HUMAN RIGHTS AND HIV/AIDS Now More Than Ever

10 REASONS WHY HUMAN RIGHTS SHOULD OCCUPY
THE CENTER OF THE
GLOBAL AIDS STRUGGLE

At the United Nations High Level Meeting on HIV/AIDS in 2006, world leaders reaffirmed that "the full realization of all human rights and fundamental freedoms for all is an essential element in the global response to the HIV/AIDS pandemic." Yet, 25 years into the AIDS epidemic, the "essential element" remains the missing piece in the fight against AIDS.

This declaration, endorsed by 24 nongovernmental organizations and networks around the world, affirms that, now more than ever, human rights should occupy the center of the global struggle against HIV and AIDS.

Universal access will never be achieved without human rights.

In 2006, world leaders committed "to pursuing all necessary effort towards the goal of universal access to comprehensive prevention programs, treatment, care and support by 2010." Yet many of those most in need of HIV services are still the least likely to receive them:

- Women and girls face widespread discrimination and gender-based violence, including within marriage, that fuel their HIV risk and impede their access to information and services.
- Children and youth lack unfettered access to HIV information, sexual and life-skills education, and pediatric formulations of HIV medicines.

▶ Criminalized populations, such as men who have sex with men, people who use drugs, and sex workers, are driven from HIV services by discrimination and violence, often at the hands of police officers and judges charged with enforcing sodomy, narcotics, and prostitution laws.

In every regional and country consultation on universal access, obstacles such as these have been cited as major barriers to achieving the goal of universal access. Yet in national responses to HIV and AIDS, hardly any political commitment, funding, or programming is dedicated to overcoming them.

The French have a simple term that says it all: HIV has become a problem mainly for les exclus, or "the excluded ones," living at the margin of society.

-Jonathan Mann, 1998

Gender inequality makes women more vulnerable to HIV, with women and girls now having the highest rates of infection in heavily affected countries.

Women now account for almost half of HIV infections worldwide and a majority of HIV infections in sub-Saharan Africa. This is due to women's deep political, social, economic, and sexual subordination, which is inscribed in law and enshrined in culture and practice. Discrimination, stigma, and violence are also daily realities for many women living with HIV and AIDS.

- In many countries, national laws restrict women's ability to own, inherit, or dispose of property. Women suffer inequality in access to education, credit, employment, and divorce. Legal and social inequality renders women economically dependent on their husbands, leaving them little choice but to remain in relationships where they cannot refuse sex or insist on condom use. Women often sink into poverty upon the death of their husband or the dissolution of their marriage, finding their choices and possibilities so diminished that they have to trade sex for survival, or rely on situations of lodging or work that expose them to sexual abuse or violence. Each of these factors places women at a heightened risk of HIV infection.
- Violence against women is itself a global epidemic that fuels high rates of HIV infection among women. Women face a higher risk of HIV infection through forced sex than consensual sex. Violence and the fear of violence can deter women

- from seeking HIV testing, insisting on condom use, or disclosing their HIV status to their sexual partners. Many countries still refuse to recognize the crime of marital rape. Even where laws prohibit violence against women, these laws are often not enforced. In many jurisdictions, survivors of rape and sexual violence have little hope of redress for such crimes due to inadequate police investigation, as well as bias and corruption on the part of the judiciary. Sexual violence survivors also rarely gain access to postexposure prophylaxis for HIV infection.
- For many women living with and vulnerable to HIV and AIDS, health systems remain places of prejudice and discrimination, rather than treatment and care. Access to comprehensive reproductive health services, which is the core of HIV prevention for women and girls, remains woefully lacking and restricted by law and practice in every region of the world. Women encounter blame and abuse when they are found out to be HIV-positive, deterring them from seeking HIV testing or treatment services. Women who become pregnant while living with HIV or AIDS often face judgment and recrimination by health care workers, rather than being offered proven treatment to prevent mother-to-child transmission of HIV.

The rights and needs of children and young people are largely ignored in the response to HIV, even though they are the hardest hit in many places.

