

**Text of the speech by Anand Grover<sup>1</sup> at the International Conference on HIV/AIDS, Toronto, 14 August 2006**

**I thank the International AIDS Society and the local hosts and other organizers of this Conference for giving me the opportunity to present the Jonathan Mann Memorial Lecture in this plenary session of the Conference. Indeed it was Jonathan Mann, who, more than anybody else, understood the vulnerabilities of sections of society to HIV and how the epidemiology of HIV is partly determined by those vulnerabilities as also the importance of human rights in combating those vulnerabilities and checking the spread of HIV.**

**The fact that over a period of time human rights have come to occupy a key place, not only in the discourse of health and HIV but also in the programs to combat the spread of HIV as also in this Conference is a tribute to his astute analyses. By this presentation I wish to pay homage to his remarkable insights and highlight some of the key issues of human rights which are central not only in the theoretical sense but also in the practical outcomes of formulating strategies to combat the spread of HIV in the coming period.**

#### **HIV—a dynamic equilibrium**

**The first issue that I would like to take up is that of the understanding of the nature of illness generally in the context of rights. This has had a direct impact in HIV related employment law.**

**Historically and classically, the concept of health and ill health has been informed and shaped, like a lot of concepts in western philosophy, by the Cartesian notion of duality. Thus, one is healthy or unhealthy, fit or unfit, in the final stage of AIDS or not in the final stage of AIDS. Human beings generally and more particularly legislators, lawyers, judges and doctors like to fit people into categories. For, once a category is formulated, it is easy to fit a host of persons or entities within it. It does away with the laborious process of individual enquiry so necessary to understand a person's complexities, strengths and weaknesses, whose life, or for that matter, death may be at stake, by what any of these legislators, lawyers, judges or doctors, may decide about the categorization of such a person.**

**But reality, as we know, is not like that.** The diversities of the real world in general, and human beings, in particular, can at the most, be cognized through categories, but not fully comprehended through them, especially the myriad of its particularities.

Thus, can one say that a person with latent TB is fit or unfit. That was the question that arose in the famous case of *Arline*<sup>2</sup> before the Supreme Court of

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<sup>1</sup> Anand Grover is a practicing lawyer in India and the Project Director of the Lawyers Collective HIV/AIDS Unit having its offices in Mumbai, Delhi and Bangalore. He can be contacted at [aidslaw@lawyerscollective.org](mailto:aidslaw@lawyerscollective.org).

the United States (US for short). Or if a person living with HIV/AIDS (PLWHA for short) who has a CD4 count less than 200 and viral load above 100,00 is “an AIDS case” and therefore not fit. That is how the Namibian Labor Court understood fitness or unfitness for the armed forces.<sup>3</sup> Or yet again is a **PLWH with pulmonary TB “an AIDS case” or “not an AIDS case”**. **This particular question is coming up repeatedly in the courts in India, particularly in cases relating to employment of PLWH in the armed forces. The implications of a decision on this issue either way are very serious for the individual concerned.** The armed forces in India, until 2003, labeled any HIV-positive soldier with TB as a case of AIDS.<sup>4</sup> The present policy requires an HIV-positive soldier with TB to be placed in a lower medical category and observed to see if s/he responds to treatment.<sup>5</sup> For if a person is labeled as “an AIDS case” s/he is considered unfit. Contrarily, if the person is not labeled as “an AIDS case” s/he is considered fit. Unfortunately it is not only the armed forces who think like that. The National AIDS Control Organization in India also classifies an HIV-positive person with extensive pulmonary, disseminated, military or extra pulmonary tuberculosis as a case of AIDS.<sup>6</sup> Now we hear that the WHO is considering redefining AIDS in a very similar manner.

**Fortunately, we know from our knowledge of HIV, and for that matter, from other ailments that all living organisms, including human beings, are in a dynamic relationship with their environment. The immune system in human beings plays a critical part in this dynamic interaction with the environment. It is the dynamic equilibrium between the CD4 cells and HIV that partly indicates the state of health of an individual.**

**But despite that there is an insistence on the part of international and national organizations to force dynamic states into fixed categories.** The result is that authorities, who anyway are prone to categorize people, get an opportunity to use such static categories to discriminate against PLWHAs. Unfortunately, courts are likely to uphold such categorizations, which would result in serious violations of human rights of PLWHAs.

