

CIVIL SOCIETY Perspectives on HIV/AIDS Policy



in Nicaragua, Senegal, Ukraine, the United States, and Vietnam

OVERVIEW

PUBLIC HEALTH WATCH



OPEN SOCIETY INSTITUTE
Public Health Program

Civil Society Perspectives on HIV/AIDS Policy

in

*Nicaragua, Senegal, Ukraine,
the United States, and Vietnam*

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For more information:
Public Health Watch
Open Society Institute
Email: phwinfo@sorosny.org
Website: www.publichealthwatch.info

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Front cover (clockwise from left) Luke Wolagiewicz, WPN: support group for people living with HIV/AIDS, Ukraine; Associated Press: a center caring for abandoned children living with HIV/AIDS, Vietnam; Donna DeCesare: 16-year-old living with HIV, and his mother, Central America.

Back cover (top to bottom) Associated Press: lab assistant tests blood for HIV, Senegal; Associated Press: coordinator with ACLU National Prison Project talks with people in the HIV/AIDS Housing Unit at Mississippi State Penitentiary.

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Preface

In June 2001, at the United Nations General Assembly Special Session on HIV/AIDS (UNGASS), 189 national governments agreed to the Declaration of Commitment on HIV/AIDS. The document commits governments to improve the responses to their domestic AIDS epidemics and sets targets for AIDS-related financing, policy, and programming.

The Declaration also stipulates that governments conduct periodic reviews to assess progress on realizing their UNGASS commitments. In recognition of the crucial role civil society plays in the response to HIV/AIDS, the Declaration calls on governments to include civil society, particularly people living with HIV/AIDS, in the review process.

Established by the Open Society Institute in 2004, Public Health Watch supports independent monitoring of governmental compliance with the UNGASS Declaration and other regional and international commitments on HIV/AIDS. Public Health Watch aims to promote informed civil society engagement in policymaking on HIV/AIDS and tuberculosis (TB)—two closely linked diseases that lead to millions of preventable deaths annually. Toward this end, Public Health Watch also supports civil society monitoring of TB and TB/HIV policies, examining compliance with the Amsterdam Declaration to Stop TB and the World Health Organization’s Interim Policy on Collaborative TB/HIV Activities.

The Public Health Watch methodology incorporates multiple opportunities for dialogue and exchange with a broad range of policy actors during report preparation. Researchers convene an advisory group of national HIV/AIDS and TB experts, activists, and policy actors. They prepare draft reports on the basis of input from the advisory group, desktop and field research, interviews, and site visits. Researchers then organize in-country roundtable meetings to invite feedback and critique from policymakers, academics, government officials, representatives of affected communities, and other key stakeholders. Finally, Public Health Watch supports researchers in conducting targeted advocacy at the domestic and international levels around their report findings and recommendations.

For the HIV/AIDS Monitoring Project, Public Health Watch civil society partners in Nicaragua, Senegal, Ukraine, the United States, and Vietnam have prepared assessments of national HIV/AIDS policies based on a standardized questionnaire, which facilitates structured review of governmental compliance with key elements of the UNGASS Declaration. The results of the two-year inclusive research and report preparation process are available in five country reports, and are highlighted in this overview.

Public Health Watch launched the TB Monitoring Project’s *Civil Society Perspectives on TB Policy in Bangladesh, Brazil, Nigeria, Tanzania, and Thailand* at the World Lung Conference on November 1, 2006, in Paris. The TB reports highlighted several key

findings: awareness of the basic facts about TB and TB/HIV coinfection are low among political officials and the general population; there is inadequate attention to the linkages between TB and poverty and measures to address the hidden costs of TB treatment; governments often lack capacity to monitor the course of the TB epidemic or the quality of services, which contribute to concerns about increasing rates of drug-resistant TB; integration of community participation in TB control shows positive results but requires additional support and funding; and, in the absence of public awareness and engagement around TB and TB/HIV, efforts to achieve political and financial accountability for TB control falter.

To access the reports of the HIV/AIDS Monitoring Project and to learn more about Public Health Watch, including the TB Monitoring Project and the TB/HIV Monitoring and Advocacy Project, please visit: www.publichealthwatch.info.

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Public Health Watch staff prepared this overview report based on findings and recommendations in country reports drafted by Public Health Watch researchers, including Miguel Orozco of the Center for Health Research and Studies at the National Independent University of Nicaragua (CIES–UNAN) in collaboration with Laura Pedraza from Harvard Law School; Daouda Diouf, program director of Enda Santé in Senegal; Andriy Bega, project coordinator with the International Centre for Policy Studies (ICPS) in Ukraine; Chris Collins, a long-time HIV/AIDS activist and independent consultant in the United States; and Oanh Khuat, head of the Social Health Department at the Institute for Social Development Studies (ISDS) in Vietnam.

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PUBLIC HEALTH WATCH INTERNATIONAL ADVISORY GROUP

Faruque Ahmed, Bangladesh Rural Advancement Committee (BRAC)
Jacqueline Bataringaya, International HIV/AIDS Consultant
Arachu Castro, Harvard Medical School; Partners in Health
Claudio Gálvez-Kóvácic, Director, SOIS Institute: Innovation and Development in Health
Hortense Gbaguidi-Niamke, Open Society Initiative for West Africa (OSIWA)
Petra Heitkamp, Stop TB Partnership Secretariat
Bobby John, Principal Partner, Global Health Advocates
René L'Herminez, KNCV Tuberculosis Foundation
Martin McKee, London School of Hygiene and Tropical Medicine
Sisonke Msimang, Open Society Initiative for Southern Africa (OSISA)
Nina Schwalbe, Global Alliance for TB Drug Development

PUBLIC HEALTH WATCH STAFF

Emily Bell, Project Officer
Helena Choi, Project Officer
Eleonora Jiménez, Project Coordinator
Manisha Nayi, Project Assistant

Rachel Guglielmo served as Public Health Watch project director until May 2007.

Public Health Program

The Open Society Institute's Public Health Program promotes health policies based on social inclusion, human rights, justice, and scientific evidence. The program works with local, national, and international civil society organizations to foster greater civil society engagement in public health policy and practice, to combat the social marginalization and stigma that lead to poor health, and to facilitate access to health information.

www.soros.org/initiatives/health

Open Society Institute

The Open Society Institute works to build vibrant and tolerant democracies whose governments are accountable to their citizens. To achieve its mission, OSI seeks to shape public policies that assure greater fairness in political, legal, and economic systems and safeguard fundamental rights. On a local level, OSI implements a range of initiatives to advance justice, education, public health, and independent media. At the same time, OSI builds alliances across borders and continents on issues such as corruption and freedom of information. OSI places a high priority on protecting and improving the lives of marginalized people and communities.

Investor and philanthropist George Soros in 1993 created OSI as a private operating and grantmaking foundation to support his foundations in Central and Eastern Europe and the former Soviet Union. Those foundations were established, starting in 1984, to help countries make the transition from communism. OSI has expanded the activities of the Soros foundations network to encompass the United States and more than 60 countries in Europe, Asia, Africa, and Latin America. Each Soros foundation relies on the expertise of boards composed of eminent citizens who determine individual agendas based on local priorities.

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Executive Summary

National governments and international agencies attempting to address HIV/AIDS continue to exclude or ignore marginalized groups that are disproportionately affected by the epidemic.

In countries ranging from the United States, with some of the world's best medicine and health care technology, to Senegal, where more than 50 percent of the population lives below the poverty line, marginalized groups—injecting drug users, sex workers, men who have sex with men, prisoners, and ethnic minorities—are frequently excluded from the design, implementation, and evaluation of national HIV/AIDS policies and programs.

The Open Society Institute's Public Health Watch HIV/AIDS Monitoring Project has documented the varying degrees and different forms that stigma and discrimination against marginalized groups can take in five developed and developing countries: Nicaragua, Senegal, Ukraine, the United States, and Vietnam. The results of this research, which are highlighted in this overview and available in five separate country reports, have made it clear that national governments and international agencies must collaborate more effectively with these groups in order to hear their concerns and address their needs.

It will only be through the active and meaningful participation of these marginalized, most affected groups that countries will be able to achieve universal access¹ to HIV/AIDS prevention, treatment, care, and support and to halt the progress of the HIV epidemic.

Background

The Public Health Watch HIV/AIDS Monitoring Project partners with civil society organizations in five countries—Nicaragua, Senegal, Ukraine, the United States, and Vietnam—to monitor the degree to which governments are living up to the commitments they made in the United Nations General Assembly Special Session (UNGASS) Declaration of commitment, which includes making HIV/AIDS prevention, care, and treatment services more widely and equitably available. For the past two years, Public Health Watch researchers engaged in an inclusive report preparation process with multiple opportunities for dialogue and exchange with a broad range of stakeholders.

Access to HIV/AIDS services, particularly antiretroviral treatment, has improved in recent years in the countries studied by Public Health Watch, but the impact has been severely limited by the failure of all five governments to make these services available to populations most affected by the epidemic. HIV/AIDS prevention and treatment services for injecting drug users, men who have sex with men, prisoners, sex workers, women, and children are inadequate and difficult to access, or are simply nonexistent.

