

## ActionAid International India

ActionAid International India is part of ActionAid International, an international development agency that is working in 43 countries to fight poverty and injustice.

ActionAid India was setup in 1972 and currently works through 14 Regional Offices with the Country Office based in Delhi. In the three decades of our work in India, we have formed partnerships with nearly 400 NGOs and Community Based Organizations (CBO) and has reached out to more than 5 million of the poorest and most marginalised people in their fight for human rights and citizenship rights.

In our work on HIV and AIDS we take sides with the poorest, most stigmatized and excluded people including people living with HIV & AIDS, sex workers, sexuality minorities, migrants, women, children and other vulnerable communities. We strive to uphold three interlinking rights: The Right to Dignity, The Right to Self Determination and The Right to Comprehensive Care.

**Our Vision:** A world without poverty and injustice, and in which every woman, man and girl and boy enjoys the right to life with dignity.

**Our Mission:** To work with poor and excluded women, men and girls and boys to eradicate poverty, discrimination and injustice.

### Our Values:

- ♦ *Solidarity with the poor, powerless and excluded people* will be at the core of our struggle against poverty and injustice
- ♦ *Courage of conviction*, requiring us to be creative and progressive, bold and innovative – without fear of failure – in pursuit of making the greatest possible impact on the causes of poverty, exclusion and injustice
- ♦ *Equality and justice*, requiring us to work to ensure equal opportunity to every person, irrespective of caste, class, race, age, gender, sexual orientation, colour, class, ethnicity, disability, location, and religion
- ♦ *Humility* and modesty in our conduct and behaviour, recognizing that we are part of a wider alliance against poverty and exclusion
- ♦ *Mutual respect*, requiring us to recognise the innate worth of every individual and peoples and the value of diversity
- ♦ *Uphold highest levels of honesty and transparency*, being accountable at all levels for the effectiveness of our actions and open in our judgments and communications with others.
- ♦ *Independence and neutrality* from any religious or party-political affiliation.

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# ACCESS TO TREATMENT

## A DISTANT DREAM

**Women Living with HIV and AIDS  
Demand Accountability from  
Civil Society and World Leaders**

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## ACCESS TO TREATMENT A DISTANT DREAM

### Acknowledgements

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### THEME HIV & AIDS

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# ACCESS TO TREATMENT A DISTANT DREAM

## Women Living with HIV and AIDS in India Demand Accountability from World Leaders and Civil Society

*"We in India have over 38 percent of women infected, which is much, much more than what it was a few years ago. I hear very disturbing stories about women and how the discrimination and stigma hurts them much, much more. Women are far more vulnerable than an HIV-infected man. Families would sell their assets, their land, their goats or sheep, whatever they had to provide medical treatment, for example, to the man. But when it is his wife who is infected, or she is widowed, she is often thrown out of the house or left without any security".*

Sujatha Rao, Director General, National AIDS Control Organisation in her 5th May 2006 speech at the Asia Society, New York.

India, like many other countries in the world, has shown a disturbing trend of feminization of the epidemic with an estimated 2.18 million women living with HIV & AIDS. The latest reports by the United Nations joint program on AIDS (UNAIDS) states that with 5.7 million HIV infections, the

country has overtaken South Africa to become the world's largest population affected by the epidemic. Women living with HIV in India belong to the reproductive age group. ActionAid International India's engagements with PLHA in different states in India shows that the majority of women living with HIV are mostly single women, widowed, deserted, engaged in domestic work, vending, daily waged agricultural/construction work, sex work, etc. They are uneducated, unskilled and engaged in occupations which belong to the unorganized sector. Evidence also shows that women in monogamous relationships and engaged only in house chores are also placed at risk for infection from their husbands. In India 60% of women marry before the age of 18 years. Their self-perception of HIV risk and awareness of HIV and AIDS is often low. Most learn of their status either when they are pregnant or when their spouse is seriously ill or has died of AIDS.

Indian women face a unique set of problems in a patriarchal society where they are expected to be

the 'givers' of every kind but rarely seen and heard in the true sense and certainly not valued. As women they have inequitable access to resources but have added disadvantages depending on the caste they are born to, livelihood options they choose and the perceived status of health in relation to HIV and AIDS. Consequently they are denied all human rights and basic constitutional rights.

In May- June 2006, world leaders at the UN High-Level Meeting on AIDS reconfirmed their commitment to Universal Access to Treatment. "[We commit] to pursue all necessary efforts to scale up nationally driven, sustainable and comprehensive responses to achieve broad multi-sectoral coverage for prevention, treatment, care and support, with full and active participation of people living with HIV, vulnerable groups, most affected communities, civil society and the private sector, towards the goal of universal access to comprehensive prevention programmes, treatment, care and support by 2010".