**It is thus necessary to abandon the paradigm of fixed categories and move towards dynamic criteria in this behalf so that justice can be truly obtained by PLWHAs.**

### **Opt-out routine testing—a flawed strategy**

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<sup>2</sup> *School Board of Nassau County, Florida, et al v Arline*, 480 U.S. 273 (1987).

<sup>3</sup> *N v Minister of Defence*, LC 24/98, Labour Court of Namibia, 10 May 2000.

<sup>4</sup> “Guidelines for Prevention and Control of HIV Infection in the Armed Forces”, India (1993).

<sup>5</sup> “Guidelines for Management and Prevention of HIV/AIDS Infection in Armed Forces”, India (23 May 2003).

<sup>6</sup> “Clinical Case Definition of AIDS (NACO, India, 1999)” in *Specialist’s Training and Reference Module*, National AIDS Control Organisation, India, available at <http://www.nacoonline.org/publication/9.pdf>

**The next point I want to address is the very important issue of opt-out routine testing.**

**For years testing for HIV has based on the Voluntary Counseling and Testing (VCT) model. From early 2004, Botswana, which is hailed as an ideal, had actively adopted opt-out routine testing in its program. In June 2004, UNAIDS and the WHO recommended the routine offer of testing based on the Botswana model. This model is now being followed in other countries including Kenya, United Kingdom and some places in the United States, in particular San Francisco.<sup>7</sup> The Draft US CDC recommendations too reflect this.<sup>8</sup>**

**The change was heralded not only because of the fundamental change in the treatment scenario of HIV, the success of the triple combination therapy from 1996, but more fundamentally on account of the availability of cheap supply of first line generic ARV drugs, primarily from India.** However, it may be pointed out that some commentators have gone as far as stating that, “Current guidelines restrict the use of routine testing to settings in which antiretroviral therapy is available. We believe that the recommendations should support routine testing wherever basic HIV care and prevention are available.”<sup>9</sup>

**What is the opt-out routine testing model? Basically, nearly all patients are tested for HIV as a routine part of medical visits unless they explicitly refuse. In contrast to the VCT model, there is very little or no emphasis on pre-test counseling. In addition, all patients should receive essential information about HIV and be informed about the right to refuse.<sup>10</sup> Moreover consent is effectively done away with**

**There is quite an active debate on this issue. Let me attempt to summarize its contours.**

**Firstly, it is the case of the proponents of opt-out routine testing that the pre-test counseling model that had been adopted earlier in the HIV epidemic may**

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<sup>7</sup> See “United Kingdom National Guidelines on HIV Testing”, *British Association of Sexual Health and HIV*, June 2006, available at [http://www.bashh.org/guidelines/2006/hiv\\_testing\\_june06.pdf](http://www.bashh.org/guidelines/2006/hiv_testing_june06.pdf); Erin Allday, “City health agencies move to streamline HIV testing San Francisco drops counseling requirement”, *San Francisco Chronicle*, 18 May 2006, available at <http://www.sfgate.com/cgi-bin/article.cgi?f=/c/a/2006/05/18/BAGHTITPRQ1.DTL>.

<sup>8</sup> See “Revised Recommendations for HIV Testing of Adults, Adolescents and Pregnant Women in Health Care Settings” (Draft March 2006), available at [www.hwadvocacy.com/update/newCDCrecomendations.pdf](http://www.hwadvocacy.com/update/newCDCrecomendations.pdf).

<sup>9</sup> See Kevin M. De Cock et al, “Unfinished Business—Expanded HIV Testing in Developing Countries”, *New England Journal of Medicine*, 354;5 (2 February 2006), 440, p. 440, available at [content.nejm.org/cgi/reprint/354/5/440.pdf](http://content.nejm.org/cgi/reprint/354/5/440.pdf).