Key findings

- Vulnerability to HIV infection and to the impact of HIV/AIDS has not been sufficiently addressed, particularly for marginalized populations.
- Significant barriers to accessing care and treatment remain, even where treatment is provided for “free.” Barriers include costs of transportation, fees associated with HIV diagnosis and treatment, lack of health care infrastructure and inadequate human resource capacity.
- Stigma and discrimination hinder people from being tested for HIV or receiving adequate care. In many cases, national laws, government policies, and law enforcement practices exacerbate stigma against people living with HIV/AIDS and groups at elevated risk of HIV infection.
- Few countries have truly integrated tuberculosis (TB) and HIV services or effectively addressed TB and other opportunistic infections, creating significant barriers to the delivery of comprehensive, accessible care and prevention services.
- Without urgent attention to these key issues, the internationally declared goal of universal access to HIV/AIDS prevention, treatment, and care is not achievable.
- Universal access cannot be achieved unless people who are most affected are involved in the response and the needs of marginalized populations are addressed. Civil society groups have the requisite knowledge and experience to articulate the perspectives of communities that may not otherwise be heard.
- Civil society can be a powerful force in responding to the HIV/AIDS epidemic. Civil society groups have a key role in holding governments accountable for serving their populations and honoring their international commitments. Increasingly, these groups are also engaged in delivery of HIV/AIDS services. Yet civil society members of national HIV/AIDS planning bodies often feel their membership is “tokenistic” and undervalued, and civil society advocates are frequently shut out of national policy discussions and processes.
- Improved accountability mechanisms are needed at national and global levels to ensure widespread and equitable delivery of HIV/AIDS services; to identify needed improvements; and to hold governments and global institutions accountable for progress on their declared commitments—including universal access.

Key recommendations

To national governments:

- Increase public awareness about the UNGASS processes and national universal access targets through mass media campaigns;
- Implement UNAIDS recommendations as stipulated in the *Guidelines on Construction of Core Indicators* to ensure civil society participation in the national UNGASS review report preparation process;
- Ensure more meaningful participation of civil society in the UNGASS review process by building civil society capacity; designating a representative or agency responsible for engagement with civil society; and following through on civil society input and recommendations; and
- Collaborate with UNAIDS and other international agencies and donors to ensure there is sufficient technical support to conduct an inclusive and transparent UNGASS review process.

To UNAIDS:

- Provide technical assistance to national governments to raise public awareness about UNGASS and universal access, and better equip governments to effectively solicit input from civil society into national HIV/AIDS planning and reporting, including the UNGASS review process;
- Emphasize the particular importance of civil society input in the National Composite Policy Index (NCPI) component of the UNGASS review report, and provide technical support to civil society organizations to ensure they understand the reporting process, indicators, and ways to collect, analyze, and submit data;
- Establish and widely disseminate concrete plans to consult with civil society regarding their participation in the UNGASS reporting process, including the designation of a primary point person responsible for liaising with civil society; and
- Ensure the accuracy and validity of national UNGASS progress reports by encouraging integration of civil society perspectives into national reporting processes.

To civil society:

- Take full advantage of representation opportunities, such as positions on the Global Fund Country Coordinating Mechanisms (CCMs) or national AIDS committees;
- Learn about the UNGASS and universal access processes and share information with other civil society organizations about these initiatives and the right of civil society to participate in them;
- Seek technical assistance from UNAIDS and others, as appropriate, to ensure civil society perspectives are adequately represented in national UNGASS review processes and in implementing policies and programs to achieve universal access by 2010; and
- Advocate for universal access to prevention, treatment, care, and support for all, particularly marginalized, high-risk populations.

Introduction

The Public Health Watch HIV/AIDS Monitoring Project partners with civil society organizations in **Nicaragua**, **Senegal**, **Ukraine**, the **United States**, and **Vietnam** to monitor and advocate for improved HIV/AIDS policies and programs. This overview highlights some of the overarching experiences and findings of Public Health Watch partners in these five countries.

One common international standard against which to measure progress in HIV/AIDS control is the 2001 United Nations General Assembly Special Session (UNGASS) Declaration of Commitment on HIV/AIDS. Most Public Health Watch researchers found that the UNGASS Declaration has not made a significant impact at the country level despite the enormous time and energy invested in its formulation and review. The Declaration has moved processes forward in some countries and has provided valuable language and tools for holding governments to account. However, it is not widely known to civil society actors. Despite specific stipulations that the UNGASS progress review process be open and accessible to civil society participation and input, Public Health Watch researchers' ability to engage meaningfully with governments in the research and preparation of national UNGASS progress reports was limited.

Civil society is uniquely positioned to offer on-the-ground perspectives that can be informative to meeting the challenges of achieving universal access. Public Health Watch's community-based research reveals that not all countries have adopted comprehensive national strategies in accordance with their UNGASS commitment. Prevention efforts often fail to target marginalized populations at high risk of HIV, such as injecting drug users, sex workers, men who have sex with men, prisoners and racial/ethnic minorities. There is still insufficient and inequitable access to treatment, care, and support in all five countries. Governments must address these critical issues with broad civil society participation in order to make universal access to prevention, treatment, and care a reality.

At the high-level UNGASS review meeting in May–June 2006, delegates adopted the Political Declaration, which calls on countries to establish ambitious national targets to achieve universal access to prevention, treatment, care, and support by 2010. The importance of involving a wide range of stakeholders—including civil society—in the national target setting process was again emphasized. However, to date, few civil society organizations have been consulted in the process, limiting their ability to monitor and hold governments accountable against these important targets.

UNGASS Declaration of Commitment on HIV/AIDS

The 2001 UNGASS Declaration of Commitment represents a milestone in the fight against HIV/AIDS. With the Declaration, 189 governments jointly declared the HIV/AIDS epidemic as “one of the most formidable challenges to human life and dignity,” and stated their commitment to “enhancing coordination and intensification of national, regional, and international efforts to combat it in a comprehensive manner.”²

The Declaration articulates the need for strong leadership and for multisectoral, national strategies and financing plans,³ and sets forth a range of specific targets related to prevention, treatment, care, and support.⁴ It emphasizes that an effective response to HIV/AIDS must be grounded in respect for the rights of people living with HIV/AIDS⁵ and must give priority to vulnerable groups such as women, children, and “other groups at greatest risk of and most vulnerable to new infection” as identified by “public health information.”⁶

Governments also committed themselves to undertake “national periodic reviews with the participation of civil society, particularly people living with HIV/AIDS, vulnerable groups and caregivers, of progress achieved in realizing these commitments; identify problems and obstacles to achieving progress; and ensure wide dissemination of the results of these reviews.”⁷

The first UN high-level review of government progress on the Declaration was conducted in 2003. Of 189 governments, 103 submitted national progress reports to UNAIDS for input into the 2003 UNGASS Global Progress Report. Many civil society organizations expressed dissatisfaction with the extent of community participation in the 2003 review, at both the national and international levels. Some claimed that they were entirely shut out of the process by which governments researched, prepared, and submitted their progress reports. Others expressed dissatisfaction with the role accorded to civil society and people living with HIV/AIDS during the review process, and felt that opportunities to make their voices heard were severely restricted by the relatively “closed” structure and format of review meetings.

Civil society engagement

In early 2005, in an effort to respond constructively to these flaws in the 2003 review process, Public Health Watch joined a broad group of civil society organizations from around the world to present a joint proposal to UNAIDS on the need for more substantive civil society participation in the subsequent high-level review in 2006 at national and global levels.⁸

UNAIDS responded by inviting the group to provide specific suggestions on civil society participation for inclusion in reporting guidelines for governments. As a direct result of this collaboration, the UNAIDS' *Guidelines on Construction of Core Indicators* for preparation of national progress reports were amended to include specific instructions for national AIDS committees to seek input from the full spectrum of civil society and to ensure there is sufficient opportunity for review and comment on the national progress report before it is finalized and submitted to UNAIDS.⁹

In addition to the formal review process, Public Health Watch and other civil society organizations¹⁰ have supported the development and presentation to governments of independent "shadow reports" in over 35 countries. The coalition also supported the direct submission of more than 25 reports to UNAIDS as input for the Global Progress Report.

Public Health Watch researchers in all five countries referred their governments to UNAIDS' *Guidelines* in requesting opportunities to participate in the development of progress reports in their countries. Many achieved some level of success in participating in the national UNGASS report preparation process; others found their governments unwilling or unable to facilitate sufficient consultation.

In **Nicaragua**, the Public Health Watch researcher participated in a meeting organized by UNAIDS to promote exchange of information and analyze the initial data presented by the government. Researchers in **Senegal**, **Ukraine**, and **Vietnam** took part in review meetings with their governments to discuss drafts of the national progress report. As a result of her participation, the **Vietnamese** researcher's comments were reflected in the final government report to UNAIDS: the Vietnamese government lowered its self-assessment rating on civil society participation and acknowledged that substitution therapy was being piloted, not made "available."¹¹ In **Ukraine**, the government disseminated UNAIDS' *Guidelines*, but did not set forth clear plans for collecting and integrating additional input from civil society groups.

