public meetings/ gatherings by "experts" working in the field.
- Misconceptions about mode of transmission even amongst professionals leads to discrimination.

### **Health Care**

- My husband and I are HIV positive. We have two small children. I am very sick, have been suffering from abdominal pain for quite sometime now. I am unable to do anything no house work, taking care of my children etc. My husband has to be with me constantly as there is no one else to look after me. As a result, his work is also suffering. I got admitted to the Government hospital, Chennai. I was admitted in the STD department. I have been there for the past 4 -5 weeks now. I still do not know what is wrong with me. My pain has reduced only a little bit, but there seems to be no solution in sight. I complained to the network representative about this....
- ...They enquired into the problem and revealed the following:
  - Doctor: I am unable to do anything in this situation. She does not suffer from an STD problem. I suspect a gastro-intestinal problem, but as that department is unwilling to treat her, I am helpless. I am not qualified to treat her. But because she has no place to go, I have kept her here and am giving her pain medication. I have spoken to the other department, but I don't think anything will happen. Even if I transfer her there she will just be lying there. What do you want me to do? (Shalini, 2002, Chennai name changed)
  - She was later transferred to the TB sanatorium even though she did not have TB

### **Health Care**

• When I go to a private eye care centre for regular check ups, I am asked by the staff there, to put eye drops in my eyes by myself. I don't have anybody accompanying me. How is it possible for me to do this myself? The staff puts drops in other people's eyes. Only when it comes to HIV positive people there is a problem. As I am referred to the centre, by a reputed health care centre treating PLWA, because getting appointments would be simpler, my status is revealed. But the treatment meted out by the lower level staff in the eye care centre is very discriminatory...

 I have spoken to the doctor about this, and he promised to take care. But he would not know what is happening four floors below where he sits. Another reason given for this, is to prevent any infection from spreading from the health care worker putting the drops to the PLWA. This is supposed to be protecting the PLWA. (Sujata, 2002, Chennai, name changed)

### **Health Care**

I am HIV positive. I was pregnant. I was tested for HIV without my knowledge at a private hospital where I normally go. When I tested positive, I was told to go to a Government hospital, and was refused treatment in the private hospital. I had not received any pre or post test counseling. When I went to the Government hospital, I was told to undergo an abortion, as it would be better for my child and myself. But I was very clear that I wanted a child. I then chanced upon a very good private care centre where I received proper counseling due to which I was able to take a decision...

...I now have a healthy nine month old baby. Because
I received help at the correct time I was able to save
myself and my child. This situation is widespread in
our country. If women receive proper information and
guidance, they would be able to lead positive lives. I
hope other women receive such happiness. (Radha,
2001, Chennai name changed)

### Family & Community Discrimination

• My husband who died of HIV, was put on a thatched mat and taken to the cremation ground. At the cremation ground, the funeral pyre was ready, but nobody was willing to touch the body and lift him from the mat to the pyre. It was a horrible situation, which nobody should ever face. Because there were two friends of my husband who were truly affected by the death of my husband, present at the ground, my husband's body was lifted and he was cremated. Whatever I am telling you now is from hearsay. I was not even allowed to see my husband's body by my in- laws. People think HIV can be spread by air and touch. Only if such misconceptions are cleared, will there be any improvement in the situation. Most of the women in our network face a similar problem. (Lata, 2002, Chennai, name changed)

### **Legal Rights**

• My husband and I are positive. I don't live with my husband any more. I am separated though not divorced. I have approached the courts many times seeking some kind of maintenance and divorce from my husband. The court has granted judgments in my favour many times, but to no avail. To escape from paying maintenance, my husband wants to get back to me. But I am not willing. I still remember the day when tired and hungry, with my new born baby, my husband had taken me to my co- sister's place, and made me wait outside... • ...He went in and never came back for about six to seven hours. After that, my co -sister came out and told me to vacate the place. When I refused, my co -sister took me by my hair and pushed me out on to the road. I was forcibly taken to my mother's house by my husband's brother and co - sister and left there. I want my freedom. At the same time, I will demand what is due to me. I am willing to go to any court to achieve this. Only if women rise to such problems and deal confidently, will we gain whatever is due to us. (Lakshmi, 2002, Chennai name changed)