<sup>10</sup> See Sheri D Weiser et al, “Routine HIV Testing in Botswana; A Population-based Study on Attitudes, Practices and Human Rights Concerns”, *Public Library Of Science Medicine*, July 2006, volume 3, issue 7, 1013, p. 1014, available at [medicine.plosjournals.org/perlserv?request=get-document&doi=10.1371/journal.pmed.0030261](http://medicine.plosjournals.org/perlserv?request=get-document&doi=10.1371/journal.pmed.0030261).

have been valid in the era when there was no treatment available. However, now that treatment is available the pre-test counseling model is redundant. Secondly, in the context of availability of treatment, it is important that people test so that treatment is made available to them. Thirdly, pre-test counseling takes a lot of time and resources that are better utilized for testing. Fourthly, it has only created HIV/AIDS exceptionalism, which has only fuelled the societal stigma around HIV. Finally, as a result, pre-test counseling has dissuaded persons from taking an HIV test or created a barrier or impediment to testing and therefore the very delivery of treatment.

These are all vital issues and no doubt we will have a lot of opportunities to debate these throughout this week. **There is indeed a need for extensive debate on this issue. Therefore let me also add a few points that I think that are important in this very vital debate.**

**Undoubtedly the vast majority of the PLWHAs do not know that they are HIV- positive. It is in their interest to know that they are indeed HIV-positive so that they can protect themselves by taking appropriate treatment and also protect others. Therefore scaling up of testing is of the utmost necessity. There can be no two opinions on this proposition. The real question is how this should be done and whether opt-out routine testing is the best option globally in the circumstances that obtain today or in the near future.**

*ART delivery is not possible throughout the world*

**It is clear that the opt-out routine testing model is conditional on the universal access to treatment. Unfortunately, with all my optimism on all issues, I am apprehensive that universal access will not be a reality in the near future for the vast majority of PLWHAs.**

**At the global level, the 3 by 5 initiative was able to reach only approximately 50% of its target by 2005.**

**In my country, India, where the estimate of PLWHAs in 2006 is nearly 5.2 million in the adult population (15 to 49 years), anywhere from 500,000 to 700,000 require ART. However the Government of India's target is to provide free first line treatment to only 188,000 and that too only by 2010. As yet there is no provision for the second line drugs that will be increasingly required.**

Most of the funding for the provision of ARV drugs comes from the Global Fund. **According to the UN 2006 Report on the Global AIDS Epidemic, the funding gap for Global Fund is US \$6 billion in 2006 and will increase to US \$8.1 billion and 2007.**<sup>11</sup> Huge efforts have to be made to close this gap.

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<sup>11</sup> "Financing the Response to AIDS", Chapter 10, in *2006 Report on the Global AIDS Epidemic*, UNAIDS, 2006, p. 249, available at [http://www.unaids.org/en/HIV\\_data/2006GlobalReport/default.asp](http://www.unaids.org/en/HIV_data/2006GlobalReport/default.asp).

**What this means is that ARV treatment may not be available to a vast majority of the PLWHAs. In that case the opt out routine testing is not really a practical option at all.**

*The principles of consent need to be protected and promoted*

**My other concern with opt-out routine testing is the fact that it does away with consent, which is a precious human right.**

The law in common law countries, (i.e. English speaking and the erstwhile British Commonwealth), is quite clear. **As the US Supreme Court judge, Justice Cardozo, put it in his classic statement, “Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation on his patient without his patient’s consent commits an assault, for which he is liable in damages.”**<sup>12</sup> This proposition has been accepted in common law jurisdictions that have held that every person’s body is inviolate.<sup>13</sup> The exceptions are limited to emergencies, persons who are not conferred the legal capacity to consent (who are not of “sound mind” and those who are minors in law) when the doctrine of necessity may come to the rescue of the health care provider. In *JWB and SMB*’s case, **Justice Brennan of the High Court of Australia pointed out that international human rights instruments also adopt the same principles.** On that basis, he held that human dignity required the protection of the physical integrity of a human being.<sup>14</sup>

**The necessity of taking consent not restricted only to treatment. It also applies to diagnostic testing. Significantly it has been held by the House of Lords in England that, “there is no doubt that a person of full age and capacity cannot be ordered to undergo a blood test against his will.”**<sup>15</sup> The House of Lords added a warning, which is relevant for our purposes and said, **“The real reason is that English law goes to great lengths to protect a person of full age and capacity from interference with his personal liberty. We have too often seen freedom disappear in other countries not only by coups d’etat but by gradual erosion, and often it is the first step that counts. So it would be unwise to make even minor concessions.”**<sup>16</sup>

As Justice Brennan, in the case of *JWB and SMB*,<sup>17</sup> pointed out, such principles are now adopted in international humanitarian law. **Do we need to sacrifice such**

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<sup>12</sup> *Schloendorff v Society of New York Hospital*, 211 NY 125, pp. 129–130 (1914).