The Public Health Watch researcher in the **United States** had little success in accessing or participating in the official UNGASS progress report preparation process despite repeated inquiries. In March 2006, Public Health Watch received a letter from the U.S. Department of Health and Human Services indicating that a review report had been submitted, but that due to the "relatively short time frame given for responding on the core indicators," the agency was "unable to engage civil society organizations in the . . . formulation of the report to UNAIDS."¹²

Public awareness of UNGASS commitments

In addition, Public Health Watch researchers found a low level of public awareness about international commitments such as the UNGASS Declaration and governments' HIV/AIDS policies. For example, a member of a self-help group in **Vietnam** commented, "People living with HIV/AIDS do not know much about the UNGASS Declaration. I don't even know much about this, and I'm an insider. It's not that ordinary people don't pay attention to this issue; it just hasn't been communicated enough."¹³ Even many government officials are not aware of international commitments or national efforts to control HIV/AIDS. Only 29 percent of officials in charge of HIV/AIDS communication activities in **Vietnam** knew about the UNGASS Declaration of Commitment and the Millennium Development Goals, and only 42 percent had read or attended a presentation about the National AIDS Strategy.¹⁴

Public support for and knowledge about national HIV/AIDS programs are also extremely limited in **Ukraine**. Only 7.3 percent of those recently surveyed were well-acquainted with the Law on the Prevention of AIDS and Social Protection of the Population (hereafter the "AIDS Law") and 28.9 percent knew something about it; the rest had either only heard about it but weren't familiar with its content, or had not heard about it at all.¹⁵

The **Nicaraguan** government has also not widely publicized its international commitments to control HIV/AIDS. According to some NGO representatives, doing so would be "inconvenient for the government since it would lead to increased demands from the population."¹⁶

2006 high-level UNGASS progress review

In 2006, high-level delegates convened to review progress in implementing the UNGASS Declaration of Commitment. Over 800 civil society organizations also attended the three-day meeting. This scale of civil society participation was unprecedented. However, many participants felt the meeting failed to review the progress achieved to date and the challenges that lay ahead, focusing instead on negotiations for the Political Declaration text. The resulting eight-page declaration¹⁷ was a disappointment to many civil society activists. For them it represented a compromise that fails to establish concrete time-bound targets on funding, prevention, treatment, and care and makes only indirect reference to high risk groups such as men who have sex with men, sex workers, and injecting drug users.¹⁸ The then-UN Secretary General Kofi Annan also expressed frustration that specific vulnerable groups were not mentioned and that the declaration did not send a clearer message. "You cannot deal with a problem without confronting the issue of the most vulnerable who need assistance most. It's counter-productive. It's like putting your head in the sand and saying 'I don't want to know.'"¹⁹

Rather than setting global targets, the Political Declaration calls on countries to establish ambitious national targets on HIV prevention, treatment, care, and support toward the goal of achieving universal access to those services by 2010.²⁰ The Political Declaration also emphasizes the importance of including a wide range of stakeholders, particularly people living with HIV/AIDS, in the universal access national target-setting process. However, few civil society organizations are aware that target setting is occurring and even fewer have been consulted and involved in the process of setting targets according to Public Health Watch researchers.

Future UNGASS reviews

There is another high-level UNGASS review meeting planned for 2008, and UNAIDS has requested that countries submit national progress reports by January 31, 2008, in line with the revised *Guidelines on Construction of Core Indicators*. The guidelines once again emphasize the importance of civil society participation in the reporting process. National governments, UNAIDS, and other international agencies and civil society must work together to ensure that civil society participation is more effective and that the 2008 UNGASS review meeting prioritizes the achievement of universal access.

Without civil society awareness of universal access targets and broad participation in monitoring efforts to reach them, the universal access process will lack credibility and legitimacy at the country level. Civil society perspectives offer critical insight into the challenges in achieving universal access. Key findings from the Public Health Watch monitoring reports indicate that the following issues remain major challenges:

- **Vulnerability.** Issues of vulnerability to HIV infection and its impact have not been sufficiently addressed, particularly for marginalized populations.
- **Stigma and discrimination.** In many countries stigma and discrimination continue to hinder people from getting tested for HIV, receiving adequate care or speaking openly about their status.
- **Barriers to Access.** Despite recent increases in the availability of necessary medicines such as antiretroviral (ARV) drugs, barriers to access to care and treatment still exist, ranging from transportation costs and poverty to lack of health care infrastructure and workers.
- **Accountability.** There is a lack of effective accountability mechanisms to ensure that governments follow through on the commitments they have made at the international level and at home.

Without addressing these key issues, universal access to HIV/AIDS prevention, treatment, and care cannot be realized.

Vulnerability

Instead of spreading out to the broad American population, as was once feared, HIV is concentrating in pools of persons who are also caught in the “synergism of plagues” that include poverty, poor health care, inadequate education, unemployment and “social disintegration.” This trend has not changed in the interceding years.

—The Social Impact of AIDS in the United States,
*National Research Council*²¹

Public Health Watch researchers have found that current HIV/AIDS interventions do not adequately address factors of vulnerability that drive the spread of HIV and exacerbate the impact of HIV/AIDS. Marginalized populations that are often at elevated risk for HIV, including injecting drug users, sex workers, men who have sex with men, and prisoners are not being targeted with effective interventions for preventing the spread of HIV. Information and education on HIV/AIDS have not considered culture, gender inequality, and other barriers and have failed to lead to changes in behavior. People living with HIV/AIDS, their families, and their communities have also received inadequate support to cope with the impacts of HIV/AIDS.

For instance, HIV/AIDS in **Vietnam** is highly concentrated among marginalized groups such as injecting drug users and sex workers, but the government has been slow to implement harm reduction interventions to curb infection rates among these groups. Instead, officials rely on forced rehabilitation in “re-education” facilities to control these “social evils.” Conditions in the centers vary, but most do not offer prevention and treatment services and are often viewed by AIDS experts as incubators of the HIV/AIDS epidemic where unprotected sex and drug use are common.²² The centers do not prepare the detainees for their transition back into society and, given high recidivism rates, there is a risk that they may transmit HIV to their drug and sexual partners as they cycle between rehabilitation centers and society.

The **United States** has failed to make progress to reduce annual HIV incidence for well over a decade. Every year, 40,000 Americans—110 people per day, approximately 55 of them African American—are newly infected with HIV.²³ Despite the alarmingly disproportionate numbers of African Americans affected by HIV/AIDS, interventions have failed to target this group effectively and the disparity has only increased over time. While African Americans accounted for 25 percent of AIDS diagnoses in 1985, they represented 50 percent of AIDS diagnoses in 2005.²⁴

Injecting drug users

When I approach them to offer needles they sometimes shout at me, saying they are not on drugs anymore. Or whenever I visit them at home, the family will say they are not home. I know it is not true. They are afraid that I will make them use drugs again.

—Outreach worker, Vung Tau, Vietnam²⁵

Public Health Watch reports indicate that needle exchange programs are not widely implemented. In the **United States**, consistent research findings on the positive impact of needle exchange programs have not succeeded in altering federal policy prohibiting federal monies for these programs. In **Ukraine**, where injection drug use is responsible for up to 70 percent of annual infections, harm reduction interventions such as needle and syringe exchange programs reach only 70,000 injecting drug users, about 20 percent of the country's estimated total number of users.²⁶ Yet studies indicate a minimum of 60 percent coverage is necessary to impact the HIV/AIDS epidemic.²⁷ Needle exchange programs have been sponsored by international organizations since the 1990s in **Vietnam**, but they remain small in scale. Harm reduction programs are reportedly implemented in 21 out of 64 provinces, but only one or two districts within each province actually implement the key interventions, resulting in only a small proportion of the 600 districts actually operating harm reduction programs.²⁸

Similarly, rollout of substitution therapy has been inadequate and slow. Despite being identified in 2001 as one of the key measures to prevent HIV among drug users in **Ukraine**, substitution therapy only became available in 2005 through a pilot project and currently reaches fewer than 450²⁹ of the estimated 60,000 to 238,000 drug users who need it.³⁰ Current pilot projects also use buprenorphine rather than methadone, at a cost that will restrict the potential for expansion to other sites across the country. Until recently, drug control officials held that methadone will never be allowed in Ukraine as it was too "dangerous."³¹ In late 2006 the Ministry of Health announced that methadone would be available in Ukraine, but current plans only call for rollout to 300 patients in 2007.³² Furthermore, policing strategies have hindered and complicated outreach to prevent high-risk practices among injecting drug users; possession of drugs is a criminal offense, regardless of whether there is any proof of intent to sell or distribute.³³

Substitution therapy with methadone was piloted in the late 1990s in **Vietnam**, but suspended when the supply ran out in 2000, and methadone has not been available since.³⁴ Substitution therapy is explicitly condoned in the new AIDS law passed in June 2006, but implementation remains uncertain. Naltrexone (not an opiate substitute, but

rather a medication that blocks the effects of opiates without reducing cravings) is currently the only approved therapy, and some activists worry that its availability may slow rollout of methadone.

Sex workers

Interventions aimed at sex workers are inadequate according to Public Health Watch reports. The **Senegalese** government has been progressive in providing health care—such as treatment for sexually transmitted infections (STIs)—for legal sex workers as part of its HIV prevention efforts, but ignores unregistered sex workers, who account for nearly 80 percent of all sex workers in Senegal.³⁵ Unregistered sex workers are often arrested and harassed by law enforcement, which makes it more difficult to target them with prevention, care, and support activities. In addition, many NGOs and community groups are reluctant to reach out to unregistered sex workers; currently, only one organization—Enda Santé—targets unregistered sex workers with HIV testing and counselling services.

Estimates of HIV prevalence among sex workers in **Ukraine** range between 4 and 31 percent.³⁶ Despite their high risk of HIV, only about a third are currently reached by prevention programs,³⁷ and relatively few sex workers report regular condom use. Like injecting drug users, sex workers are also frequent targets for police harassment and detention. In exchange for release, police allegedly demand payment of fines, information about drug users, or sex.³⁸ Approximately 60 percent of sex workers also report drug use, indicating a need for coordination of services for drug users and sex workers.