### Legal Rights

I am positive. My husband is negative. My husband cannot work as he is handicapped. I have a one year old child. But I am unable to provide good nutrition to my baby. I was the second wife. My husband's first wife could not have children, so I was married to him. I got HIV through blood transfusion. When my HIV status became known, I was discriminated very badly by my in -laws. Women take care of their husbands, irrespective of whatever happens. Why is this not applicable to men also? (Sita, 2003, Chennai, name changed)

### **Building a human rights framework**

### Vesting placing HIV/AIDS within the human rights discourse

The recognition of the integral link between human rights and the growing concern of HIV/AIDS, clearly emerged within the health discourse of the 1980's.¹ By the end of the 80s, there was an amplified debate to embody within responses to HIV/AIDS, the protection of the human rights of people living with HIV/AIDS.² This mandated that issues, such as testing, access to health care facilities and confidentiality, be located within a human rights framework. Increasingly, the protection and promotion of human rights has been emphasised as the vital link to mitigate the impact of HIV/AIDS. Integrating the paradigm of human rights, into emerging developmental concerns, led to the focus on the linkage between vulnerability and HIV/AIDS. This has further necessitated a shift in government and inter-governmental strategies, calling for greater programmatic responses and, consequently, increased accountability to human rights standards.

### Emerging gender concerns—An overview

The decade of the 1960's witnessed globally the emergence of a new feminist consciousness and the realisation that women have been historically discriminated and marginalised by a patriarchal social ethos and polity. In the wake of this realisation, there "was concern that the general human rights regime was not working as well" as it needs to in order "to protect and promote the

<sup>1.</sup> Since the formation of the Global Programme on AIDS under the World Health Organisation, in 1986, public policy responses to HIV/AIDS, have urged governments to ensure the rights of people living with HIV/AIDS. World Health organisation, World Health Assembly, Avoidance of discrimination against HIV infected persons and persons with AIDS, 1988.

<sup>2.</sup> World Health Organisation, World Health Organisation resolution WHO 40.26, Global Strategy for the prevention and control of AIDS, Geneva, WHO, 1987.

rights of women".<sup>3</sup> Commenting on the conventional human rights framework, in the chapter on the short history of the Convention, the CEDAW document states that although the Committee on Status of Women (CSW) ensured that the instruments such as the International Bill of Human Rights were adequately expanded to include guarantees of non-discrimination from a gender perspective, much of this effort reflected an approach that was "fragmentary" in approach. The Convention on the Elimination of Discrimination against Women emerged in response to this felt need.

Meanwhile, in the Indian context, since the mid-1970s, the adverse impact of growth and development on vulnerable sections such as women became quite evident and even compelling. The Government of India responded in many ways. For instance, by the mid-1980s, the government set up an exclusive governmental focal point such as the Department of Women and Child Development. In the 1990s, they it not only ratified the Convention (1993), but also expanded the Constitutional provisions to provide affirmative actions for women, in the form of the 73<sup>rd</sup> and 74<sup>th</sup> Amendments.

### Gender rights and HIV/AIDS

The strong focus on human rights has underscored its importance as a factor in determining people's vulnerability to HIV, risk of acquiring infection and in accessing adequate care and support.<sup>5</sup> The inter-relationship between human rights and HIV/AIDS, which is revealed often in the neglect, denial and violation of rights, however manifests differently in the way that it applies to men and women. The rights of those at risk are often largely affected by and, in turn, influence the violations of other fundamental rights. In today's context, when an increasing number of people being affected by HIV/AIDS are women and girls;

<sup>3.</sup> The International Bill of Human Rights, which includes the Universal Declaration of Human Rights (1946), International Covenant on Economic, Social and Cultural Rights and International Covenant on Civil and Political Rights (1966), sets forth the principles of gender equality in a legally binding manner.

<sup>4.</sup> The Commission on the Status of Women attempted to elaborate the guarantees of equality through the creation of many related Conventions – Convention on the Political Rights of Women (1952), Convention on the Nationality of Marriade Women (1957), and Convention on Consent to Marriage, Minimum Age for Marriage and Registration of Marriages (1962).

<sup>5.</sup> Human Rights and HIV/AIDS, April 2002. Daniel Tarantola, Harvard School of Public Health.

discrimination against women, their lack of social and economic influence, drastically decreases the degree of agency women have over their bodies and in decision-making. On the other hand, this increases women's risk of violence and vulnerability, both within the private and the public sphere.