<sup>13</sup> In England: *Sidaway v Governors of Bethlem Royal Hospital*, [1985] AC 871, *St. George’s Healthcare NST v S*, [1998] 3 All ER 673 (CA); In Canada: *Reibl v Hughes*, [1980] 2 S.C.R. 880 : (1980) 114 DLR (3d) 1, *Mallet v Shulman*, (1990) 67 DLR (4th) 321 (Ont CA); In Australia: *Secretary, Department of Health v JWB and SMB*, [1992] HCA 15 : (1992) 66 ALJR 300.

<sup>14</sup> *ibid.*

<sup>15</sup> *S v S*, [1970] 3 All ER 107.

<sup>16</sup> *ibid.*

<sup>17</sup> *JWB and SMB supra* note 13.

**important principles adopted by domestic and international law for scaling up HIV testing? I would respectfully submit that such principles cannot be sacrificed easily.** At the minimum there must be compelling reasons to do so. Are scaling up of treatment and the Botswana model compelling enough reasons? That is the key question.

The doctor-patient relationship is inherently unequal for reasons of knowledge, skill that the doctor possesses and trust reposed by the patient in the doctor. Necessary information is given to the patient to enable her/him to give consent. The skill that the doctor possesses and the trust reposed by the patient remains intact though modified. However, knowledge is imparted. The information assists the patient to make a decision.<sup>18</sup> Though consent has been well rooted in the common law tradition, informed consent is of recent origin. Most jurisdictions now accept that consent means informed consent and it implies at least informing the patient about the benefits, risks and alternatives. From *Canterbury v Spence*<sup>19</sup> in the US, it has traversed through *Riebl v Hughes*<sup>20</sup> in Canada, and to an extent accepted in *Pearce v United Bristol Healthcare Trust NHS*.<sup>21</sup> The trend is clear. Even outside HIV the trend has been to adopt informed consent principles.

**While in developed countries informed consent is well-rooted not only in the law but also in practice, more particularly in the health care setting, that is not the case in most developing countries.**

In India for instance, as is the case with a lot of the erstwhile Commonwealth countries, the principles of consent developed in the common law of England are readily followed by judicial authorities. However, these principles are not strongly rooted at the field level in the health care set up. **Thus, for example, consent is a formality in case of admission to a hospital and surgical interventions in India. Consent is not really voluntary. Informed consent is not a reality even in major interventions outside HIV.**

It is in this context that HIV came on the legal scene in India and perhaps in a lot of the developing countries. **The HIV epidemic in developing countries, in one sense, provided an opportunity to reaffirm the principles of consent and confidentiality in the legal sphere and try to firmly root them in the health care set up.** Most of our advocacy efforts in the last ten years have been to promote and protect these principles in the health care system. I would say that we have achieved some measure of success. However, given that these require a change in the mind-set of the health care provider, who is most interested in getting a job done, it has been a long haul with a lot of resistance. Ironically one

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<sup>18</sup> See Lawrence Gostin, “The HIV Infected Health Care Professional: Public Policy, Discrimination, and Patient Safety”, (1990) 18 (4) *Law, Medicine and Health Care*, 303–10.

<sup>19</sup> 464 F.2d 772 (DC Cir. 1972).

<sup>20</sup> *Reibl supra* note 13.

<sup>21</sup> [1998] EWCA Civ 865 (20 May 1998) : (1998) 48 BMLR 118 (CA) (basing the doctor’s obligation to inform on the significant risk to the patient).

of the factors that assisted us in the advocacy to reaffirm these basic principles was the lack of treatment for HIV and the enormous stigma associated with it. **We are a long way off from getting these principles accepted at the ground level in practice. In this scenario if opt-out routine testing is recommended globally the clear message for all the medical fraternity in the developing world would be to test all persons without consent, i.e. mandatory testing.**

Even the proponents of opt-out routine testing fear that such a policy may turn out to be coercive. Thus, Kevin De Cock has this to say, “Careful guidance is required, however, to determine how to implement such testing without coercion and how to limit the negative social consequences of a pre-marital diagnosis of HIV infection, especially for young women.”<sup>22</sup> I fear that in most developing countries implementation of the test will be with coercion.