Men who have sex with men

Despite their elevated risk for HIV, men who have sex with men are frequently neglected by prevention efforts. In **Nicaragua**, there are no government-supported prevention campaigns for men who have sex with men, which is troubling given that 9 percent of men who have sex with men in Managua have been found to be HIV-positive.³⁹ Men who have sex with men have also been largely ignored in **Senegal's** prevention policy. The 2007–2011 National Strategic Plan on HIV/AIDS includes STI control among men who have sex with men, but implementation remains uncertain. Men who have sex with men are often reluctant to test for HIV due to lack of care and support services. Social workers admit that existing prevention services for the general population must be adapted to meet the needs of men who have sex with men by, for instance, offering mobile testing sites with flexible hours and placing greater emphasis on psychosocial support.⁴⁰

Since the beginning of the HIV/AIDS epidemic in the **United States**, men who have sex with men have been disproportionately impacted: this group accounted for 46 percent of all new AIDS diagnoses in 2004. A Centers for Disease Control and Prevention (CDC) survey of 1,800 men who have sex with men in five metropolitan areas⁴¹ indicated that one in four (and nearly half of the African American men who have sex with men) were HIV-positive, and that about half of those infected were not aware of their serostatus, revealing that targeted testing and counseling and other proven effective interventions are urgently needed.

Prisoners

Prisoners are another group whose vulnerability to HIV and opportunistic infections has not been adequately addressed. The HIV prevalence rate in prisons exceeds the rate in the general population in the **United States**⁴² by three and a half times, and studies indicate risky behaviors are common in prisons—over 57 percent and 86 percent of those interviewed in a study reported direct knowledge of risky sexual behavior and substance abuse, respectively.⁴³ Despite this evidence, there are inadequate measures to prevent HIV transmission within prisons. Condoms are only available in a few facilities, bleach kits for cleaning needles or needle and syringe exchange programs are generally forbidden, and methadone maintenance therapy is rarely used.

Due in part to an aggressive policy of criminal prosecution for possession of even small amounts of drugs in **Ukraine**,⁴⁴ a large number of people in prison are HIV-positive drug users. As of December 2003, approximately 15 percent of inmates had tested positive for HIV⁴⁵ and an estimated 70 percent of HIV-positive inmates are current or former drug users. However, HIV prevention and drug treatment services are limited in prisons. As of September 2006, prevention programs were available in only 29 out of 136 prisons.^{46, 47} While the government intends to use a Global Fund Round 6 grant to provide services to 5,000 inmates in 2007 and up to 50,000 inmates by 2011,⁴⁸ plans for implementation remain uncertain.

Suboptimal living conditions in prisons also increase the risk of other infections such as TB. The TB prevalence rate in **Ukrainian** prisons is 112 times higher than among the general population. In the presence of high rates of both TB and HIV, the incidence of TB/HIV coinfection in prisons is on the rise, as is prevalence of drug resistant TB,⁴⁹ which results from incomplete TB treatment. TB/HIV coinfection is also inadequately addressed in prisons in the **United States**. A CDC survey of TB prevention efforts in large city and county jails found that fewer than half of prisons surveyed had policies in place to offer HIV testing to patients who test positive in TB skin tests.⁵⁰ In addition, while nearly 20 percent of

inmates evaluated for TB were also HIV-positive, nearly a third of these coinfecting inmates' medical records lacked information on their HIV status.

Women and youth

[Feminization of AIDS] is related to power dynamics. We cannot make the mistake of addressing women without addressing the men too, because they're part of the root cause behind this phenomenon.

—Roundtable participant, Senegal⁵¹

Interventions have failed to effectively reach newly identified vulnerable groups such as women and youth. For example, sexual transmission has increased dramatically in **Vietnam** in recent years, accounting for more than 70 percent of all new infections in 2005. However, prevention of sexual transmission has not been prioritized in the HIV/AIDS response. There is little effort to provide comprehensive sex education in schools and for the general population, though pre- and extra-marital sex is not uncommon and rates of condom use remain low. Only 30 percent of young people reported condom use during sexual intercourse even though many admitted to having more than one partner in the past 12 months.⁵²

Sex education and condom availability for young people is also a contentious issue in HIV prevention policy in the **United States**. The Youth Risk Behavior Survey consistently reports that approximately half of all high school-aged youth indicate they have had intercourse at least once.⁵³ Yet the federal government has allocated almost \$1 billion for abstinence-only-until-marriage programs since 1996 even though studies and program evaluations have failed to find abstinence-only programs to be effective.⁵⁴

Condom promotion in **Senegal** does not take into account the socioeconomic and cultural reality of gender inequality; in this region, many women lack the decision-making or negotiation powers to control condom use. For instance, only about 5 percent of young women between the ages of 15 to 24 indicated that they used a condom with a regular partner, compared to approximately 50 percent of young men in the same age group.^{55, 56} A group of HIV-positive women in a self-support group confirmed that being in a monogamous relationship was a risk factor for HIV for women; the majority of the members had been infected by their husbands. One member added, "Sex workers are more protected than married women because they can better negotiate condom use."⁵⁷

Similarly, a prevention model emphasizing abstinence, sexual fidelity, and delay of first sexual intercourse is incongruous with the characteristics of **Nicaragua's** youth population, which presents a very young average age of first sexual intercourse. However, the

“Together We Decide When” campaign has demonstrated moderate success in increasing condom use among adolescents and youth.⁵⁸

Limited impact of information, education, and communication efforts

Information, education, and communication (IEC) efforts have increased public awareness about HIV/AIDS in many countries where Public Health Watch conducted research. Levels of awareness are near universal in **Senegal**,⁵⁹ **Vietnam**,^{60, 61} and the **United States**. However, this knowledge has not translated into positive behavior changes. Messages are either too general, or fail to take cultural contexts such as gender inequality into account (as indicated above) or to provide specific information on ways individuals can protect themselves against HIV infection.

In **Vietnam**, IEC messages have tended to focus on high risk *groups* rather than on risky *behaviors*. Many people understand that injecting drug users and sex workers are at high risk for HIV infection, but they do not understand how HIV is transmitted or what specific behaviors could expose them to HIV. As a result, there is a sense of immunity among the general population, and a man who engages in sexual activity with a sex worker may not believe he is at risk of HIV infection since he does not belong to a high risk group, that is, because he is neither a drug user nor a sex worker. A 2002 survey of 493 men in Hanoi illustrates this disconnect between risky behavior and perception of personal risk: while 76 percent of respondents admitted to having intercourse with sex workers, 72 percent did not worry about getting HIV and 65 percent believed they would never contract HIV. Meanwhile, only 36 percent of the respondents reported to consistent condom use with a sex worker.⁶²

In some cases, IEC focuses more on *what* HIV is than *how* to prevent it and *where* to obtain necessary services. For instance, a survey of sex workers in **Ukraine** demonstrated that even though knowledge about HIV transmission was high, levels of awareness about available services were much lower. Approximately 40 percent of respondents knew about governmental or nongovernmental organizations that provide services for sex workers and drug users, and only 27 percent had actually accessed these services.

Care and support for people living with HIV/AIDS

*The health system...is only concerned about keeping people alive,
not how they feel.*

—HIV/AIDS care specialist, Vietnam⁶³

People living with HIV/AIDS are subject to stigma, discrimination, poverty, illness, psychosocial stress, and other impacts of HIV/AIDS, yet many lack access to adequate care and support to deal with this array of issues, according to Public Health Watch researchers.

NGOs and community-based organizations have started to provide care and support activities ranging from peer counseling and self-support to home-based care, many with assistance from international donors.⁶⁴ However, in **Ukraine, Senegal, and Vietnam** these programs are available in urban centers only and rural residents lack access to care and support services. For instance, only a handful of large, national NGOs in the capital of **Senegal** that work closely with hospitals are currently involved in providing care and support for people living with HIV/AIDS. In the countryside, residents have reported serious shortfalls in care and support activities for people living with HIV/AIDS and their families, even though rural residents may be more vulnerable to HIV and its impact due to poverty, conflict, cross-border migration, and such traditional practices as polygamy, female circumcision, and widow inheritance.

Many home- and community-based caregivers also lack capacity and training opportunities. Caregivers in **Vietnam** do not have information on how to avoid infections or properly care for people living with HIV/AIDS, nor do they have ready access to food and supplies such as clothing, gloves or bleach. Communities and families are most often left to cope with the burden of caring for ill members themselves. However, governments in **Vietnam, Ukraine, and Senegal** have not allocated any resources to train or provide financial support to family and community caregivers. In addition, HIV/AIDS can make even potential community and family resources unavailable as fear of contagion often leads to discrimination against people living with HIV/AIDS. Many people living with HIV/AIDS claim that stigmatizing behavior most often comes from their immediate families and communities.⁶⁵

With the exception of the **United States**, where people who are able to access HIV care receive some of the highest quality care in the world, access to palliative care for AIDS patients is limited or unavailable in the other four countries. **Nicaragua** and **Senegal** do not maintain hospice facilities equipped to provide palliative care for HIV/AIDS patients. In **Ukraine**, neither palliative care nor use of opioid analgesics is defined in the legislation, and the All-Ukrainian Council for Patients' Rights and Security (UCPRS) estimates that less than 10 percent of patients' needs for opioid analgesics for pain management are met.⁶⁶

Access to essential pain management medication to alleviate severe, chronic pain among people living with HIV/AIDS is also limited in **Vietnam**.⁶⁷ Most hospitals are reluctant to stock opioid-based medicines and doctors are unwilling to prescribe them for fear of legal consequences. Due to the lack of appropriate pain management medication, many people living with HIV/AIDS suffer for a long time and die in severe pain, or turn to heroin or other drugs from the black market.⁶⁸

Stigma and Discrimination

The question in people's minds is why they got HIV in the first place.

Normal people don't get it. They must have done something to get it.