HIV is significantly an epidemic of young people. Children are born with HIV at alarming rates despite proven methods of preventing HIV transmission during pregnancy and childbirth. Youth aged 15 to 24 account for over half of new HIV infections worldwide, despite unprecedented awareness of HIV and AIDS and its causes. Children orphaned or affected by AIDS are denied their basic right to social protection, even as their numbers swell to the tens of millions in sub-Saharan Africa alone.

- Although transmission of HIV from mother to child has been virtually wiped out in developed countries, less than 10 percent of pregnant women in the developing world are offered services to prevent the spread of HIV to their children. The result is that some 1,500 children are newly infected with HIV every day. While this gross inequality could be mitigated if children had access to the same lifeprolonging HIV medicines as adults, in fact close to 90 percent of children do not have access to the HIV treatment they need.
- ➤ Young people at risk of HIV through sex or injecting drug use often lack access to basic information and services to prevent HIV, as well as independent access

- to HIV testing, counseling, condoms, and treatment. In schools and youth programs, frank and complete information about sexual and reproductive health is often censored in favor of messages that emphasize abstinence and sexual morality. Young people who inject drugs often face legal restrictions on the use of sterile syringes and orally administered methadone substitution therapy to prevent HIV.
- Orphans and children living in AIDSaffected families, who number in the tens of millions in sub-Saharan Africa alone, routinely face abuse, exploitation, discrimination, and property-grabbing by relatives, rather than receiving the care and protection they deserve. AIDS-affected children drop out of school at higher rates than their peers, representing a form of systemic discrimination in access to education. As AIDS wipes out a generation of parents, the care of orphans and vulnerable children is typically left to aging grandmothers whose work is not counted, valued, or remunerated. Like the children in their care, these elderly people are denied their right to protection in countries that lack systems of child welfare or social security.

The worst affected receive the least attention in national responses to HIV.

Many of those at highest risk of HIV have one thing in common: their status is effectively criminalized by law. Police officers charged with enforcing antidrug, antiprostitution, and antisodomy laws routinely extort bribes and confessions from defenseless people, sometimes committing heinously violent acts against them, including rape and murder. Punitive approaches to drug use, sex work, and homosexuality fuel stigma and hatred against socially marginalized groups, pushing them further into hiding and away from services to prevent, treat, and mitigate the impact of HIV and AIDS.

- People who use illicit drugs represent the smallest fraction of individuals receiving antiretroviral treatment in many countries, despite accounting for a majority of people living with HIV. Harsh drug laws effectively criminalize the status of being a drug user, leading police officers to extort bribes and confessions from vulnerable groups in order to meet arrest quotas. People who use drugs end up in prison or in a revolving door of ineffective and coercive rehabilitation programs, rarely receiving the services for drug addiction or HIV prevention and treatment they desperately need.
- ▶ Sex workers, whose conduct also attracts criminal penalties under laws prohibiting prostitution, soliciting, pimping, brothel-keeping, and trafficking, often lack access to HIV services due to widespread police abuse. Forcible displacement of sex workers from commercial development areas further interferes with sex workers' access to community-based HIV services. Prejudicial and coercive treatment of sex workers in health facilities deters them from seeking HIV treatment and care.

Aggressive efforts to abolish human trafficking often translate into opposition to programs that focus on the health and human rights of sex workers.

- Men who have sex with men face widespread violence and discrimination around the world, as well as continued criminalization of sodomy in many countries. The continued stereotype of AIDS as a "gay disease" fuels social exclusion against gay men and people living with HIV alike, often driving both populations from mainstream health services. In many jurisdictions, police officers are more likely to ridicule or compound violence against gay men and transgender persons rather than investigate these crimes properly. Politicians in many countries pander to antigay prejudice rather than demonstrating the political will needed to combat HIV among vulnerable groups.
- Prisoners and detainees in many countries have little or no access to voluntary HIV testing and to treatment. They are often denied access to HIV prevention information and tools, even in places where these are available outside prison. Condoms and sterile syringes are often not provided, despite strong evidence of their effectiveness in preventing HIV without posing a risk to the wider prison population. Segregation of HIV-positive prisoners and detainees, denial of medical release, and failure to take effective action against prison rape are among the many human rights abuses that fuel HIV and worsen the impact of AIDS in prisons and other places of detention throughout the world

Effective HIV-prevention, treatment, and care programs are under attack.