The leaders also agreed "set in 2006, through inclusive, transparent processes, ambitious national targets, including interim targets for 2008 ... that reflect ... the urgent need to scale up significantly towards the goal of universal access to comprehensive prevention programmes, treatment, care and support by 2010".

This booklet is an attempt to look at the core issues of women living with HIV and AIDS in India, particularly in the context of Access to Treatment. The voices of women are collected and narrated by positive women themselves. We hope that these lived-in experiences of women will prick the conscience of world leaders and civil society leaders who have the power and authority to make a difference in the lives of millions of women and urge all to wake up to realities and "Deliver" their commitments. These are the voices of Death, Desperation and Struggle!

## VIOLATION OF RIGHTS IN THE PRIVATE SPHERE

In India, the patriarchal institutions of family and religion are at the root of stigmatisation of women living with HIV. Women have scarce access and control over resources and fewer choices in making decisions about their lives and bodies. This is imbibed as a value reinforced by the patriarchal institutions of family and religion in the form of culture. In a patriarchal society, women are burdened with 'upholding moral values' and the association between HIV and sex seems to justify the stigma faced by every positive woman. Family, society and religion, has moulded the mindsets of people looking at HIV & AIDS from a narrow moralistic perspective leading to stigmatisation of all women with HIV. Discrimination becomes an extension of stigmatisation and irrational fear within and outside the home. Families and communities look at positive women as moral outcasts who deserve to suffer and fear that if they live, they will be a risk to others.

Violence against women thus is a way of life for most women living with HIV. Violence manifests in a variety of ways- physical, mental and verbal, forcing many to commit suicide to escape the harassment and torture. Many women have gone

on record saying that if they did not take their own lives, it was only because their children would then be bereft of all support. For those who put up a fight, it is still a life of slow death.

### Abandonment by Families

*"The minute my husband died, my parents-in-law started accusing me of having had pre-marital and extra-marital relationships and transmitting the disease to their son. My mother in law refused to give me food, hurled abuses and threatened to push me out of the house, making me feel I must not exist. Even my parents started neglecting me and I felt orphaned. I fell in love with my husband, married him and cared for him till he died. Isn't there any justice? Why are women allowed to suffer? Who will help us if the family and our own communities abandon us. Can't the Government bring in a law to stop violence against women?"*

Jhansi, a young woman from Chitoor in Andhra Pradesh is traumatized by the injustice. There are many women like Jhansi abandoned by families.

***“Going to a hospital for treatment is such a humiliating experience. I have to prepare myself not to break down and cry. Are we not like other ill people who get respect and attention in a hospital?”***

**Women living with HIV in Bangalore**



### ***Girl Child Cast-away by Callous Father***

*“Particularly heartbreaking is the story of my 11 year old foster-daughter Mukta who has been abandoned by her own father. While he remarried after her mother’s death and went on to have other children, neglected by her father, she was forced to do all the work at home and mercilessly beaten up by her step-mother. She came to us pitifully malnourished, sick and vomiting worms! One of us had to take her into our home and care for her and I volunteered”. Chandrika who is now a caring mother to two positive children and is also a peer counselor at MILANA, a family support network for PLHA.*

### ***Desertion by Husband***

*“When I was 20 years old, I met my husband who was working as a mechanic and got married. We were very happy after the birth of our son. In 2003, I started getting fever and cough and lost appetite and weight. My condition deteriorated day by day. I was admitted to G.T. Hospital, Mumbai, where I was diagnosed with TB. The doctor asked for a HIV test and I tested Positive. My husband was informed and was also tested but did not disclose his test result to me. After that I have not seen him again. I came to know later that he had sold all our belongings and left the house. My sister then took me to her house. My in-laws also told me not to call their son, and that they were happy their son had returned home. By then I knew it was because of my HIV status that my husband was not ready to accept me. The next piece of news I received was that his family had got him married to a girl within their own community. This news shattered me. I did not have any support. I do not know how I and my child can carry on? What is the law in this country for abandonment? Whom should I turn to?”*  
Sunita, Mumbai

### ***Denial of Property Rights***

*“I was married at 18 and my husband took pride in talking about his various affairs with other women. I bore his torture even when he burnt me with cigarettes and nursed him on his death bed. Forget about getting support from my in laws, they threw me out of the house when he died. When I decided to fight for my property rights, his Lawyer told me, ‘Why do you need property? You are anyway going to die’...”*  
Cheated by her in laws, Vaishali had to seek support from the Gujarat State Network for PLHA to continue living and fighting for her rights.