—Medical doctor, Vietnam⁶⁹

Although Public Health Watch researchers found that countering stigma and discrimination is a priority in their respective countries, progress has been slow, and people living with HIV/AIDS, particularly those in marginalized groups, report high incidence of stigma and discrimination. In some countries such as **Nicaragua** and **Senegal**, belief that HIV/AIDS is associated with “improper” sex and promiscuity, and therefore divine punishment from God, persists despite high levels of public knowledge about HIV/AIDS. Years of negative propaganda about HIV/AIDS in **Ukraine** in the 1980s and 1990s continues to influence popular attitudes toward those living with the disease. In **Vietnam**, the close link between HIV/AIDS and drug use and sex work, which are widely regarded as “social evils,” has contributed to HIV/AIDS-related stigma. Acts of stigma and discrimination not only violate the rights of people living with HIV/AIDS or marginalized groups, but often hinder access to important services.

In the **United States**, HIV/AIDS and discrimination is a two-way relationship; many believe discrimination is at the root of current status of the epidemic, which disproportionately affects African Americans and the poor. The legacy of racial discrimination and ongoing poverty in the southern region of the country has put individuals and communities at elevated risk of infection and complicate efforts to deliver appropriate HIV care, and as a result, the region has led in the number of new AIDS diagnoses for years. It is estimated that nearly four out of ten of people living with AIDS reside in the South.

Health care setting

Health care personnel discriminate against HIV/AIDS patients and this represents the principal source of confidentiality breaches.

—Medical doctor, Nicaragua⁷⁰

Ironically, stigma and discrimination are particularly frequent in health care settings, illustrating a need to provide accurate information about HIV transmission to health care providers. In **Ukraine**, approximately two-thirds of all reported cases of discrimination against people living with HIV/AIDS occur in hospitals and other medical facilities.⁷¹ Doctors some-

times refuse to operate on HIV-positive patients,⁷² and in some cases, people living with HIV/AIDS are forced to leave hospitals out of fear they could infect other people.⁷³ Beyond refusal of treatment, many people living with HIV/AIDS recounted unpleasant experiences, ranging from doctors wearing plastic gloves over heavy gardening gloves during a gynecological exam, to nurses fainting in fear when patients disclosed their HIV status.⁷⁴ In addition, people living with HIV/AIDS, like others seeking medical assistance, reported that health care workers often request payment as a condition for delivering services despite existing legislation that guarantees free treatment and care.⁷⁵ According to a 2004 survey, drug users said they were charged fees for services at medical or drug treatment centers about 60 to 70 percent of the time.⁷⁶

A doctor in **Nicaragua** noted that one surgeon “kicked up a fuss when [he] realized that a patient they had just operated on had AIDS,” and health care workers are “highly alarmed when they [find] HIV-positive patients drinking coffee in the cafeteria also used by them.”⁷⁷ Investments have been made to train doctors on mechanisms of infection and biosafety measures; however, some doctors refuse to attend training courses.⁷⁸

There are laws prohibiting discrimination against people living with HIV/AIDS in the **United States**, but such discrimination certainly exists and is one additional factor inhibiting access to care and treatment.⁷⁹ In addition to medical care, discrimination against people living with HIV/AIDS has also been reported in employment, child custody, and housing.⁸⁰

Wrongful disclosure

Illegal HIV testing and confidentiality breaches also contribute to stigma and discrimination and prevent people from being tested and seeking other services. Approximately 40 percent of people living with HIV/AIDS surveyed in **Ukraine** indicated that they were tested without consent,⁸¹ and among those who tested voluntarily, only 30 percent had been given both pre- and post-test consultations. In addition, over 41 percent reported that medical staff had disclosed their HIV-positive status to relatives or employers without their consent,⁸² which can lead to serious consequences. One of the most common complaints of people living with HIV/AIDS is loss of employment once their HIV status has been revealed—despite legislation that prohibits discriminatory denial or dismissal from employment.⁸³

Disclosure of status can also lead to discrimination from families and communities. In **Senegal**, married women “often get divorced when their status is disclosed, even if it’s the husband who infected her.”⁸⁴ Fear of rejection by family members led one woman to keep her status secret for 12 years; she died during childbirth because she refused medical assistance in case her HIV status would be revealed.⁸⁵ In **Nicaragua**, stigma and

discrimination lead to the seclusion of HIV-positive individuals to their own homes for fear of being called “*sidosos*.”⁸⁶

Women

When a pregnant woman who is HIV-positive goes to the hospital, her case is passed from nurse to nurse because no one wants to deal with an HIV-positive person.

—*Woman living with HIV/AIDS, Senegal*⁸⁷

Women tend to be stigmatized more severely than men in **Vietnam** because of the assumption that HIV is acquired through “immoral” means and the social expectation that women should uphold the moral integrity of family and society. While in some countries pregnant women are prioritized for ARV treatment in order to prevent mother-to-child-transmission, their greater likelihood of needing health care also means more chances to encounter discrimination. In a survey of 40 pregnant HIV-positive women in **Ukraine**, the majority reported that they had been pressured by medical personnel to have an abortion,⁸⁸ despite the fact that prevention of mother-to-child transmission (PMTCT) services, including appropriate use of nevirapine and safer breastfeeding techniques, can significantly lower the risk of HIV transmission. Many also noted that health care personnel were slow to respond to their requests for help—they were kept waiting while others were treated, and that they were often separated from other patients. Similarly in **Senegal**, pregnant women are passed from one nurse to another. The stigma continues to plague HIV-positive women even after childbirth. “When HIV-positive women don’t breastfeed their babies, people talk and assume that it’s because they are sick.”⁸⁹

Marginalized populations

Marginalized populations, including drug users and sex workers, also face substantial stigma and discrimination. For example, a **Vietnamese** government official commented, “I agree that we shouldn’t discriminate against HIV-positive patients. But I can not agree that we shouldn’t discriminate against drug users and sex workers. They are illegal. Even by law, they are criminals. And you see drug users create chaos in society. How can you not be angry? They must be discriminated against.”⁹⁰ Even a member of a self-help group of people living with HIV/AIDS asserted that drug users should be locked up in forced rehabilitation centers since they “commit crimes.”⁹¹

Injecting drug users in **Ukraine** report severe mistreatment. Many health facilities refuse to admit or treat active drug users, and doctors frequently call the police to turn in a patient as an injecting drug user if they see an abscess. These practices lead drug users to avoid seeking treatment or to administer home remedies on their own.⁹² The police, who are often ill-informed about the requirements of AIDS treatment, have been known to confiscate ARV drugs at the time of arrest, forcing patients to interrupt their treatment.⁹³

In the **United States**, advocates have raised concerns that most AIDS housing programs actively discriminate against people who use illegal drugs, making it more difficult to bring drug users into care and help them adhere to treatment regimens.

In some countries, men who have sex with men face stigma and discrimination regardless of their HIV-status. For instance, in **Senegal**, one man who has sex with men admitted, “As soon as people know... the reaction of health staff becomes aggressive, and their derogatory looks discourage any attempt to solicit care... many doctors who refuse to treat us often do so in the name of religion, as they fear that a spell would be cast on them for having spoken to or touched us.”⁹⁴ Due to the enormous stigma against same-sex relationships, an overwhelming majority of men who have sex with men have relationships with women to conceal their sexual orientation.⁹⁵

Lack of legal recourse

Many countries lack mechanisms to protect people living with HIV/AIDS or marginalized populations from stigma and discrimination. Despite many reported incidents of stigma and discrimination against people living with HIV/AIDS in communities, hospitals, and workplaces, no formal complaints have been registered in **Senegal** due to the lack of legal recourse.

The government has strengthened legal protection of people living with HIV/AIDS in **Vietnam** in recent years, but enforcement mechanisms are still lacking: there is no ombudsperson or a channel through which to lodge complaints. Likewise in **Ukraine**, there has been minimal effort to provide clear and accessible information about mechanisms that can protect people living with HIV/AIDS against discrimination, and as a result, legal provisions that provide some measure of protection to people living with HIV/AIDS are often violated. The AIDS law’s clear provisions on voluntary counseling and testing are not observed in practice: HIV tests are often given without consent, particularly in TB hospitals and drug clinics.⁹⁶ Clients in drug and TB clinics, who are at high risk of being HIV-positive, often have little or no information about their rights.

In the **United States**, legislation outlawing discrimination against people with disabilities makes no specific mention of HIV/AIDS, so the extent to which people living

with HIV/AIDS are protected at the federal level is not entirely clear. The 2004 Kaiser Family Foundation Survey of Americans on HIV/AIDS indicated that 28 percent of respondents would be “somewhat” or “very uncomfortable” working with someone who has HIV/AIDS.⁹⁷

Media

Public Health Watch researchers found that media coverage of HIV/AIDS is often superficial and fails to convey useful or accurate information. At worst, the media can contribute to the increase of HIV/AIDS-related stigma by publishing sensational stories about HIV transmission or widely disclosing HIV-positive status.

There is no independent and professional media sector in **Vietnam**, and there are a limited number of journalists who are trained to cover AIDS-related stories. As a result, media coverage of HIV/AIDS has been weak; articles on AIDS are infrequent and tend to focus either on high-level speeches or sensational stories. For instance, newspapers report cases about HIV-positive drug users attacking police officers and security guards with used needles and claim that such attacks are common.⁹⁸ Stories like these help feed perceptions that drug users “deserve to get infected,” and work to exacerbate stigma against all drug users and other marginalized groups.⁹⁹

The media in **Senegal** hinder people from coming forward to report cases of stigma and discrimination. One person living with HIV confided that “we have to give up [formulating complaints] for fear that the media would seize the opportunity to reveal our HIV status to the general public.”¹⁰⁰

In **Ukraine**, years of negative propaganda about HIV/AIDS still color public attitudes about people living with HIV/AIDS, as noted above. Accurate and up-to-date information about HIV/AIDS is not widely available, and there is widespread ignorance of how HIV is transmitted. One survey found that only 14 percent of those aged 15 to 24 years were fully informed about modes of HIV transmission: 70 percent thought they could get the disease from an insect bite.¹⁰¹ Such low levels of public awareness fuel fears and misconceptions about the disease, and in this environment, it is not surprising that people living with HIV/AIDS claim that they frequently experience discriminatory and even illegal treatment.