### **Vulnerability**

Vulnerability is understood as a limitation of the extent to which women are capable of making and effecting free and informed decisions. Within the context of HIV/AIDS, it translates as the lack of power on her part to regulate or minimise the risk of exposure to HIV. Within a population regarded as generally vulnerable, women may be more vulnerable than the others in the population.

"Vulnerability can be considered on three inter-dependent levels: personal, programmatic and societal". The personal vulnerability focuses on a woman's development or the environment that makes her vulnerable. These range from physical and mental development, knowledge and awareness, behavioural characteristics, life skills and social relations. Programmatic vulnerability, emphasises on the impact of programmes towards reducing or decreasing a woman's personal vulnerability, addressing issues ranging from information on education, health, social services and human rights programmes.

Finally, the societal vulnerabilities study the factors that "define and constrain personal and programmatic vulnerability." It refers to the broader context of women's lives, including the political situation, culture, tradition, gender relations, attitude towards sexuality, religious beliefs and poverty. Consequently, greater vulnerability is likely to lead to greater involvement in risk-causing and risk-taking behaviours. Appreciating vulnerability builds on the risk- factors approach and locates the context in which individual experiences are located. Within the context of gender related vulnerability, it helps us to understand these factors and the manner in which they operate to limit and deny a woman's capacity to negotiate her rights.

Moreover, understanding these vulnerabilities also provides an appreciation of the circumstantial challenges posed by poverty, lack of choice, lack of legal capacity and so on for women. Here, the women's lives are further negatively impacted by denials at both the individual level and the lack of

<sup>6.</sup> AIDS in the World, J Mann, D Tarantola. Cambridge, MA: Harvard University Press, 1992.

Lack of information on reproductive health, sexuality.

Lack of access to information on HIV/AIDS and sexuality.

Lack of personal skills - ability to negotiate safe sex.

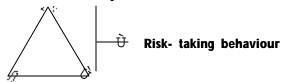
Lack of self-confidence.

Low level of self-esteem.

Lack of perception of personal risk.

Lack of access to education

### Individual vulnerability



### Socio - cultural vulnerability

Early marriage
Sexual coercion
Lack of social support
Attitudes towards sexuality
Lack of choice
Religious beliefs
Poverty

### Programme related vulnerability 7

Lack of adequate health services for basic and reproductive health concerns

Lack of information on family planning practices, STDs/RTIs including HIV/AIDS

Absence of health services to cater to adolescents concerns

Neglect to incorporate awareness of how gender inequalities contribute to spread of HIV

programmatic responses on the part of the State. Coalescing, these susceptibilities into a rights framework creates a responsibility to prevent the direct violation of rights and of creating enabling conditions for the realisation of these rights.

#### Relevance of CEDAW

CEDAW makes a departure from other Conventions and extensively delineates the various forms of discrimination that occur. The Convention is premised on the notion that despite various instruments having been mandated under the United Nations, they have been unsuccessful in redressing the continuing discriminations against women. CEDAW recognises discrimination as any "distinction, exclusion

<sup>7.</sup> Source :Gruskin S, Tarantola D. HIV/AIDS, health and human rights. In: Lamptey P, Gayle H, Mane P, eds. HIV/AIDS prevention and care programs in resource – constrained settings: A handbook for the design and management of programs, Arlington, VA

**Article 4:** States should take measures to ensure that de facto equality achieved between men and women. Special measures to protect the function of maternity is not a discrimination.

**Article 5:** States should to take measures to ensure "proper understanding of maternity as a social function" and shared responsibility for the upbringing of children.

**Article 10(a),10(h):** State parties to take all necessary steps to eliminate discrimination against women in education, and to provide women equal access to educational materials and advice on family planning.

**Article 11(2):**State parties to undertake appropriate measures to prohibit dismissal of women workers on the grounds of pregnancy, to introduce maternity leave, to promote the development of a network of child care and to provide pregnant women with special protection from work that may be harmful.

**Article 12:** State parties to provide women with appropriate services where necessary during the ante- and post-natal stages of pregnancy.

**Article 12(1):** State parties to eliminate discrimination against women in the area of health care and to ensure that men and women have equal access to health care services, including family planning services.