*Botswana cannot be the only model*

**The opt-out routine testing model is largely based on the experience in Botswana. What is the experience there?** According to Alexander Jarvis, in a study of antenatal clinics in Botswana’s second city, Francistown, **it was found an increase in uptake of women testing for HIV from just over 75 percent in the last four months of the VCTC approach to 90.5 percent in the first three months of the new policy of opt-out routine testing.**<sup>23</sup> **But compare that to India and you realize that it is not a great jump.** What are the figures for India? **In 2005, across India nearly 1,134,839 had registered on the PPTCT program. 88.13% of those counseled in the PPTCT program went in for the HIV test.**<sup>24</sup> Another case in point is Uganda where **95% of those who were counseled in home visits agreed to test for HIV. Of these, 88% were first-time testers.**<sup>25</sup> **Therefore Botswana does not appear to be a case that needs to be followed globally.**

*Can we do something about the Counseling?*

**Apart from jettisoning effective consent the other change in opt-out testing is to effectively do away with pre-test counseling.**

**Counseling strategies were developed in the era when treatment was not available to the PLWHA. Pre-test counseling prepared a person not only for the test but also for the consequence of coping with a positive result without any treatment. It could not have possibly prepared one for treatment that became available later. As the treatment situation changed in the HIV**

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<sup>22</sup> De Cock *supra* note 9, p. 441.

<sup>23</sup> Alexandra Zavis, “Botswana adopts new approach to HIV tests”, courtesy *South African Press Association*, 5 January 2006, available at <http://ww4.aegis.org/news/sapa/2006/SA060102.html>.

<sup>24</sup> “UNGASS India Report”, National AIDS Control Organisation, Ministry of Health and Family Welfare, Government of India, New Delhi, 2005, available at [data.unaids.org/pub/Report/2006/2006\\_country\\_progress\\_report\\_india\\_en.pdf](http://data.unaids.org/pub/Report/2006/2006_country_progress_report_india_en.pdf).

<sup>25</sup> See “High discordance rates among Ugandan ART clients new prevention approaches”, *AIDSMAP News*, available at <http://www.aidsmap.com/en/news/0619D2A9-1319-41D6-8515-244E05F2B60F.asp>

**context, both in terms of triple combination being found effective and the drugs becoming affordable and accessible, protocols for counseling, both pre-test and post-test needed to be overhauled drastically. However that does not appear to have been done.**

It is well documented that though the process of counseling was changed over a period of time, the content did not change to include information about availability of treatment even after treatment became available.<sup>26</sup>

What about Botswana? Why were people in Botswana not going in for testing? One would expect that a person informed of the benefits of testing would opt for testing. Undoubtedly, stigma is a factor that dissuades a person from testing. Was not the health care system in Botswana tackling stigma? **What about counseling in Botswana?** Was there a problem in the content of pre-test counseling or in the way that it was administered? **In a report according to Dr. Howard Moffat, medical superintendent at Princess Marina Hospital in the capital, Gaborone, “People who were not sure they wanted to know their HIV status often emerged from counseling determined not to be tested.”<sup>27</sup> He added, “I think the medical profession itself ... played a major role in creating this fear of AIDS and this quite irrational reluctance to be tested.”<sup>28</sup> According to the same report, “Doctors here believe pulling patients aside for special counseling is intimidating and helps fuel the stigma that keeps patients from seeking help.”<sup>29</sup>**

It appears, therefore, that the manner in which counseling was being administered in Botswana raises a lot of concerns. We do not know about the content of counseling. But it appears that it was the pre-test counseling that pushed persons away from testing. **Thus, pre-test counseling which was meant to help PLWHAs to cope with life had become a tool of terror in the hands of the health care providers.** If that be the case, one can hardly come to the conclusion that pre-test counseling in the manner that it is to be actually administered has become an impediment.