Barriers to Access

It is a big lie that Nicaragua has universal access to ARV treatment...

—*Agua Buena Foundation, Nicaragua*¹⁰²

Access to ARV treatment and treatment for opportunistic infections has increased dramatically in several of the five countries in recent years. For example, the number of people on ARV treatment in **Ukraine** increased from 268 in 2004 to over 4,000 by mid-2006.¹⁰³ (However, an estimated 17,300 people are still without access to ARV treatment.¹⁰⁴) Even with these gains, the four low- to middle-income countries Public Health Watch monitored—**Nicaragua**, **Senegal**, **Ukraine** and **Vietnam**—fell short of the “3 by 5” target of providing treatment to at least half of those in need,¹⁰⁵ and whether they will be on track to achieve universal access by 2010 remains to be seen. In **Nicaragua**, it is estimated that only 16 percent of all people living with HIV/AIDS receive ARV treatment, despite legislation that stipulates free access to all.¹⁰⁶ Even in the **United States**, which spends nearly \$16 billion a year on HIV/AIDS domestically, approximately 50 percent of all people living with HIV/AIDS are not receiving regular HIV-related health care, and half of those who meet the government medical criteria for ARV treatment are not receiving it^{107, 108} due to inequities in the health care system, and structural issues such as discrimination and poverty.

Several barriers to accessing care and treatment have been identified in all five countries. For instance, there are hidden costs associated with treatment such as fees for diagnostic tests and transportation costs. When treatment is available, there is often inadequate follow-up to ensure adherence and to monitor treatment efficacy and side effects.

Hidden costs of treatment

Unless the whole package of care is provided, it's not effective treatment.

We still ask people to pay fees for services when they're poor. If we want to guarantee access, we must make it free.

—*Person living with HIV/AIDS, Senegal*¹⁰⁹

Significant hidden costs constitute a major barrier to access to treatment. **Senegal** was the first sub-Saharan African country to establish an ARV program in 1998 and is currently one of the few African countries to provide free treatment.¹¹⁰ However, diagnostic tests (beyond HIV and CD4 count tests) and treatment for opportunistic infections require fees, with the exception of TB treatment.¹¹¹ A simple blood test to determine efficacy of treatment during

a semi-annual check up costs 5,500 CFA, (about \$11)¹¹² in a country where per capita gross national income is approximately \$700.¹¹³

In **Vietnam**, results from fee-based testing are a prerequisite for enrollment in the free ARV treatment program. For poor patients, such testing fees often present an insurmountable barrier to treatment. The AIDS law in **Ukraine** also stipulates free ARV treatment and other medical care, but patients often have to pay out-of-pocket for diagnostic tests and treatment of opportunistic infections. Hospitals referring patients for treatment are also required to reimburse them for transportation costs to and from treatment centers, but the majority of hospitals do not have a separate budget allocation for transportation and cannot afford to cover such expenses.

In addition to payment for diagnostic tests and treatment, people living with HIV/AIDS often have nutritional and other care and support needs that require additional resources. One person living with HIV/AIDS in **Senegal** explained, “We should eat well, as the drugs we take have to be accompanied with good food....[but] the majority of us are poor.”¹¹⁴ However, such comprehensive support is not available in any of the five Public Health Watch countries.

Marginalized populations

Marginalized populations such as injecting drug users have unequal access to treatment. Worldwide, an estimated 36,000 injecting drug users were receiving ARV treatment by the end of 2005, of which 80 percent were in Brazil, with the remaining patients distributed across nearly 50 countries.¹¹⁵ There is no accurate global aggregate estimate on the number of injecting drug users in need of ARV treatment, but evidence suggests their access to treatment is far below the proportion of HIV cases attributable to injecting drug use. For instance, in Central and Eastern Europe, less than 14 percent of people on ARV treatment are current or former injecting drug users though injection drug use accounts for more than 80 percent of HIV cases.¹¹⁶ When ARV drugs first became available in **Vietnam**, active drug users were excluded from treatment programs. This prohibition was officially lifted recently, but injecting drug users are still subject to discrimination in accessing treatment. Many health care workers and even some people living with HIV/AIDS consider drug users to be unreliable and unable to adhere to treatment. One provincial AIDS official explained, “Drug users don’t care about anything, so they don’t need ARVs.”¹¹⁷

People living with HIV/AIDS suspected of being drug users in **Ukraine** are often denied treatment, expelled from hospitals, provided with inadequate services, or are forced to pay for services that should be free.¹¹⁸ Moreover, lack of broad access to substitution therapy means that many HIV-positive drug users find it difficult to stay in hospitals where

full detoxification is required upon admittance.¹¹⁹ Reportedly, doctors keep addicted patients in locked wards to prevent them from taking drugs while in the hospital.¹²⁰

People with substance abuse or mental health problems also face increased barriers to receiving HIV care and adhering to treatment regimens in the **United States**.¹²¹ The government acknowledges that lower access to and utilization of HIV care among injecting drug users involves several factors, including “active drug use, younger age, female gender, suboptimal health care, not being in a drug treatment program, recent incarceration, and lack of health care provider expertise.”¹²²

Geographical disparity and transportation costs

People sometimes have to travel more than 100 kilometers to get to the nearest health center, which can take four to six hours each way. That's why patients don't return for follow-up visits or to get their test results. And care and support should not be based in a referral hospital, but in communities so it's more accessible for people.

—Local official in Senegal¹²³

In some countries, there is stark geographical disparity in access to treatment. In **Senegal**, the majority of the approximately 5,900 people on ARV treatment are in the capital, Dakar.¹²⁴ People in rural areas in the **United States** also face a variety of barriers to HIV/AIDS care, including “geographic isolation, poverty, unemployment, lack of education, lack of childcare services, and attitudinal and cultural factors.”¹²⁵

Regional disparities in access to care often stem from weak health care systems and lack of human resource capacity outside of cities. Technical capacity tends to be concentrated in capital cities and other major urban centers. Despite an incipient decentralization process in **Nicaragua**, ARV distribution is still extremely centralized, and rural populations must often travel great distances to receive treatment. Primary health care centers lack basic supplies, infrastructure or personnel to carry out HIV/AIDS diagnostic tests and counseling,¹²⁶ and some regions lack infectious disease specialists and do not have the capacity to store clinical samples. Out of approximately 80 physicians trained to prescribe ARVs in **Senegal**, more than 50 are in Dakar.¹²⁷ Until recently, only doctors could prescribe ARVs in Senegal, and since many rural clinics are staffed with nurses only, patients had to travel to nearby towns. There are now a few national NGOs approved to dispense ARVs, but these are primarily based in Dakar and other major cities as well, which does little to improve accessibility in rural areas.

Due to limitations in numbers of facilities and trained physicians in rural areas, transportation costs—both in time and money—are serious burdens, and effectively deny medical care, including AIDS care, to a large portion of the rural population. In **Vietnam**, transportation, food, and lodging increase the financial burden associated with treatment for those who live far from ARV clinics. For example, a person from a district in Quang Ninh will have to take several buses and local transportation to get to a hospital in Hanoi with a CD4 count machine, where he or she may have to wait a day or two for the test. A single trip—combined with the cost of the test itself—could cost a minimum of 700,000 to 800,000 VND (approximately \$50), or almost 10 percent of an average individual’s annual income.¹²⁸

Lack of adherence monitoring and treatment literacy

Many people don't know what drugs they are taking...and why they need to take them, so problems like side effects are not dealt with. People just stop taking the drugs.

—Person living with HIV/AIDS, Senegal¹²⁹

Public Health Watch researchers found that many people on treatment are not regularly monitored. In **Nicaragua**, the lack of access to diagnostic and maintenance tests leads to incomplete follow-ups, and antiretroviral drugs are frequently provided without any kind of counseling or support.¹³⁰

Of nearly 5,900 people on ARV treatment in **Senegal**, approximately half are followed up with on a regular basis to ensure adherence to treatment and to monitor side effects and effectiveness of treatment.¹³¹ In the absence of regular monitoring, AIDS activists emphasize the importance of treatment literacy to educate patients about their treatment and possible side effects.

Financial resources and sustainability

Insufficient financial resources also pose a barrier to access to treatment and other services. For instance, an official in **Vietnam** admitted that the government’s investment in HIV/AIDS programs is inadequate.¹³² With the exception of the **United States**, all Public Health Watch countries rely on donor support to implement HIV/AIDS programs. In some countries, donor funding represents the bulk of resources available for HIV/AIDS, which raises questions of sustainability.

Despite significant increases in both domestic and international donor support, the total funding available in **Ukraine** is not sufficient to address the scale of the epidemic. In 2005, total spending on all HIV/AIDS-related programs and services amounted to approximately \$40 million,¹³³ while an estimated \$50 million per year would be required to provide ARV treatment to all 17,000 people who need it,¹³⁴ not to mention the cost of prevention and care services. The financial gap between overall needs for the 2007–2011 period and committed contributions exceeds \$464 million, only 24 percent of which will be covered by Global Fund Round 6 funding if disbursed in full.¹³⁵

In **Senegal**, government contributions to the national AIDS budget for the 2002–2006 period amounted to approximately 14 percent¹³⁶ while the World Bank and the Global Fund, the largest donors, contributed 38 and 6 percent of the total budget, respectively.¹³⁷ While activists acknowledge that Senegal cannot afford to finance an effective and comprehensive HIV/AIDS response without donor support, they believe donor funding can be more strategically utilized to ensure sustainability, for instance by helping to build local capacity.¹³⁸ Some stakeholders point to the financing of the executive secretariat of the *Conseil National de Lutte contre le SIDA* (National Council for the Fight against AIDS, or CNLS) by a single donor as short-sighted, as it creates uncertainties in sustaining a critical entity responsible for coordinating the national response.