**Article 16**: State parties to eliminate discrimination against women in all matters regarding marriage and family relations.

form of discrimination against women, which "impairs or nullifies women's enjoyment of their human rights, including their rights to life and to the highest attainable standards of physical and mental health." or restriction made on the basis of sex ... which ... impairs, nullifies ... the human rights and fundamental freedoms in the political, economic, social cultural, civil or any other field."8

Another important factor, which helps to underscore the relevance and importance of CEDAW above other instruments, is its approach to Violence Against Women. CEDAW has been able to centre- stage the debate of women's rights as human rights. successfully bringing violence of the sphere out the family and community, and into the sphere of State accountability. Though violence has not been explicitly included as an article, the General Recommendation on Violence Against Women recognises gender- based violence as a

### General Recommendation 24: Women and Health (1999):

"Access to health care, including reproductive health, is a basic right under [CEDAW]" and is fundamental to women's health and equality. State parties are responsible to "[e]nsure the removal of all barriers to women's access to health services, education and information, including in the area of sexual and reproductive health," and to "[p]rioritize the prevention of unwanted pregnancy through family planning and sex education and reduce maternal mortality rates through safe motherhood services and prenatal assistance."

<sup>8.</sup> Adapted from Article 1, Convention on the Elimination of all forms of Discrimination Against Women.

**Article 7:** State parties to eliminate discrimination against women in political and public life.

**Article &** State parties to ensure to women the opportunity to represent the government at the international level, to participate in international forums.

**Article 9:** State parties to ensure that women have rights to acquire, change or retain their nationality. Neither marriage to an alien nor nationality change by husband should result in change in status of wife.

**Article 5**: State parties to ensure that social and cultural patterns of men and women are modified with a view to achieving the elimination of prejudices, all other practices based on the idea of inferiority or superiority of sexes or on stereotyped roles for men and women.

The General Recommendation presents a clear explanation of the Articles relating to employment, health care, education, family and marriage and the manner in which women are susceptible to violence.

CEDAW provides the strongest international legal support for women's reproductive rights, by explicitly outlining the right to health and family planning. This aspect is a departure from other human rights instruments. Apart from recognising "maternity as a social function", the instrument also requires the State to take special measures to ensure that these rights are adequately promoted and protected, which includes access to information and services, while making decisions on her reproductive choices.

The Convention upholds the civil rights and legal status of women. Included within the purview is the accountability of governments to ensure to women their rights of political participation. Drawing attention to the existing scenario, wherein women's status is often linked to that of their husband's, the Convention seeks to separately establish a woman's identity in so far as her legal identity and citizenship rights are concerned. These concerns are further reinforced by asserting that women are entitled to equal opportunities in employment, education, economic and social activities.

Another key area, which makes the CEDAW far more relevant in terms of a rights- based approach, is the formal recognition given to the influences of culture, tradition as constraining factors in women's achievement of their fundamental rights. Recognising the critical role of stereotypes and customs in shaping the legal, political, economic barriers that impede the progress of women, CEDAW stresses on the need to change stereotyped notions of the role of men and women in society and within the family, in order to reduce and eliminate discrimination.

Health Care: Articles 24, 25 of Child Rights Convention, Articles 14, 15, 21 of the Indian Constitution - Individuals of State Party nations have the right to be provided with the necessary health care information and infrastructure to enable them to achieve acceptable standards of physical and mental health.

It also includes the right to be provided with drugs to treat opportunistic infection, relieve associated pain and suffering and includes providing individuals with anti- retrovirals. These rights include treatment of sexually transmitted infections, providing male and female condoms, voluntary counselling and testing.

**Article 14, 15, and 21 of the Indian Constitution** – provide HIV/AIDS affected individuals access to basic pain prophylaxis and medicines for treatment of sexually transmitted infections and treatments.

Article 14 - States shall not deny to any person equality before the law or the equal protection of laws in India on grounds other than those considered constitutionally valid.

Article 21 of the Indian Constitution, Article 16 of Child Rights Convention. The right to privacy is ingrained within Article 21, which underscores a citizens' right to life. State parties are required to ensure that counselling and testing are voluntary, and any testing to ascertain HIV status is kept confidential. This includes the right to non -disclosure to third parties.

### The right to be free from cruel, inhuman or degrading treatment /punishment.

Articles 15 (discrimination), 21 (life), 23 (trafficking/prostitution) of the Indian Constitution, Sections 114A(custodial rape), 498A (cruelty) of the Indian Penal Code, Dowry Prevention Act of India, Sati Prevention Act of India.

The Constitution of India embodies many of these issues. Issues of access to treatment and care, violence, information and education, equality in employment, etc. can be read either directly or implicitly from the Articles. The Indian judiciary has also, over the years, played a guiding role into reading these issues into the Constitutional provisions.