**In these circumstances, I would submit that serious issues arise about the content of counseling and the manner that it is to be administered. Certainly it does not warrant a global strategy of testing based on the Botswana model of opt-out routine testing.**

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<sup>26</sup> See Nicholas Sheon, “Theory and Practice of Client Centered Counseling and Testing”, Center for AIDS Prevention Studies, University of California, San Francisco, HIV Insite Knowledge Base Chapter, June 2004, reviewed in January 2006, *available at* <http://hivinsite.ucsf.edu/InSite?page=kb-07-01-04>. See for example, “HIV Counseling and Testing”, *Family Health International*, *available at* <http://www.fhi.org/en/Topics/Voluntary+Counseling+and+Testing+topic+page.htm>.

<sup>27</sup> Alexandra Zavis *supra* note 23.

<sup>28</sup> *ibid.*

<sup>29</sup> *ibid.*

*How do we ensure non-discrimination?*

**All the proponents of opt-out testing articulate that the model should be adopted on the basis of certain guarantees and/or assurances. Kevin De Cock states, “We recommend routine testing for HIV for persons in key occupations, with guarantees of confidentiality, protection against discrimination, free treatment for infected persons, and post-exposure prophylaxis as appropriate.”<sup>30</sup> Edwin Cameron states, “There must be some assurance that the consequence of diagnosis will not be discrimination and ostracism; and the patient should be secure that the testing procedure and its outcome will be treated as confidential.”<sup>31</sup>**

**It is difficult to understand how these guarantees or assurances, especially in the area of stigma would have any meaning in real terms. Unfortunately, it is impossible to control stigma because it operates in silent, secretive and subversive ways. The law only steps in much later, after the event, after the damage has been done. Even then, at best, it compensates the individual in monetary terms but cannot restore the damage that is caused to the psyche of an individual.**

**The real challenge is to control stigma within communities. We should focus our energies on that. What we need is a massive investment in programs to de-stigmatize HIV and make PLWHAs acceptable in society.** With such general awareness, the content of pre-test counseling has to change making an HIV test a positive step to be taken rather than frightening the person away from it. Pre-test counseling is essential not only because it is the only entry point of information for persons who may test negative but also for those who test positive so that messages of safety, treatment availability and adherence are imparted. The more that ART becomes the norm, the more the money and resources that will have to be spent on counseling, even post-test. Pre-test counseling will become a routine part of the counseling continuum.

It is in this context that I would respectfully disagree with Edwin Cameron who, while supporting opt-out routine testing, has made the point that though pre-test and post-test counseling are both useful they should not be carried out at the expense of draining away time and energy of health care personnel whose priority should be diagnosis, testing and treatment.<sup>32</sup> The point is not of pitting one against the other but viewing pre-test counseling as an aid to testing.

### **Vulnerabilities—specific and traditional in HIV**

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<sup>30</sup> De Cock *supra* n. 9, p. 442.

<sup>31</sup> “AIDS: Building on Hope and Reason”, (Speech delivered by Justice Edwin Cameron, Judge, Supreme Court of Appeal at South Africa, Bloemfontein, at Oxford University on 23 June 2006).

<sup>32</sup> *ibid.*

**The next point that I want to touch on is the issue of the vulnerabilities of sections of our societies to HIV. This is the area we have to thank Jonathan Mann most for. It is because of him that we have an understanding that communities that are marginalized by society are vulnerable to HIV. At a theoretical and programmatic level the international community has accepted this thesis of Jonathan Mann to some extent.** Of course, there are some countries that do not accept this, either in theory or practice. However, of the countries that do accept this paradigm, many have even undertaken programs that are contrary to their laws. Thus, for example, India has a program of condom promotion among sex workers in brothels, men having sex with men and injecting drug users. All these condom promotion activities could be deemed illegal under the law.

**However, the understanding of vulnerabilities has been limiting. Communities are identified as vulnerable because policy makers can easily draw the connections between HIV transmission and the vulnerability of such communities. However, other sections that are also marginalized in society on other counts, such as for reasons of race, ethnicity, sex, gender, caste, class, poverty, what I would term the traditionally marginalized sections of society, are not seen as vulnerable to HIV.** Their vulnerabilities are also on account of the inequality, disempowerment, and poverty that they face. **I feel that such issues have not been addressed sufficiently.**

*The Afro-American community in the US*

**Although Afro-Americans constitute 12 to 13% of the population in the US, they account for a more than half of the prison population.** The doubling of the overall number of prisoners in the 1980s and 1990s due to tougher sentencing laws resulted in more than doubling the number of blacks in US prisons over a 14-year span.<sup>33</sup>

**According to a detailed study by Johnson and Raphael shows that, “Roughly one-fifth of black adult males in the U.S. have served time .... and many of these men have cycled in and out of correctional institutions for fairly long periods of their early adult lives.”<sup>34</sup>**

**This, in my opinion, is a scandal of the highest order, in any society, but more so in the US which prides itself on protection of rights of its citizens.** Yet, I am sure that the US is not the only society that has such disproportionate numbers of minority men and women in jail. We need to look into our own societies and see parallels like this.