In the last 25 years, it has been shown time and again that HIV programs are most effective when based on people's voluntary, informed, and open engagement with evidence-based health services. Such services should inform and educate people about HIV, support them to adopt healthy behaviors, and offer them a variety of proven prevention and care options that acknowledge the realities of their lives and allow them to choose what is most effective. However, recent trends toward coercive and "one size fits all" approaches have placed proven HIV and AIDS services in unprecedented jeopardy.

- ▶ In many countries that have fought hard to establish access to comprehensive services to prevent sexual transmission of HIV, pressure by foreign donors, religious conservatives, and other ideological forces has resulted in restrictions on information that emphasizes safer sex and condom use. This has resulted in young people being denied life-saving information about HIV transmission; young women being denied access to reproductive health information and services; and men and women being denied access to condoms and comprehensive HIV information.
- ▶ In many countries, governments are resorting to coercive methods of HIV prevention such as criminalization of "reckless" or "negligent" HIV exposure and/or transmission, and mass HIV testing without informed consent. Such policies have the potential to promote stigma against people living with HIV and to deter people from coming forward for needed health services.
- ▶ Despite the risk to both sex workers and clients posed by unprotected commercial

sex, in many countries police confiscate condoms from sex workers and use them as evidence of illegal prostitution. Recently, many organizations working with sex workers have been denied funding unless they adopt an explicit policy "opposing" prostitution—a requirement that restricts freedom of expression and undermines efforts to work respectfully with sex workers to prevent HIV and provide care and treatment to sex workers.

- Pressure on the United Nations and many governments has weakened official support for needle and syringe programs, one of the most proven methods of preventing HIV among people who inject drugs. Needle and syringe programs and methadone substitution therapy remain restricted by law or policy in many countries, despite incontrovertible evidence of their effectiveness. Even where these programs are legal, people who use drugs may fear using these programs because of the risk of arrest for possession of drug paraphernalia or controlled substances.
- Access to opioid pain medication for palliative care remains out of reach to most people who need it worldwide. Despite some progress, countries hard-hit by HIV and AIDS still fail to strike the appropriate balance between controlling illicit morphine use and making morphine available for medical purposes. Restrictions on importing and prescribing morphine persist, due in large part to exaggerated fears of morphine's addictiveness and the failure of governments to educate doctors and other health workers about the importance of morphine to palliative care for AIDS and other life-limiting illnesses.



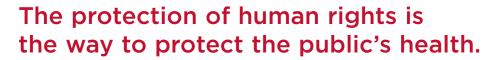
AIDS activists risk their safety by demanding that governments provide greater access to HIV and AIDS services.

In many countries, activists who demand access to HIV and AIDS services face the threat of censorship, defamation, violence, imprisonment, and other recriminations by their governments. Whether it is South African activists demanding access to antiretroviral treatment; Chinese farmers demanding compensation for having been infected with HIV through a government blood plasma collection program; Moroccan demonstrators opposing excessive patent protection in the U.S.-Morocco Free Trade

Agreement; Nepali transgender people trying to distribute HIV information and condoms; or people who use drugs in Thailand opposing their country's violent "war on drugs," peaceful demonstrations by AIDS activists have been met with intimidation and violent dispersal. Laws placing restrictions on the establishment of nongovernmental organizations make it even harder for civil society to develop an independent voice for sound and effective AIDS policies in their countries.

The link between HIV/AIDS and marginalized, "different," or socially "deviant" populations in the collective consciousness has been strong from the beginning. Hence the public health and human rights question: Which would be more effective—further repression of marginalized populations, or working with them in a way that respects their rights and dignity?