*“I am married with two sons. Life became very difficult in my matrimonial home in Banavasi after my husband died of AIDS. I was also HIV positive. My in-laws made me suffer every day and then forced me out the house. I came to Sagar with my sons, without any job or savings and decided to fight for my share of my late husband’s property. As per documents, the house inhabited by my in-laws was in my husband’s name. I gave an application in March 2003 to the Banavasi Grama Panchayat asking for the property to be transferred in the name of my sons and this was agreed. Since this property was in my husband’s name I filed a case with the Deputy Commissioner, Karwar, Uttara Kannada. The Court gave the judgment in March 2004 that I was the rightful owner of the property. Despite the judgment, I was not allowed to inhabit the house and two years have passed. My in-laws have again filed a case at civil court, Sirasi, asking to be named the sole owners of the property and asking me to reimburse all their court expenditure. Will I ever get justice?”*  
Jayalakshmi, Shimoga district, Karnataka

For many women, abandonment leads to a life on the streets, a life dependent on larger families to strangers where they are forced into sex and sex work and sometimes willingly for a livelihood and for access to treatment. The lack of legislations and personal laws by religions that can protect women from abandonment and violence makes

life difficult for these women. India has very recently passed the Domestic Violence Act but its implementation is weak since accessing courts with evidence requires energy and resources, which most women do not have. Hence, access to treatment should include policies to address issues of stigma and discrimination at the familial level.

## **VIOLATION OF RIGHTS IN THE PUBLIC SPHERE**

Discrimination is the act of exclusion of women based on perceived notions. In the public sphere too, women continue to face different forms of violence and discrimination almost from everybody. Many a time, it is the protectors of law and order and civil society leadership, particularly health care providers, which deny women the access to treatment and life. In extreme cases, women have reported community attempts to murder them.

### **BY LOCAL LEADERSHIP**

#### ***Honour Killing by Village Panchayat?***

*“In my village, a person who is HIV positive is simply taken away to the hills and killed after a ‘kangaroo court’ decision by the local leaders. I got to know from other women in the community that they had planned to shoot me in the hills. I was scared but coughed up courage and met the person who had thought out this idea and challenged him. All the women in my Dalitwada (lower caste hamlet) offered great support. It was the men who stoned me, both literally and figuratively. Even if the police are informed, they too remain mute spectators and do not take any action,”* says Bhavani from Ammapalyam village near Srikalahasti in Andhra Pradesh. Bhavani is an exception because she had the courage and support to confront the diktats of village panchayats. She asks *“Are they local leaders or local goons? There is a need to sensitise village Panchayat heads and take strong action against leaders and people who take law into their own hands. How can the police be made more accountable?”*

This is in spite of the UNAIDS International Guidelines on HIV&AIDS and Human Rights adopted in 1996. Article 21 of the Constitution of India protects right to life and right to health of people. Yet, why are these killings not considered as crimes and action not taken?

### **BY HEALTH CARE PROVIDERS**

AIDS related discrimination arises out of fear, ignorance of routes of transmission, pre-existing discrimination against certain groups, social and religious disapproval of certain behaviors, life styles and groups. However, levels of knowledge on HIV&AIDS do not always correlate with discriminatory attitudes. AIDS related discrimination and violation of rights can coexist with high level factual knowledge. For example, in India, a large number of health professionals discriminate against people living with HIV&AIDS, despite having higher levels of knowledge on HIV&AIDS when compared with the general population. From direct discrimination to proactive discrimination women face all forms of discrimination at health care settings. Perhaps the most painful of all discrimination faced by people living with HIV & AIDS is when the doctors they turn to for help turn them away into the jaws of death. *“Uneducated people in our families may have irrational fear but if doctors and health care professionals stigmatise us, where else can we go for treatment?”* asks Sushma, a young mother from Bangalore. Innumerable testimonies echo the same anguish that people have faced in hospitals.



**“Where you find violence-whether it is physical, psychological or sexual, there will be AIDS”.**

Violeta Ross, ICW, Bolivia

### **Neglect and Death in the Hospital**

“Married to a contractor, we have a 7 year old daughter. When I was six months pregnant, I visited the Lady Hardinge Hospital with a complaint of severe pain. The doctors had my blood tested without my knowledge and declared me HIV positive. “There’s nothing we can do for you,” they told me and I had to leave the hospital and also lost my baby. During my next pregnancy, I went to the LNJP hospital where I was asked to wait for two hours in the labour room. Then I was taken to the operation theatre. I was shocked when my still-born baby was packed in a box and polythene bag and handed over to me. Later shifted to the general ward, I remained unattended to by a doctor or nurse for almost three hours. Other hospital staff told me “When you know you are positive, why must you think of getting pregnant?” I was not even given water to drink. They looked upon me as an outcast. I left the ward to come home”.