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<sup>33</sup> See Richard Morin, “Answer to AIDS mystery found behind bars”, *The Washington Post*, 9 March 2006, available at <http://www.washingtonpost.com/wp-dyn/content/article/2006/03/08/AR2006030802201.html>.

<sup>34</sup> Rucker C. Johnson and Steven Raphael, “The Effects of Male Incarceration Dynamics on AIDS Infection Rates among African-American Women and Men”, Goldman School of Public Policy, University of California, Berkeley, July 2005, p. 13, available at [are.berkeley.edu/johnson\\_raphael.pdf](http://are.berkeley.edu/johnson_raphael.pdf).

**Unfortunately, this societal discrimination resulting in putting Afro-Americans into prisons translates into high HIV infection rates, much higher than other communities. They represent nearly half of all new HIV diagnoses in the US.**<sup>35</sup>

That HIV infections in the Afro-American community in the US is the direct result of incarceration is fairly established. This is what Johnson and Raphael conclude:

“Our results reveal that the higher incarceration rates among black males over this period explain a large share of the racial disparity in AIDS infection between black women and women of other racial and ethnic groups. During the decade of the 1990s, the largest component of the growth in the racial disparity in female AIDS infection rates resulted from infection occurring through heterosexual sex (as opposed to intravenous drug use), while homosexually-contracted AIDS was a growing component of the black-white AIDS gap among men. These results taken together suggest that high black male incarceration rates is a principal explanation for the relatively high rate of infection among black women. The strong link between incarceration and AIDS is further evidenced in our findings that the black-white gap in homosexually-contracted AIDS infection rates among males can be fully accounted for by black’s higher incarceration rates.”<sup>36</sup>

**Of course, the glaring question in prisons in the US is the complete inability of prisoners to access condom. “The overwhelming majority of prisons and jails (95 percent) in the United States do not provide condoms to inmates.”**<sup>37</sup>

**President Bush has to be told again that his ABC policy is killing people in the US.**

The US has the advantage that these questions can be looked into thoroughly by competent researchers and money is available for that. Are we, in developing countries, doing that sort of research? Is structured discrimination for the traditionally marginalized sections in our societies resulting in higher infection rates in them? If so, what we going to do about it?

The point I want to make is that HIV exposes the fault lines and what is wrong in our societies. We need to take cognizance of that and address these issues.

#### *Women and PPTCT*

In this context, it will be interesting to pause and think about how women have been treated within HIV programs.

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<sup>35</sup> *ibid*, p. 1.

<sup>36</sup> *ibid*, pp. 3–4.

<sup>37</sup> *ibid*, p. 9.

Any intervention for women ought to be based on their rights being promoted and protected. But what happened in the PPTCT programs? When the one-shot Nevirapine prophylaxis became available to prevent parent-to-child transmission, there was a huge flurry of activity to make sure that the unborn child does not become HIV-positive. However, little thought was given to the rights of the woman who would be subject to Nevirapine prophylaxis. That resistance was likely to develop was well known. Despite that, Nevirapine prophylaxis went on in full swing. If, for a moment, programmers had thought of the rights of the women, we would have come to the conclusion that this is only a short-term gain. Now that resistance on account of Nevirapine is well established,<sup>38</sup> the trend is to go in for triple combination therapy even for PPTCT. The point is: why did this take so long and why were women's rights overlooked?\_hese questions need answers and cannot be just glossed over.