-Joanne Csete, 2005



The protection of a full range of human rights is the key to protecting public health. Building on this reality, human rights activists have achieved great gains in the fight against AIDS: the right to nondiscrimination on the basis of HIV status; the right to treatment as part of essential health care; and the right of people living with HIV and AIDS to participate in the development of AIDS policies and programs. Yet some have criticized these activists as being more concerned with "individual rights" than with the public's health. In fact, human rights are essential to public health and to a successful response to HIV.

► Human rights activists were among the first to emphasize the importance of increasing access to HIV testing as part of the right to the highest attainable standard of health. Recently, some proponents of "routine" HIV testing have accused human rights activists of allowing the "three Cs" of consent, counseling, and confidentiality to override the importance of widespread and early detection of HIV.

Yet it is possible to increase access to HIV testing without sacrificing the three Cs, and easier to engage people in sustained HIV prevention and treatment efforts if the three Cs are protected. Moreover, efforts to increase access to HIV testing must be accompanied by vastly scaled-up efforts to confront the stigma and human rights abuses that deter people from seeking HIV tests in the first place, as well as increased access to antiretroviral treatment and evidence-based HIV prevention.

▶ Human rights activists have also led the fight for increased access to evidence-based prevention measures, insisting that governments provide access to information, condoms, needles and syringes, methadone, drugs needed to prevent HIV transmission from mother to child, and protection from violence and property rights abuses that increase vulnerability of women. These demands have been based both in human rights and in effective, science-based prevention.

"Why didn't you tell us you're a hemophiliac?" a nurse in a downtown Toronto teaching hospital asked activist James Kreppner when he was in hospital with an AIDS-related illness in the 1990s. "We would have treated you much better."

-Ann Silversides, 2003



AIDS poses unique challenges and requires an exceptional response.

More than any other modern epidemic, AIDS challenges governments' responsibility and accountability. Deep fears and prejudices surrounding sex, blood, disease, and death—as well as the perception that HIV is related to "deviant" or "immoral" behaviors such as sex outside marriage, sex between men, and drug use—causes political leaders to shy away from addressing the epidemic. Controversial issues such as gender equality and adolescent sexuality are neglected in the

global response to AIDS, not least because women and children lack the political power to keep their issues high on the agenda. Governments therefore continue to devote scant resources to HIV interventions targeting marginalized populations, a pattern the Joint United Nations Programme on HIV/AIDS (UNAIDS) has called "a serious mismanagement of resources and a failure to respect fundamental human rights."

With the expanded resources now available for HIV/AIDS, it is finally possible to imagine HIV treatment programs joining HIV prevention efforts in an integrated, rights-respecting continuum of services. Unfortunately, moralistic approaches to HIV prevention, which place new obstacles in the way of reaching populations that most need information and services, hinder such a comprehensive approach.

-Joseph Amon, 2006



"Rights-based" responses to HIV are practical, and they work.

Human rights approaches to HIV are not abstract, but real, practical, and cost-effective. Countries, such as Brazil, that have placed human rights at the center of their AIDS responses have seen epidemics averted or slowed. Examples of human rights responses to HIV include the following:

- Ensuring that national HIV programs include measures to combat discrimination and violence against people living with HIV or AIDS and those at risk of infection
- ▶ Ensuring that young people have full access to HIV information, sexual and life skills education, as well as to condoms and services for sexually transmitted infections and family planning
- Investing in legal empowerment of people living with HIV and AIDS so that they know their rights and can mobilize around them

- ▶ Making policy changes to reduce prison overcrowding so that people are not incarcerated illegally, and consequently less vulnerable to HIV from sexual violence and needle-sharing while incarcerated
- Removing legal and other barriers to evidence-based HIV prevention and treatment for people who use illegal drugs
- ► Establishing clear legal remedies for violence and discrimination against sex workers, men who have sex with men, and other marginalized groups
- Providing women with effective remedies against all forms of gender-based violence, inside and outside marriage, as well as redress against legally sanctioned discrimination in access to economic opportunities, property, and inheritance

States' refusal to distribute condoms to prisoners in most developing countries leaves huge numbers of people vulnerable to HIV, a vulnerability heightened by overcrowding and sexual violence.