Kanta, age 30, Delhi

### **Denial of Surgical Health Care in Hospitals**

“I was to be operated in a private hospital for a gland disorder and was tested for HIV during a pre-surgical medical test. On hearing, I have HIV, the surgeon told me outright that they could not attend to me because it is risky and that the hospital did not have facilities. My world crashed on my face. I locked myself up and cried for weeks. My family members’ plea to start treatment even after a deposit of Rs.10, 000 fell on deaf ears”.

Meherina, widow and mother of 12 year old positive girl child, Bangalore

### **Ignorance of Doctors leads to Early Death!**

“After the death of my school-teacher husband in Delhi, I got tested for HIV and started my treatment at a Delhi clinic. I was put on ART medication right from the beginning. With great difficulty me and my son survived by working as laborers or house assistants at various places over the next few years. In 1998, my son and I came to Canning hoping to stay with my in-laws. However my in-laws blamed me for the death my husband and refused to allow us to stay with the family. I then got free ART from the local hospital. But my comfort was short lived. Due to co-infection with TB, the doctor stopped giving me any ART for 7 months while I was put on Anti-TB medication. As a result my condition is deteriorating day by day”.

Parbati Majumdar of South 24 Paraganas. She died on 5th May 2006.

### **Discrimination by Nurses and even NGO Heads**

“I had started to become very weak. My uncle, the Director of a Dimapur based NGO was visiting my village along with his staff. He took me to Dimapur saying that he will help me to get treated and employ me. I was taken to the Government Civil Hospital, Dimapur and the NGO staff motivated me to go for HIV testing. On testing positive in 2004, the attitude of my uncle’s family towards me changed a great deal. The next time I fell sick, the way the nurses treated me was very different and their non-verbal language clearly told me that I was not wanted in the hospital. They gave instructions from afar and visited me only once a day while other patients were visited more than twice a day. After three days of

mental torture, I came out of the hospital. I continued working on voluntary basis with my uncle waiting to get employed but he gave a lame excuse and let me down. I returned to my village and had no other option but to start selling vegetables. The income just cannot support my family of three children”.

Lengbe, educated woman in Dimapur

If it is not deliberate discrimination at hospitals, other factors like poor diagnostic facilities, lack of medicines for treatment of Opportunistic Infections (OI), absence of simple equipment like gloves and other disposables needed to adopt universal precautions and even shortage of trained care givers, denies people living with HIV and AIDS treatment access.

### **BY STATE**

The International Human Rights Framework states that all people have a human right to a standard of living adequate for health and wellbeing, to food, clothing, housing, medical care and social services, civil and political freedoms. But people living in poverty are without health services, food, adequate shelter, security, voice, and so on. By definition poverty is a human rights violation. People living in poverty are actively denied human rights. Despite their best efforts, the world around them works against their freeing themselves from poverty.

### **Poverty- A Human Rights Violation in Itself**

“I come from a poor family where my father was working as a daily wage earner. Due to poverty neither my sisters nor I could ever go to school. When I was 18 years old, my parents got me married to a man who was working as a coolie. I used to pick rags with which I earned a meager amount. We soon had two sons. In 2003, I started falling ill repeatedly and the doctor in local hospital asked me to get a blood test called HIV test. The test showed I had a serious illness I knew nothing about. My husband and my in-laws blamed me for getting this illness and drove me out of the house. I was shelter less, helpless; I didn’t know what

to do. I was on the streets with my sons. I still stay on the footpath struggling with my illness and have to beg to feed my children. In this meager amount, how can I manage medication costs?”

Surekha, Pune

### **Lack of Access to Livelihood by State**

“I work as a maid, wash dishes and clothes and earn around Rs.500 per month (10USD). I am HIV positive. My husband was detected HIV positive in 2001 and passed away in July 2004. My son is now only 5 years old. I stay with my parents and my monthly expense is around Rs.2000/-(40USD). I have no means to educate my child, have no ration card under the Public Distribution System. I have not been able to access any schemes or benefits from the Government. Why do poor people here have to suffer so much? When will the Government think about us and our children; my son, who will become an orphan soon?”

Juli Bibi, North 24 Paraganas, West Bengal

Unless issues of poverty are addressed by the State and related provisions are implemented, the number of women living with HIV will continue to increase.