Lack of coordination

Donors and the government do not have a single, common paradigm on HIV/AIDS. There is no consensus among donors or within the government about how to address problems.

—Denis Poltavets, HIV/AIDS consultant, Ukraine¹³⁹

There is food for the pig, but not in the trough, so the pig stays hungry.

—Local Communist Party official, Vietnam¹⁴⁰

Public Health Watch researchers found that lack of coordination between international donors and governments, between governments and NGOs, and among NGOs can also hinder implementation of necessary interventions and create barriers to access.

Some **Vietnamese** officials have voiced concern that donors are pushing their own agendas without regard to Vietnam’s priorities and objectives.¹⁴¹ For instance, the U.S. President’s Emergency Program for AIDS Relief (PEPFAR) has promoted the “AB” approach (abstinence and be faithful) but not condom use, and does not permit the use of its funds

to purchase clean needles for drug users—whereas condoms and clean needles have been promoted by the Vietnamese government since the approval of the National Strategy on HIV/AIDS in 2004. On the other hand, the United States does allow the use of its funds for substitution therapy (although limited to HIV-positive drug users), which was not permitted in Vietnam until its AIDS law was passed in June 2006. Due to these conflicting policies between the donor and recipient countries, PEPFAR funding has not been utilized to fund harm reduction interventions, which the Vietnamese government has identified as a priority.

The government's difficulties in managing and coordinating its HIV/AIDS programs have led some multilateral donors to reconsider their funding support in **Ukraine**. In April 2006, the World Bank suspended a \$60 million, four-year project to stop the spread of HIV and TB due to the government's failure to distribute funds and implement programs.¹⁴² The loan has since been reinstated (in November 2006),¹⁴³ but the incident resulted in significant delays in implementation of projects that are urgently needed. In addition, donors in Ukraine have expressed dissatisfaction about difficulties coordinating with government on policy. For example, even though substitution therapy is not prohibited by law, requests from NGOs and international organizations to the Ministry of Internal Affairs to buy methadone abroad for use in Ukraine had repeatedly been denied.¹⁴⁴ Methadone was finally registered in December 2006 and will be piloted for up to 300 patients in 2007,¹⁴⁵ far below the estimated 60,000 to 238,000 drug users in need of substitution therapy.¹⁴⁶

While there are some consultations between donors and the government to determine priorities in **Senegal**, donors can and do exert significant influence over the design and implementation of HIV/AIDS policies. For example, from 2003 to 2005, the main focus of the National AIDS Council was on general social mobilization and prevention, reflecting the World Bank's priorities, even though the National Strategic Plan had identified care and support for people living with HIV/AIDS as a priority and epidemiological data pointed to a need to target high risk groups.

TB/HIV coinfection

The majority of people living with HIV/AIDS are drug users, and about half of them have TB, so it's important that these programs cooperate better. People shouldn't have to visit up to three clinics to get proper treatment. Patients in TB clinics should be able to get ARVs.

—Roundtable participant, Ukraine¹⁴⁷

TB is the leading killer of people living with HIV/AIDS. In the five countries where Public Health Watch conducted research, TB/HIV coinfection rates were reported at levels as high as 55 percent among some populations.¹⁴⁸ However, few countries offer integrated services for TB and HIV/AIDS, which hinders access to comprehensive care.

Resurgence of TB and TB/HIV coinfection

The HIV/AIDS epidemic has led to a resurgence of TB in many countries. Despite achieving a case detection rate of 89 percent and a treatment success rate of 92 percent, far exceeding established international targets for TB control, there have been no signs of decline in **Vietnam's** TB burden.¹⁴⁹ The number of HIV-positive TB patients has increased ten-fold since 1995,¹⁵⁰ and TB is becoming more difficult to treat because 10 percent of TB patients are also coinfecting with HIV, according to the National TB Control Program.¹⁵¹

High rates of TB/HIV coinfection have also been reported in the **United States** and **Senegal**. The U.S. CDC estimates that 9 percent of all people living with HIV/AIDS and 16 percent of people living with HIV/AIDS aged 25 to 44 years also have TB. In **Senegal**, HIV prevalence among TB patients is estimated at approximately 15 percent in Dakar and Kaolack.¹⁵² One physician in Dakar estimates that out of 2,000 registered HIV-positive people in his facility, approximately 30 to 40 percent have TB.¹⁵³

In **Ukraine**, TB has been spreading in parallel with the HIV/AIDS epidemic. The number of cases of HIV-associated TB has been increasing by approximately 23 percent a year over the last several years. In 2004, TB was diagnosed in 55 percent of all AIDS cases,¹⁵⁴ and TB is the leading cause of death among AIDS patients, accounting for over 1,300 or 60 percent of AIDS-related deaths in 2005 alone.¹⁵⁵

TB/HIV coinfection is a particular risk for marginalized groups such as injecting drug users in **Ukraine**. As indicated earlier, incarceration rates are high among drug users. Continued drug use in prisons,¹⁵⁶ coupled with limited HIV prevention and drug treatment services, and crowded, suboptimal living conditions, all significantly elevate the risk of contracting HIV and/or TB. A recent study revealed that the current TB treatment system is not

reaching the vulnerable and marginalized groups who are most likely to acquire TB infection. Individuals who are homeless, jobless or have substance abuse problems are much more likely to visit TB clinics and hospitals at an advanced stage of TB disease, and therefore exhibit high mortality rates and a greater risk of infecting others.¹⁵⁷

While TB incidence has declined by 50 percent in the past 10 years in **Nicaragua**,¹⁵⁸ experts worry the accelerated spread of HIV/AIDS could lead to a resurgence in TB and to the development of drug-resistant strains.

Lack of coordination between HIV/AIDS and TB programs

Despite evidence of increased TB/HIV coinfection and the clear linkage between drug use and HIV/AIDS in **Ukraine**, there is currently little coordination between HIV/AIDS, TB, and drug treatment programs. A part of Ukraine's Soviet health system management legacy is that separate vertical institutions and programs deal with these issues all under the umbrella of the Ministry of Health. Policies and programs in each area are developed and managed by specialists, who are reluctant either to relinquish control over their area of expertise or to cooperate with other sectors. The integration between TB and HIV/AIDS programs is expected to improve upon implementation of the Global Fund Round 6 grant. The recently approved proposal addresses several barriers to effective management of TB/HIV coinfection, including lack of unified protocols and trained specialists, and lack of access to TB services for injecting drug users and people living with HIV/AIDS.¹⁵⁹

Although many governments have made efforts to link HIV/AIDS and TB programs, often with assistance from international donors, implementation has been weak. The WHO provided technical assistance to the Ministry of Health in **Senegal** to develop standards and protocols for TB/HIV integration, but the guidelines are still in development, and a strategy document designating specific roles, responsibilities, and objectives has not yet been adopted. In the meantime, TB and HIV/AIDS programs are managed in parallel by two independent departments. Despite the lack of central level coordination, some facilities have managed to integrate service delivery. For example, every TB patient is encouraged to test for HIV and vice versa at the *Centre de Traitement Ambulatoire* (Ambulatory Treatment Center, or CTA) in Dakar.¹⁶⁰

Nicaragua's Ministry of Health integrated its HIV/AIDS and TB programs and adopted protocols for the treatment of coinfecting patients, but has not been able to achieve efficient coordination of the two programs in practice. In **Vietnam**, the government called for the establishment of TB/HIV coordinating committees at all levels of government to pilot collaborative TB/HIV interventions in 2004, but such committees have not yet been established.¹⁶¹ Recently, the Life-GAP project, funded by the U.S. CDC, piloted TB/HIV col-

laboration in three provinces, which may help to establish best practices in implementing joint TB/HIV activities.

There are several guidelines for diagnosing and treating TB/HIV coinfection in the **United States**,¹⁶² but these guidelines are not adhered to in all settings. For example, one study of TB prevention efforts in city and county jails found that fewer than half of all prisons surveyed had policies in place to offer HIV testing to patients who test positive on TB skin tests.¹⁶³

Accountability

Despite committing publicly to fight HIV/AIDS, not all governments have either established a multisectoral body to effectively coordinate a response to HIV/AIDS or adopted a comprehensive national strategy. In addition, many national AIDS coordinating bodies fail to facilitate meaningful engagement in the policymaking process by civil society organizations, which limits their ability to hold governments to account for policy implementation.

National coordinating body

Both the **United States** and **Nicaragua** lack a comprehensive national AIDS strategy; in the case of the **United States**, this is despite professed commitments of political leaders and a domestic HIV/AIDS budget of nearly \$16 billion a year. Without a national strategy across federal, state, and local agencies that identifies clear roles, responsibilities, and timelines to achieve measurable results, and without a single national authority to coordinate the efforts of multiple agencies, it is difficult to set meaningful targets and objectives, ensure measures are taken to accomplish them, and hold agencies accountable for their realization. In the meantime, the number of new HIV infections in the **United States** has remained constant, at 40,000 per year for more than a decade, and more than half the people living with HIV/AIDS are not receiving appropriate care.