-Mark Heywood, 2004

Despite much rhetoric, real action on HIV/AIDS and human rights remains lacking.

On paper, the place of human rights in the response to HIV is well established. Governments involved in the 2001 Declaration of Commitment on HIV/AIDS agreed to take action on HIV and human rights, and reconfirmed this commitment five years later. However, in practice, there have been few efforts to cost, budget, and implement national programs that would secure legal and human rights protections for people living with, affected by, or vulnerable to HIV and AIDS.

- ▶ As of 2003, almost half of governments in sub-Saharan Africa had yet to adopt basic legislation specifically outlawing discrimination against people living with HIV or AIDS. Only one-third of countries worldwide had adopted legal measures specifically outlawing discrimination against populations especially vulnerable to HIV.
- ▶ Despite vastly increased funding for global HIV and AIDS programs, there has been little investment in basic human rights initiatives, such as:
 - "Know your rights" campaigns and legal services for people living with and affected by HIV;

- ► HIV-related audits of national legislation and law enforcement;
- ➤ Training in nondiscrimination, confidentiality, and informed consent for health care workers, police, judges, and social workers; and
- ▶ Self-advocacy and participation by women, young people, people living with HIV, people who use drugs, sex workers, men who have sex with men, prisoners, and migrants in national AIDS action frameworks, coordinating authorities, and monitoring and evaluation systems.
- An evaluation of the implementation of the Declaration of Commitment on HIV/AIDS, undertaken in 2006 in 14 countries, concluded that "human rights abuses of vulnerable populations continue unabated, denying them access to services and effective tools for preventing HIV infection and to life-saving AIDS drugs that will keep them alive."
- In 2003, UN Secretary General Kofi Annan stated, "HIV-related human rights are not high enough among the priorities of national governments, donors, or human rights organizations."

Realization of human rights and fundamental freedoms for all is essential to reduce vulnerability to HIV/AIDS.

-United Nations General Assembly Special Session on HIV/AIDS, Declaration of Commitment on HIV/AIDS, para. 58

Websites:

Accion Ciudadana Contra el Sida (Venezuela)

This Spanish-language website contains many relevant materials including a manual on HIV/AIDS and human rights. www.accsi.org.ve

AIDS Law Project (South Africa)

Together with the website of the Canadian HIV/AIDS Legal Network, this site is the most comprehensive source for information on legal and human rights issues related to HIV/AIDS. www.alp.org.za

AIDS Law Unit of the Legal Assistance Centre (Namibia)

www.lac.org.na/alu/default.htm

AIDS Legal Network (South Africa)

Among other things, this website contains HIV/AIDS and the Law: A Trainer's Manual, and information on another training manual, HIV/AIDS & Human Rights: Towards a Supportive and Enabling Environment for Women, Children and Other Vulnerable Groups.

AIDS & Rights Alliance for Southern Africa (ARASA)

www.arasa.info/

Botswana Network on Ethics, Law, and HIV/AIDS (BONELA)

www.bonela.org

Canadian HIV/AIDS Legal Network

Together with the website of the AIDS Law Project (South Africa), this site is the most comprehensive source for information on legal and human rights issues related to HIV/AIDS. All materials are in English and French, and some are also available in Spanish, Russian, and other languages.

