NACO in denial about realities of ARV access in India

Focus on second line ARV access in India / Un point sur la situation de l'accès aux ARV de seconde ligne en Inde /

- VIH/Sida - Accès aux ARV et aux soins -

5 décembre 2006 - By Richard Stern and Eugene Schiff, Agua Buena Human Rights Association

Author's Note : Comments from readers are welcome, and the authors would like to thank many of those in India who shared information and contributed to this report. We would welcome further opportunities to meet and communicate with organizations interested in the issues raised here (see contact info below or call +91 986856 9206). In spite of many calls to the Indian National AIDS Control Organization (NACO) to reach the Director, Mrs. S. Rao, and other officials, NACO staff have thus far been unwilling to set up an appointment for an interview to discuss the issues mentioned below.)

On the eve of World AIDS Day, NACO, the government run National AIDS Program of India, continues to neglect and deny the basic human rights of people living with HIV/AIDS in India. The following are key issues the Indian government must urgently address in order to improve access to treatment for Indian PLWA. Indian Government Denies PLWA Access to Second Line Medicines Estimated 450,000 Lack Treatment yet NACO says : "There is no waiting list"Indian Government's Charge for CD4 test is Deadly and InhumaneMillions of Dollars Available from GFATM for HIV/AIDS Treatment : Where is the Money ?

1) Indian Government Denies PLWA access to Second Line Medicines. India is one of the only developing countries in the world still not providing at least some second line AIDS medicines (or rescue therapy) to people who need them. The government has thus far refused to purchase these medicines for the National AIDS Program, despite the fact that India, unlike almost any other country in the world, has a robust local generic production capacity and Indian generic pharmaceutical companies that are already producing most second line antiretroviral drugs in India at this time.

Currently NACO offers PLWA only five medications in the public sector : AZT, 3TC, D4T, Neverapine, and Efavirenz. Of the estimated 40,000 people on antiretrovirals some receive triomune - a combination of d4T, 3TC, and Nevirapine, while others receive Duovir + Efavirenz, or some combinations of these five drugs. Of those currently receiving first line treatment in the public sector, an estimated 3,000-5,000 people in India are now urgently in need of second line medications, but NACO has failed to supply these drugs to PLWA, some of whom have been forced into poverty trying to purchase these medicines themselves, while others have already died or are near death because they simply cannot afford the private sector prices of second line medicines that the Indian government does not provide.

Doctors at various public hospitals in New Delhi confirmed they have no access to protease inhibitors, an important and powerful class of antiretroviral drugs. Physicians lack many of the antiretrovirals that are used as second line medications, rescue therapy, or even as first line drugs in other countries. For example, many medicines that are available in other countries even poorer than India (with no local production capacity), such as the drugs Ritonavir, Lopinavir, Tenofovir, Indinavir, Abacavir, Emtricitabine, Atazanavir, Nelfinavir, Fosemprenavir, Didanosine, and others are totally unavailable in the public sector in India. Generic versions of most of these drugs are already sold by various local drug companies in India including Ranbaxy, CIPLA, and Emcure. There are currently no restrictions on the sale of generic versions of most of these medications due to patent issues.

NACO, and others who defend the government policy claim that if second line treatment is offered, the government of India would be unable to afford to purchase enough medicines or increase the number of additional people on first line treatment. This argument presents an unacceptable choice that negates the needs of people living with AIDS in India. It is incredible that the Indian government, and international agencies and donors including the WHO, DFID, USAID, the Bill and Melinda Gates Foundation, UNAIDS, the World Bank, the Clinton HIV/AIDS Initiative, and others have either accepted or not done more to effectively address this issue and influence drug policy to favor greater treatment access in India. The current situation violates all the basic principals of human rights and best practices

promoted in donor countries and by the same international agencies in terms of the right to lifesaving ARV access. Even other lower middle income countries, such as Honduras, Guatemala, El Salvador, the Dominican Republic, Thailand, Rwanda, Botswana, and South Africa are currently providing at least some second line ARVs and often paying drug prices much higher than those available for the same drugs in India.

It is both inhumane and unethical for the government to provide only first line treatment to people living with HIV/AIDS. When drug resistance develops for a small percentage now and in the future, sometimes two or three years after starting on first line ARVs, even though alternative rescue therapy is being produced in India and sitting on the shelves of private pharmacies, the physicians and government essentially tell poor people with HIV : "we are sorry, you have resistance to your ARVs, if you cannot afford to pay for costlier second line medicines yourselves there is nothing we can do for you."

2) Estimated 450,000 lack treatment yet NACO says : "there is no waiting list". The failure of NACO to recognize the realities of the epidemic in India are further illustrated is their statement that there are no waiting lists in major ARV centers around the country. However, UNAIDS estimates 100,000 people died of AIDS in 2005. Current estimates indicate that 500,000 people now need ARV access in India, but only that only 40,000 have access in the public sector. In developing countries, at least 20% of people in the advanced stages of AIDS will die each year of opportunistic infections without antiretroviral treatment. Mortality statistics for AIDS in India are scarce. What data does exist is probably unreliable underestimates, because many people die of AIDS before even reaching an ARV center, or perish without ever even being tested for HIV. Many of these people are not only living in rural areas, but also in huge urban slums in major Indian cities where ARV roll-out is available.

NACO and the Indian government still appear to be in denial and lagging in their efforts and responsibility to expand the healthcare infrastructure. The health system must reach out to the poorest and most marginalized people affected by the AIDS epidemic, so that they can receive free HIV testing in their first contact with a health care provider, if they are showing possible symptoms of HIV, or as routine screening for pregnant women and people with tuberculosis.