### **BY MEDIA AND CORPORATES**

The print and television media in India has a wide reach and can contribute towards advocacy efforts to improve access to treatment. However, irresponsible reporting has often made things worse for people living with HIV and once again, women are paying a heavier price. Coming to the corporate sector, while the Confederation of Indian Industries (CII) talks about Corporate Social Responsibility (CSR) in the fight against AIDS, deep rooted bias exists within business houses particularly since workplace policies are largely absent.

### **Fictitious Media Reports**

Insensitive reporting has only served to heighten stigma against people and many prefer not to access treatment to escape being labeled by media. Ganga, a young woman who earns a livelihood

***“To ensure equitable access to prevention and treatment services for women and girls, it is important for countries to set their own national targets. The targets must match the proportion of men, women and children who are living with HIV and in need of treatment”.***

**Dr Lee Jong-Wook, Director General, WHO**



through sex work paid a very heavy price after an irresponsible investigative journalist put her picture in a local paper and labeled her ‘sex worker is AIDS patient’. Ganga tried to burn herself to death to escape from the stigma she feared but was saved in the nick of time. With extensive skin burns, she refused to go to hospital and hid herself in her mother’s home in Shimoga district of Karnataka. *“I am not even HIV positive but who will believe me when the newspaper has reported lies?”* she asks.

### **Corporate Bias**

The corporate sector in India is not far behind in perpetuating stigma and discrimination. In the capital city of Delhi, 24-year old Seema was asked to leave the I-T company she was working in because her employers found out that she was HIV-positive. *“People in the canteen just stopped talking to me. They would not eat with me. Then they told me in office that I should not come in any more,”* Seema recalls. Since the last three years, she is struggling to

support herself and her HIV-positive husband by working in an NGO.

Seema’s is not a one-off case. A recent study by the National Council for Applied Economic Research and United Nations Development Programme reveals a horrific picture. While 29 per cent of people living with HIV and AIDS have been refused loan facilities, 30 per cent have been denied promotions and 16 per cent were forced to quit their jobs. These findings come at a time when a draft Bill called the HIV-AIDS Bill 2005 is waiting for a green signal from the Union Health Ministry. The Bill, expected to be tabled in the monsoon session of Parliament, will be looking at discrimination against people living with HIV and AIDS at the work place. *“Discrimination which flows from stigma is rampant both in the public sector and mostly in the private sector. Now in order to tackle discrimination in the private sector, you have to have a law and there is no such law,”* says Anand Grover from the Lawyers Collective, an NGO working on legal issues related to HIV & AIDS.

## **GAPS IN POLICY AND IMPLEMENTATION**

### **POORLY CONCEIVED AWARENESS PROGRAMMES**

Contributing to the stigma and discrimination in the private and public sphere is the way facts about HIV and AIDS are presented by Governments in poorly conceived awareness programs where HIV is synonymous with AIDS- ‘a dreaded incurable disease where prevention is the only answer.’ Government programs called the National AIDS Control Program (NACP) II and the forthcoming NACP III are focused on prevention with targeted interventions (TI) being the mainstay of programs. A majority of NGOs and CBOs have been roped in by large donor agencies for TI, mostly through

programs with female sex workers who are considered ‘high-risk’ groups. The reality is that female sex workers form less than 2% of the women living with HIV & AIDS in India. The TI programmes have a very high focus on condom usage. Awareness programmes are organised without taking into consideration the cultural contexts and the ability of women to negotiate.

### **Lack of Information Despite Awareness Programmes**

*“After my father’s death, mother could not send me to school and made me work with a lady who runs a local wine shop. It was this*

*lady who introduced me to selling sex and I was initially happy because I was earning more money. As I was not educated, I did not have any knowledge about safe sex nor of what will be the outcome of unprotected sex. I became pregnant and my mother and I came to know about my pregnancy after many months. With fear and anxiety, she sent me to stay with some relatives till the birth of my child. At the government hospital, I was tested and found HIV positive. I wish I had known how to protect myself”.*

Lily, 18 year old single mother from Dimapur, Nagaland

## **LOPSIDED PLANNING AND LOW PRIORITY TO CARE AND SUPPORT**

India is spending \$300 million on the current National AIDS Control Programme, and has taken a World Bank loan of \$191 million. The Global Fund has pledged a grant of \$107 Million to India to fight HIV, malaria and tuberculosis. The Bill and Melinda Gates Foundation has pledged 464 crore rupees to control HIV transmission in the six high prevalence states through targeted interventions.