Health Action AIDS (USA)

A project of Physicians for Human Rights (www.phrusa.org) in coordination with Partners in Health (www.pih.org), this site contains a section on HIV/AIDS and human rights. www.phrusa.org/campaigns/aids/index.html

Human Rights Watch

The website of Human Rights Watch contains an extensive section on HIV/AIDS and human rights, with many reports and other materials on human rights abuses in the context of the global HIV/AIDS epidemic. www.hrw.org

Hungarian Civil Liberties Union

Among other things, the HCLU has produced a book on HIV/AIDS and human rights in Hungary and a policy paper on HIV/AIDS. Their website is in Hungarian and English. www.tasz.hu

International Council of AIDS Service Organizations (ICASO)

This website contains documents on issues related to HIV/AIDS and human rights, including an advocates' guide to the International Guidelines on HIV/AIDS and Human Rights. www.icaso.org

Lawyers Collective HIV/AIDS Unit (India)

www.lawyerscollective.org

Office of the United Nations High Commissioner for Human Rights

This website contains a section dedicated to HIV/AIDS and human rights, including an "Introduction to HIV/AIDS and Human Rights" and a list of documents, including resolutions, general comments, and reports by various UN bodies on issues related to HIV/AIDS and human rights.

www.ohchr.org/english/issues/hiv/index.htm

Open Society Institute Public Health Program

The Open Society Institute Public Health Program includes initiatives on HIV/AIDS, tuberculosis, harm reduction, palliative care, Roma health, sexual health and rights, law and health, health media, and the Global Fund to Fight AIDS, Tuberculosis, and Malaria. www.soros.org/health

Program on International Health and Human Rights (United States)

This website contains a number of publications and other information about HIV/AIDS and human rights, including a paper entitled "HIV/AIDS and Human Rights in a Nutshell." www.hsph.harvard.edu/pihhr/index.html

The Center for HIV Law and Policy (United States)

www.hivlawandpolicy.org/

Uganda Network on Law, Ethics, and HIV www.uganet.org

UK AIDS and Human Rights Project

Among other things, this website contains a series of fact sheets on HIV/AIDS and human rights and on HIV/AIDS and prisoners' rights. www.aidsrightsproject.org.uk

Joint United Nations Programme on HIV/AIDS (UNAIDS)

This website contains a section on HIV/AIDS, human rights, and law. It explains why protection of human rights is critical to a successful response to HIV/AIDS, and contains links to many resources on issues related to HIV/AIDS and human rights produced by UNAIDS and by the UNAIDS Global Reference Group on HIV/AIDS and Human Rights.

United Nations Development Programme (UNDP)

This website contains materials related to human rights and HIV/AIDS, including a discussion paper on human rights, gender, and HIV/AIDS prepared for the 2006 UN General Assembly High Level Meeting on HIV/AIDS. www.undp.org/hiv/focuso3.htm

World Health Organization (WHO)

This website contains information about WHO's work on health and human rights and a number of publications on the topic.

www.who.int/hhr/en/

Zambia AIDS Law Research and Advocacy Network (ZARAN)

www.zaran.org

Copyright ©2007 by the Open Society Institute. All rights reserved.

Human Rights and HIV/AIDS: Now More Than Ever was coproduced by the 24 endorsing organizations with the support of the Open Society Institute.

Second Edition, September 2007

For more information:

Law and Health Initiative
Public Health Program
Open Society Institute
400 West 59th Street
New York, NY 10019 USA
www.soros.org/initiatives/health/focus/law

Now More Than Ever was written by Ralf Jürgens and Jonathan Cohen, based on previous work by a large number of organizations, including the AIDS Law Project, Human Rights Watch, and the Canadian HIV/AIDS Legal Network. The authors gratefully acknowledge Joseph Amon, Joanne Csete, and Mark Heywood, as well as all those who provided comments on the first version of the paper and others who have contributed to it in various ways, including Volha Baraulia, Theodore de Bruyn, Richard Elliott, Françoise Girard, Sofia Gruskin, Sai Jahann, Whitney Johnson, Ari Korpivaara, Kasia Malinowska-Sempruch, the late Jonathan Mann, Kevin Moody, Rebecca Schleifer, Sue Simon, Susan Timberlake, and Daniel Wolfe.

Designed by Andiron Studio
Printed in the United States by Prestone

The Following Organizations Endorse This Declaration









Central and Eastern European Harm Reduction Network







