However, according to physicians, even in Delhi's hospitals, only some, not all TB patients are offered HIV tests. For antenatal screening, perhaps as many as half of all pregnant women in India do not give birth in hospitals or clinics but instead outside of the public health sector and often through midwives, and are thus never tested for HIV, particularly in rural areas and among the poor, who in both cases represent the vast majority of Indian women. There also are reports of poorly trained health care workers with little knowledge and high levels of stigma about HIV/AIDS.

Some are encouraged that NACO recently placed an ad in local newspapers announcing the availability of ARVs. However, even these steps fail to take into account that many people living in poverty may be unable to afford newspapers, or even illiterate, and unable to read in either English or Hindi, yet they also deserve and have the same right to health care, HIV/AIDS testing and antiretroviral treatment if needed.

In one of the largest public hospitals in New Delhi, staff indicated that only two full time AIDS counselors must respond to the needs of 1,500 HIV+ people. Such staff shortages present real obstacles to providing adequate information about adherence, stigma, discrimination and many other issues. In the same hospital just two doctors must also attend to the needs of the same 1,500 people.

3) Indian Government's Charge for CD4 Test is Deadly and Inhumane : Current Policy does not reflect a commitment to supporting poor people living with AIDS.

The Indian Government's charge (250 rupees, about $6 USD) for baseline CD4 tests is a deadly and incongruent

barrier to lifesaving treatment access for millions of poor HIV positive people in India. As result of pressure from activists and PLWA, the government has apparently revised its policy and reduced the fee for CD4 tests from 500 to 250 Rupees in recent months, but these halfway incremental approaches are still woefully inadequate for a country with the resources, large impoverished population and an HIV/AIDS epidemic with the size and characteristics of India.

The CD4 test is an important tool for doctors and sometimes prequisite, but often a barrier for PLWA to begin antiretroviral treatment. The government must recognize the disproportionately harmful and pernicious effects of these user fees on those who are sick and poor and unable to get antiretroviral treatment because they cannot afford to pay for the first CD4 test. In a report this week published in The Tribune of India (Nov. 23, 2006), one Punjab woman living with HIV describes the effects of the fee charged for CD4 tests :

"The HIV test was conducted free. But to get further tests done, I will have to pay for travel. I also have to deposit Rs 250 each for all three of us to get registered for treatment. For me the choice is between feeding my children for a month or two or to get the tests done. With no source of income, I give the tests a go-by"

The government must eliminate this policy immediately, offering free, government subsidized CD4 tests, to stimulate the immediate scaling up AIDS treatment access in the public sector.

4) Millions Of Dollars Available from GFATM for HIV/AIDS Treatment - Where is the Money ? Meanwhile, more than $500 million US dollars (2250 crore rupees) in Global Fund grants have been approved for India, yet according to information provided by the Global Fund only $55 million dollars has been disbursed as of this date. Alarmingly few seem to be aware of the existence of the Global Fund project and the purpose of these funds.

Several GFATM projects in India were "restructured" because of the poor performance of the Country Coordinating Mechanism (CCM) and Principal Recipients (PR), and phase one disbursements were delayed and even reduced due to the inability of the CCM and PR to act rapidly.

Incredible as it may seem, although $77 million US (346.5 crore rupees) was approved in June of 2004 in a round four project specifically "for the purchase of anti-retroviral medications" only $2,972,000 has been disbursed as of this writing. This project would have would have provided more than enough money to cover the costs of treating 40,000 people with first line medicines (which cost $5.8 Million USD in 2005, according to one report), and also place thousands of PLWA on second line medicines, even at the high prices currently charged by Indian generic companies for these medications.

Embarrassingly for a country with as many PLWA needing antiretroviral medicines as India, the project was restructured because of previous delays so that only $22 million was approved for the first two years of the grant. This fourth round grant agreement was signed in August 2005, and since then this amount has been available. Yet NACO still claims there is no money left to save the lives of those currently needing second line treatment.

As difficult as it may be to maneuver through the Geneva-based GFATM and Indian bureaucracies, why have NACO and the Indian government not been utilizing the money from these multi-millionaire dollar grants as quickly as possible and requesting further disbursements ?

Why is the Country Coordinating Mechanism (CCM) allowing this to occur when they are fully aware of the scale up problems currently occurring in India, not only with regard to second line medications, but also for the 450,000 PLWA who still need but lack first line medicines ?

What are the current priorities of the Indian Government to PLWA ? Why is NACO also now considering the implementation of a sliding scale payment scheme for ARVs, further penalizing the Indians with HIV/AIDS who already confront severe poverty, when millions of dollars and hundreds of millions of rupees are sitting in banks in Geneva, Delhi and Mumbai ? Why is there no second line treatment in India ?? Why is NACO so inaccessible and secretive about its budget and the availability of these funds ?

While the Ministry of the Economy apparently places "ceilings" or limits on the amount of funds that can be committed to AIDS in India, based on NACO's own budget requests, that money from the Global Fund is exempt from these limits.

Now, India has a $259 million grant tentatively approved by the GFATM for round six, exclusively for up scaling ARV access. This enormous sum could be made available as soon as some additional information is sent to Geneva to the Technical Review Panel. Why isn't the CCM meeting more frequently to speed up the approval and disbursement process for this grant, including eligibility of two of the three Principal Recipients, followed by signing of the contract. Incredibly, we were told that the CCM is currently meeting only once every two months. The last CCM meetings minutes posted on the India GFATM CCM website are from July 28th, 2006 - four months ago.

During each two months between CCM meetings, about 20,000 PLWA die of AIDS in India, and 75,000 more Indians need antiretroviral medicines.

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