Yet, today few programs on the ground address the needs of vulnerable women and girls even as Ante Natal Clinic (ANC) prevalence continues to rise in most states. Positive living is much less spoken about and care and support programs and facilities are in acute short supply. Statistics in India reveal how little is being done to uphold people’s right to health. According to the WHO, roughly 7,10,000 PLHA are in need of ART treatment immediately and only a lucky few actually get the life saving drugs. Experts opine that lack of will and not lack of medicines is responsible for this denial. *“Indian pharmaceutical companies are global exporters of low cost generic ARV drugs to over 200 countries. Their supply is not a problem,”* says Dr. Alka Gogte, a counsellor with UNAIDS. *“The problem is the slack delivery systems not reaching out to people,”* she believes. Others say that dismal infrastructure of public hospitals across the country is creating logistical problems in setting up testing labs and in training doctors and counsellors for the programme.

In 2004 the government committed itself to providing free treatment for 1,00,000 people living with HIV by the end of 2005. Only 32,977 people in India are on treatment in both Global Fund and Non-Global Fund supported states even 16 months after the target date and the majority of them are men. According to the data available, only 10,608 women and 3,259 children have access to treatment in National AIDS Control Organization (NACO) supported ART centres as against 19,110 men at the end of June 2006. There is no data available on access to treatment for opportunistic infections but PLHA report an acute shortage of diagnostic facilities and medicines for OIs at government health centers. CD4 testing facilities are woefully inadequate and each test costs upwards of Rs.500 even for the poor who receive ART from the Government. Fewer than 4 per cent of pregnant positive women in the country are receiving testing and counseling and just 2.74 per cent have received the antiretroviral prophylaxis in Prevention of Parent to Child Transmission (PPTCT) centers, as against the promised 20 per cent. According to the 2005 United Nations General Assembly Special Session (UNGASS) India Report released by NACO, of the estimated 1,89,000 HIV infected pregnant women, only 4,500 women actually received the Nevirapine dose given to protect newborns from their mothers infection! This translates into an estimated 56,706 HIV infected babies born in one year.

Official reports say that fifty-four ART centres are currently operational as on April 30, 2006 in India. In a country with 27 large states and 3 union territories, this small number is almost an embarrassment. Forty six new Anti Retroviral Treatment centres have been announced this year to meet the increasing demand. In these total 100 centres, an estimated 85,320 patients may get free treatment during the current financial year. The revised target for 2006 is still well short of the initial target of 1,00,000 people on ART by 2005 and a long way from the promised ‘Universal Access by 2010’.

### **No ART Centres in States**

*“There are no ART centers in my entire state of Madhya Pradesh. I have to leave my children with someone else and spend a lot of money to travel long distances to access my monthly supply of medicines in Varanasi situated in the neighbouring state of Uttar Pradesh. I travel 6 hours each way by bus from my home, wait long hours for my turn at the ART centre and return late at night or*



***“If we want to get ahead of the epidemic we must put women at the heart of the AIDS response.”***

**Peter Piot, Director, UNAIDS**

*the next day. Each time I come back, I feel so exhausted and unwell. Besides, I can't afford even the travel costs which is about Rs.350/ for much longer. Soon I may have to just give up and pray”.*

Ramola, 32 year old mother and widow

### ***Moving Back and Forth between States for Treatment***

*“After my husband's death in Chennai, I had to return to my maternal home in Chittoor. When I started falling ill, I had to return to Chennai where my in laws cold shouldered me. At the Tambaram Hospital, an ELISA test confirmed that I was HIV positive and I was treated for opportunistic infections. With no home open to me, I went back to Chittoor and for two months continued taking the tablets prescribed in Tambaram. I had to again return to Chennai as my health deteriorated further and this time I was given ARV drugs because my CD4 count was very low. How long can I move back and forth all alone? Will I never get treatment in Chittoor?”*

Bhuwaneshwary, widow supporting her 14 year old daughter

### **THE PATENT HURDLE IN TREATMENT ACCESS**

Another major area of concern for PLHA currently on first-line free ART is continued access to treatment needed life long. Former NACO Director Dr. Quraishi also evokes concern about the rapid growth of resistance for first-line regimens and the unavailability of second-line ARV drugs to counter them. *“I am extremely worried about this. The Patents Act prevents generic production of second-line ARV. They are nearly 21 times costlier than first-line ARV”.* Despite provisions available within TRIPS, not

enough is being done by the government to counter the patent regime for people to have access to life saving new drugs.