### **Access to Medicines**

**The final point I want to make relates to the violations of PLWHA's fundamental rights relating to access to affordable medicines by private companies and governments.**

**Today after hard struggles in different countries the right of PLWHAs to affordable ART is well recognized internationally. It has been possible to translate this right into practice partially because in 2000 Indian generic companies were able to force the reduction of prices of ARV drugs. They were able to produce cheaply because there was no protection for product patents in India. There was only protection for process patents. Product patent protection means monopoly production, no competition and high prices. No product patent protection means more generic producers, competition and lower prices.**

**Indian generics supply about 50% of the ARVs in the developing world. Even with the cheap generic drugs that are available from India the right to affordable ARV has not been translated into an entitlement domestically. As a result, the majority of PLWHAs around the world are unable to access affordable ART in their respective countries.**

**The situation is going to become worse in the near future because in January 2005 India enacted a law the patent law to protect product patents pursuant to the TRIPS regime.**

**Now there are thousand of frivolous applications filed for patenting of drugs in the Patent Controllers Offices in India. The Patent Controllers Office does**

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<sup>38</sup> See "Comprehensive HIV Prevention", Chapter 6, in *2006 Report on the Global AIDS Epidemic*, UNAIDS, 2006, p. 133, available at [http://www.unaids.org/en/HIV\\_data/2006GlobalReport/default.asp](http://www.unaids.org/en/HIV_data/2006GlobalReport/default.asp).

not have the trained infrastructure and personnel to deal with the numbers. Pre-grant opposition is permitted in India and civil society has filed oppositions against some of the key ARV drugs where applications are frivolous. Despite the success we achieved against Novartis AG, whose patent application for Gleevec was rejected by the Patent Controller, considering the enormity of the task, the meager resources we have, compared to the money power and resources that the US and European pharma MNCs wield **there is a real danger that frivolous patent applications may be granted even though they are not really inventions under Indian patent law.**

**This means that Indian generic companies will not be able to supply the drugs at affordable prices domestically or to other developing countries. This is true even for the existing first line and second line ARVs and other drugs.**

**Indian law is unique in that it does not allow patenting of new forms of drugs (like combinations, isomers, esters etc) unless the new form significantly enhances the efficacy of the drug. The law is in conformity with the TRIPS agreement.** Now, Novartis AG, has challenged that provision of the Indian patent law in the Madras High Court. We will have to wait and see what happens in that case.

**The TRIPS agreement was the brainchild US pharma lobby, represented by the US Pharmaceutical Manufacturers Research Association (USPhMRA) and their interest articulated by the US Trade Representative (USTR). Their agenda was very clear from the start, to have a US type of patent law in the whole world. During the TRIPS negotiations, developing countries were able to bargain for the TRIPS agreement to provide the minimum standards and allow flexibilities within the minimum standards. Thus a country can provide whether a new form of drug would be patented or not. That is left to the individual country to decide. Then again with crisis of AIDS the world community agreed with the Doha Declaration for the countries to have the power to protect the health and lives of their people. These are hard won victories of the developing world.**

**Now these victories of the developing world are sought to be scuttled by the US pharma lobby and the USTR. They are now pushing for laws in developing countries, either thorough Free Trade Agreements or bilateral agreements or by other means, which are beyond TRIPS.**

**Thus, in India, there has been continuous pressure to introduce what is known as 'Data Exclusivity'. In sum, this will prevent the State Drug Authority from relying on data about the safe and efficacious nature of a first drug for permitting market approval of the second or generic drug.**

**In Thailand intense pressure is being exerted to include set of clauses which include Data Exclusivity and that go beyond TRIPS agree to a free trade agreement with US.**

**In Kenya pressure is being exerted to amend the patent law so that import from generic companies becomes more difficult.**

**These are just some of the most recent instances. Of course all the pressure is exerted covertly through lobbying with Government officials and politicians.**

**These measures not only challenge the sovereignty of each country in framing its laws but also have the direct effect of violating the human rights of the people throughout developing countries. For the moment they have been thwarted because of the active and exemplary role of civil society in each of these countries.**

**It is high time that we tell the US pharma companies and the USTR with one voice that we shall not succumb to their money power and we will fight to see that the rights of our people to affordable drug prices are protected.**

**My appeal to the governments of the developing world is not give up the hard won rights and fall prey to these pressures. The lives of your people are far more precious than anything that the pharma lobby might offer to you. My appeal to the civil society is to don't give up the fight, as ultimate victory will be ours.**

**Thank you.**