### **Table of respondents and stakeholders**

### **Informant Interviews**

### Civil Society Organisations

- 1. Vasanthi, Perambalore Rural Welfare Scheme NGO, Perambalore
- 2. Ms. Usha (*name changed*), Woman receiving economic assistance from schemes, Perambalore
- 3. World Vision, Perambalore
- 4. Ms. Chandana Thangaval, Principal, Vellala college, Erode
- 5. Father Ebeneizer, Churches of South India, Chennai
- 6. Ms. Usha, President, WADS NGO for sex workers, Chennai
- 7. Mr. Abraham, State Management Agency, Trivandrum
- 8. Ms. Jasmine, Janneeti, Trichur
- 9. Ms. Sanghmitra Iyengar, Director, Samraksha, Bangalore
- 10. Merlyn Martis, Director, Deeds, Mangalore
- 11. Ms. Jaishree Ramakrishnan, Department of Health Education, National Institute of Mental Health and Neurological Sciences, Bangalore
- 12. Ms. Anya Saini, Medical Officer, Asha Kirana, Mysore
- 13. Mr. Janardhan, Project Officer, Basic Needs India, Bangalore
- 14. Ms. Gauri, Advocate, Deeds, Mangalore
- 15. Mr. Arvind Narayanan, Alternate Law Forum, Bangalore
- 16. Ms. Sophia Pais, Population Services International, Mangalore
- 17. Ms. Sapna Ravindran, Project Manager, PSI, Mangalore
- 18. Mr. Sathyendra Prakash, Project Officer, Cardts, Mangalore

### **Doctors**

- 19. Dr. Kandiappan, VCTC in-charge, Perambalore
- 20. Deputy Superintendent, Ghosh Hospital, VCTC in charge, Chennai
- 21. Dr. Sreelekha, Amrita Hospital, Ernakulam
- 22. Dr. Ajay Kumar, General Hospital, Ernakulam
- Dr. Criton, Trichur medical hospital, Trichur
- 24. Dr. K.B Mohan, Trichur

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- 25. Dr. John, Kasturba Gandhi Medical College, Mangalore
- 26. Dr. E Sunder Moorthi, Siddha Practitioner, Bangalore
- 27. Dr. Sateesh, Cardiologist, Specialist HIV/AIDS, Bangalore
- 28. Dr. Y Laxman, Superintendent, TB Hospital, Mysore
- 29. Dr. Janet, Social Worker, Kidwai cancer hospital, Bangalore
- 30. Dr. Suniti Solomon, YRG Care, Chennai.
- 31. Dr. Mahadevan, Asst. Surgeon, General Hospital, Coimbatore

#### Nurse

- 32. Ms. Lizzy, Nurse, General Hospital, Trivandrum
- 33. Ms. Rekha, Nurse, KMC Mangalore

#### Counsellor

- 34. Ms. Manju Mathew, General Hospital, Counsellor, Ernakulam
- 35. Ms. G. Saroja, Counsellor, KR Hospital, Mysore
- 36. Ms. Poonam Kamal, Counsellor, Mysore

### Administration

- 37. Mr. Rajesh Lakhani, District Collector, Perambalore.
- 38. Project Officer, Women Development Corporation, Perambalore
- 39. District Collector, Namakkal

### Elected representative

- 40. P. Devamani, Panchayat Vice President, Perambalore
- 41. Panchayat President, Perambalore
- 42. Mr. Thenrse, MLA, Erode
- 43. Dr. Mallaka Reddy, Formel Health Minister, Bangalore

### Individual

- 44. Mr. HM Girish, Science Teacher, Mysore
- 45. Ms. Vani Venkatraman, Social Worker, Mysore
- 46. Lawyer, Erode
- 47. Ms. Nirmala Laxman, Media, Chennai

- 48. Mr. Gokul Dass, Activist, Trichur
- 49. Mr. Ramanand Rao, Homeopath, Bangalore
- 50. Bank Official implementing economic scheme, Perambalore

### State AIDS Control Officials

- 51. Consultant, TANSACS, Chennai
- 52. Mr. Deenabandhu, Project Director, TANSACS, Chennai
- 53. Mr. Hari Kumar, NGO advisor, KSACS, Trivandrum
- 54. Mr. Gunavardhan, Project Director, KSACS, Trivandrum
- 55. Ms. Vandana Gurnani, Project Director KSAPS, Bangalore

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