### **FAILING PUBLIC HEALTH SYSTEM IN INDIA**

Driven by the policies of the International Monetary Fund (IMF), India has made drastic cuts on the already inadequate national health budget. According to the Human Development Report-2005, India spends 1.3% of its GDP on public health. The private health sector however is rapidly growing, receiving an expenditure of 4.8% of GDP. The result, the primary health care system, the sole health facility available to much of the rural poor is in shambles. Many Primary Health Centers (PHCs) are non-functional, with inadequate facilities, medicine and trained health professionals. Consequently, less than 20% of the Indian population utilizes public health facilities (India Development Report 2004-05). The public health infrastructure in the country is in shambles with no doctors and medicines.

### **GEOGRAPHICAL VARIABLES IGNORED**

India is a vast country with diverse issues and regional variations. The strategies that may seem to be working in the South do not help in the North East where armed conflict, drug trade and lack of economic development make interventions difficult. Moreover, the HIV situation is complicated by an overlap of sexual transmission and Injecting Drug Use. This has resulted in a disturbing increase of HIV prevalence among women attending Ante Natal Clinics in the Northeastern states of Arunachal Pradesh, Manipur, Nagaland, and Tripura.

Even within a region or state, pockets of very high prevalence districts co-exist with less affected districts where the epidemic may have been controlled.

In Tamil Nadu for example, ANC prevalence in the state has declined from 1.13% in 2001 to 0.5% in 2005 but in many districts and pockets within, it continues to be much higher than the national average of 0.88%. The need is for district level disaggregated data, particularly on women and children, for planning interventions and improving access.

Other geographical and cultural issues that need to be considered in framing policy and strategy include poverty and migration, trafficking and sex work, the state of public health infrastructure, blood safety and many other variables. For instance, migration from states like Bihar and Orissa is very high and many workers in Gujarat's 'Diamond City', Surat are migrants. But migrants who are HIV positive are not given ART in the government centre at Ahmedabad because they are not from Gujarat! Are the health needs of migrants the responsibility of

the state of origin or state of destination? While bureaucrats debate people are dying! Also, a woman who has been put on government ART in Hubli cannot get her monthly supply of medicine in Bangalore's ART centre. Even though she is ill and admitted to a care home in the city, she will have to travel over 400 kilometers to Hubli to collect her medicines if she wants to live!

Poor standards of blood safety continue to cause concern in many states like Assam, UP, Manipur and even Kerala, where children of negative parents have tested HIV positive after blood transfusions in hospitals.

Keeping all these factors in mind, National AIDS Control Policies need to consider having regional policies instead of one national policy.

### **THE FIGHT FOR SURVIVAL**

In supporting women and their children in their courageous fight for survival, all factors that affect access to treatment need to be understood and debated in order to try and set right the wrongs that prevent equitable access to women. When we talk about access to treatment, it is not just ART but also treatment for OIs, Prophylaxis for PPTCT, nutrition, counseling, health seeking behaviour, livelihood support and related services that is within their right to health.

### ***Positive Peoples Networks and NGOs are Showing the Way***

Small organisations and positive peoples networks have fought for survival and in the bargain battled the infection that threatens their lives and that of their children. It has been an uphill task with the odds stacked against them. From uncaring families to stigmatizing societies and worse still, poor government policies and a callous administration that does not have the will to implement what has been committed to its people. Their fight has been supported by AIDS activists and organizations and the government has slowly begun to respond.

Nitu is one such courageous young woman at Positive Peoples Foundation (PPF) a small organization in Mumbai. She says, *“When all doors were shut in my face, I heard about an*

*organization that supports positive people. My mother and I went to Positive Peoples Foundation (PPF) and for the first time I got to see a different face of HIV & AIDS. I came to know about my infection and also my right to health care. It was there that I came to know that I could save my child from being HIV positive. Accessing treatment in the nearby municipal hospital was not easy. When I went to see the doctor, along with the PPF counselor the doctor again stated the various reasons like lack of gloves and medicines, absence of suitable instruments etc due to which they were unable to get the delivery done. Even though PPF counselor informed the doctor that government hospitals couldn't deny treating a HIV positive person according to the National HIV and AIDS policy, the doctor refused to register me. So we approached the Medical Superintendent who heard us and accepted the fact that they could not deny treatment. She also saw to it that I was registered and given medicine under PPTCT (Preventing Parent to Child Transmission). Finally I delivered a baby boy in that hospital.”*

Not every woman fighting for survival gets the care and support which is her fundamental right. It is the duty and responsibility of International agencies and every government to deliver on the promises made to its people. They have the mandate and the resources to support women through policies and legislation and ensure their implementation for equity and justice, in access to information, treatment and care in the face of HIV & AIDS.

***“We demand governments listen and respond to civil society, especially women’s groups and women living with HIV and AIDS, in setting of goals and priorities, design, planning, implementation and evaluation of HIV and AIDS policies and programs. Women’s rights are not negotiable. The time to act is NOW.”***

**Women’s Groups demanding action and accountability during UNGASS Review, 2006**



## CALL FOR URGENT ACTION

While people friendly policy and legislation is the responsibility of the State, People Living with HIV and AIDS must be meaningfully involved in all decision making in the fight against HIV & AIDS. A top-down approach will not work and Community Based Programs and solutions are the way forward.

### ***To Stop Feminization of the HIV & AIDS Epidemic, Guarantee Human Rights***

- Adopt a Human Rights Approach!
  - ❖ Involve women living with HIV while framing policies
  - ❖ Policies and legislations for special protection of women living with HIV and their children, particularly against stigma and discrimination
  - ❖ Review and take action against States which do not honour the International Guidelines on HIV and AIDS and Human Rights
- STOP Violence Against Women!
  - ❖ Implement laws which protect women living with HIV and AIDS from violence
  - ❖ Regulatory policies and guidelines should ensure women access rights
  - ❖ Action against Health Care professionals who violate the health rights of women
  - ❖ Penalisation for violation of women’s rights
- Equal Access to Treatment NOW!
  - ❖ Provide access to voluntary testing and counselling
  - ❖ Treatment access at the Primary Health Centre level
  - ❖ Anti Retro Virals and medicines for Opportunistic Infections
  - ❖ Mothers to be given high priority in ART
  - ❖ Prevention of Parent to Child Transmission to be made accessible to all women
  - ❖ Sexual and reproductive health services
- Right to Information our Need!
  - ❖ Ensure access to relevant information to improve prevention services
  - ❖ Information to reach women for access to care and services
- Value Women who are Care-givers!
  - ❖ The burden of caring for the sick falls on women, young or old. Equip them with the information and resources they need
  - ❖ Adopt comprehensive policies taking into consideration women’s needs for Livelihood, Employment, Nutrition, Pension, Shelters, Care Homes

## WOMEN DEMAND ACTION AND ACCOUNTABILITY NOW!

### ***Response from Women’s Groups to the negotiations on the Political Declaration for the UNGASS Review, June 2006***

**We are outraged** that critical women’s rights issues that are central to the goal of halting this pandemic—such as the right to health and the right to live free of sexual coercion and violence, universal access to sexual and reproductive health services and education, and protection of sexual and reproductive rights of women and girls—are still up for negotiation.

**We are appalled** that governments are still reluctant to commit to targets and resources and to take responsibility to comprehensively protect and promote women’s rights, the lack of which fuels the pandemic.

**We demand that governments urgently commit to implement, resource and monitor the following actions:**

- ▶ Intensify efforts to increase the capacity of women and adolescent girls to protect themselves from the risk of HIV-infection including by creating and committing adequate resources to an enabling environment for the empowerment of women;
- ▶ Protect and promote women’s and girls’ full enjoyment of all human rights including their rights to have control and decide freely on all matters related to their sexuality, including their sexual and reproductive health, free of coercion, discrimination and violence, ensuring access to comprehensive health care and health services, including male and female condoms; and invest in the fast-track development of female controlled prevention methods and microbicides.
- ▶ Ensure full access to comprehensive information and education, including sexuality education
- ▶ Strengthen women’s economic independence; and reiterate the importance of the role of men and boys in achieving gender equality.
- ▶ Commit to strengthening legal, policy, administrative and other measures for the prevention and elimination of all forms of violence against women and girls, including harmful traditional practices, abuse, early and forced marriage, rape, including marital rape and other forms of sexual violence against women is addressed as an integral part of the national and international HIV and AIDS response; and providing post-exposure prophylaxis to women survivors of violence.

Governments must fully guarantee that HIV prevention, treatment, care and services are provided to all vulnerable populations, including women and girls (especially in situations of conflicts and emergencies), active injecting drug users, children, men who have sex with men, transgender, youth, sex workers, prisoners and migrant populations; and recognize and address the ways in which the pandemic is racialised as well as gendered across the globe.

Finally, we demand governments listen and respond to civil society, especially women’s groups and women living with HIV and AIDS, in setting of goals and priorities, the determination of funding streams and program guidance, design, planning, implementation and evaluation of HIV and AIDS policies and programs.

**Women’s rights are not negotiable! Don’t miss another opportunity!**

**The time to act is NOW**