Nicaragua's national strategic plan expired in 2004 and the 2006–2010 plan is still in draft form. This constitutes one of the principal obstacles to coordinated development and implementation of programs to address HIV/AIDS at the national level. Moreover, the draft plan for 2006–2010 lacks a monitoring and evaluation strategy. Without explicit benchmarks and targets on prevention, treatment, and care it will be difficult to hold implementing authorities accountable for progress, and could lead to disappointing outcomes.

In **Ukraine** and **Senegal**, national AIDS coordinating bodies largely fulfill donor requirements and serve donor-funded projects. The National Coordinating Council (NCC) in **Ukraine** was created to satisfy Global Fund requirements for a multisectoral body with civil society representation.¹⁶⁵ While the NCC's innovative structure presented a unique opportunity for broader stakeholder participation in policymaking, its effectiveness as a coordinating body has been severely limited by the lack of clear lines of authority and reporting requirements, and by the absence of accountability mechanisms. The NCC has not met quarterly as required by the 2005 Resolution (no meetings were held between June 2005 and April 2006); its primary function to date has been to submit proposals to the Global Fund, convening just before fund application deadlines on an ad hoc basis. For example,

in the period between the call for Round 6 proposals in May 2006 and the completion of Ukraine's proposal in August 2006, the NCC met four times.¹⁶⁶ In addition, decisions by the NCC were originally supposed to be implemented by other government ministries and agencies, but due to challenges to its legitimacy from high-ranking officials, it was downgraded to an advisory role in October 2006.¹⁶⁷

The CNLS (the equivalent of the National AIDS Council) in **Senegal** has focused primarily on coordinating projects funded by the World Bank and the Global Fund, rather than providing a platform for coordinating all stakeholders' interventions, including those of civil society and religious groups. One local NGO representative summarized, "It's like they are holding up the flags of the World Bank and Global Fund rather than holding up the Senegalese flag."¹⁶⁸

In **Vietnam**, the multisectoral National Committee for AIDS, Drug, and Prostitution Control (NCADP) has actually contributed to increased stigma on HIV/AIDS by reinforcing the link between HIV/AIDS and "social evils." NCADP is supposed to set national priorities, coordinate all program activities, and oversee implementation of the relevant strategy for each of the three program areas, but without sufficient resources or staff support, it does not exercise meaningful authority over these programs. The national AIDS program is managed by the Ministry of Health in practice. Due to the NCADP's limited focus, it is ill-prepared to effectively address the increasing risk of sexual transmission within the general population. A truly multisectoral approach to HIV/AIDS control would need to coordinate closely with other ministries and programs beyond those responsible for controlling drug use and sex work, including education, transportation, and labor.

Monitoring and evaluation

It is only in name that people living with HIV/AIDS are on the CCM. All other CCM members—they have a job, they have a salary. I have no job and no income but they keep asking me to participate in meetings, and so many meetings! What do I live on? Do they care about that? Before each meeting, they send us a lot of documents. Who can read all of them? And even when I try to read them, I don't understand.

—Person living with HIV/AIDS, Vietnam¹⁶⁹

People who live with HIV/AIDS are convened to validate [the government's strategies] but in the end their recommendations are not taken into account; these people are being used so the government can claim that it has consulted with civil society groups.

—Nicaraguan Network meeting on human rights and HIV/AIDS¹⁷⁰

A number of the five countries examined by Public Health Watch lack a comprehensive monitoring and evaluation system, and few processes allow for civil society input and participation. In countries where civil society groups do provide project-level data, they do not receive feedback or are excluded from data analysis processes. As a result, it is difficult for citizens to hold governments accountable for measurable results. While there is some representation of civil society—including people living with HIV/AIDS—on national level enforcement bodies such as the Global Fund Country Coordinating Mechanism (CCM), many informants participating in this research felt the CCM representation is often tokenistic.

For example, two people living with HIV/AIDS serve on the CCM in **Vietnam**. However, one representative expressed that his role is more symbolic than substantive, and that he is not motivated to stay involved since he doesn't have the capacity or level of support he would need to participate meaningfully.¹⁷¹ At the same time, organizations of people living with HIV/AIDS expressed disappointment at the way the CCM has selected HIV-positive and other civil society representatives, and that these representatives have not reached out to the larger constituency they are meant to be representing.¹⁷²

Civil society representatives have not been involved in the development of the monitoring and evaluation framework in **Vietnam**, nor have they been informed about its progress. In general, civil society representatives have had minor and occasional involvement in monitoring and evaluation at the project level, but not on a national scale.

Several advocacy groups in the **United States** raised concerns that the 2004 Program Evaluation and Monitoring System (PEMS) introduced by the CDC did not adequately consult community organizations during the development stage and that the gathering and reporting of the information required by PEMS will complicate HIV prevention outreach activities.¹⁷³ The CDC then announced in March 2006 that it would suspend implementation of PEMS in response to community concerns.

In **Ukraine**, various governmental and nongovernmental agencies collect a considerable amount of data, including epidemiological information, behavioral and socioeconomic surveys, financial management, and project-specific impact assessments.¹⁷⁴ However, there is no central agency to coordinate or amalgamate these efforts, and as a result they tend to stop short at evaluating individual organizations or programs rather than national-level policy. There are also gaps in important areas, such as programs that target marginalized populations.

National level monitoring and evaluation efforts are often driven by donor requirements for quantitative indicators, as is the case in **Senegal**. The national monitoring and evaluation system is comprised largely of indicators that take into account data from projects implemented by CNLS, the majority of which are funded by the World Bank and the Global

Fund. A group of NGOs have criticized the narrow scope, stressing that national monitoring and evaluation should consider the entire national response, not just the government response,¹⁷⁵ and should consider progress reports from the community level to help build capacity and to allow local needs to guide the response.¹⁷⁶ NGOs never receive feedback on the data they submit to the government, nor is the information they submit reflected in national monitoring and evaluation reports, according to one NGO staff member.¹⁷⁷ There are no mechanisms in place to support analyses of data at the local and regional levels, which limits ownership of information.

As described earlier, Public Health Watch researchers have had mixed success in participating in national processes to ensure implementation of international commitments such as the UNGASS Declaration. With the exception of the **United States**, researchers in all countries participated in meetings organized by UNAIDS or the government to discuss national progress data or draft reports, though the researchers' input was not always taken into account in the final drafts of national progress reports submitted to UNAIDS. The process of conducting community-based research allowed some researchers to participate in the UNGASS process more actively. In **Senegal**, a draft of the Public Health Watch report was presented alongside the government's national UNGASS progress report at a roundtable meeting in April 2006 to promote and facilitate open dialogue between civil society and government perspectives on Senegal's progress in upholding the UNGASS commitments. The **Vietnamese** researcher was selected as one of four civil society representatives of the official delegation to the UNGASS high-level review meeting at the UN in May–June 2006; this was the first time civil society was invited to participate in such a high-level delegation.

Conclusion

The Public Health Watch HIV/AIDS Monitoring Project reports for Nicaragua, Senegal, Ukraine, the United States, and Vietnam indicate that marginalized populations, including injecting drug users, sex workers, men who have sex with men, prisoners, and ethnic minorities, are disproportionately impacted by HIV/AIDS. However, the research also found that these groups continue to be excluded from the design, implementation, and evaluation of national HIV/AIDS policies and programs.

Universal access to HIV/AIDS prevention, treatment, care, and support can only be achieved by addressing the needs of these marginalized, most affected populations. National governments, donors and international agencies must collaborate closely with civil society and marginalized people in order to understand their needs, develop appropriate strategies, and implement effective programs.

Civil society representatives must look ahead to the UNGASS review meeting in 2008, which will be the halfway mark between the agreement to establish national universal access targets in 2006 and the deadline by which to achieve these targets in 2010. There is an opportunity now to strengthen the UNGASS review process at both national and international levels. This must include efforts to enhance the role of civil society—and thereby strengthen the voice of marginalized populations—in the review process, and in the development and implementation of programs that can move us toward the goal of universal access.

Recommendations

Based on the research conducted by Public Health Watch partners in Nicaragua, Senegal, Ukraine, the United States, and Vietnam, a number of recommendations have been formulated. These are addressed to national governments, UNAIDS, and civil society. They aim to ensure that civil society perspectives, and the needs of marginalized populations, are taken into account in the ongoing assessment of national governments' progress against the commitments they signed up to in the UNGASS Declaration.

To national governments:

- Increase public awareness about the UNGASS commitments and review processes through mass media campaigns; disseminate national universal access targets and plans for monitoring progress toward achieving them;
- Implement UNAIDS recommendations as stipulated in the *Guidelines on Construction of Core Indicators* to ensure civil society participation in the national UNGASS review report preparation process, including *at minimum*:
 - providing civil society access to data collection plans and mechanisms for submitting input;
 - convening a workshop to determine how civil society can best support the UNGASS review process;
 - providing opportunities for civil society to review and comment on the draft national UNGASS review report; and
 - widely disseminating the national UNGASS review report once it is submitted to UNAIDS;
- Ensure more meaningful participation of civil society in the UNGASS review process by: building civil society capacity; allowing civil society to select their own representatives in consultative meetings; designating a representative or agency responsible for engagement with civil society; holding a series of meetings throughout the review process; and following through on civil society input and recommendations; and
- Collaborate with UNAIDS and other international agencies and donors to ensure there is sufficient technical support to conduct an inclusive and transparent UNGASS review process.

To UNAIDS:

- Provide technical assistance to national governments to raise public awareness about UNGASS and universal access, and better equip governments to effectively solicit input from civil society into national HIV/AIDS planning and reporting, including the UNGASS review process;
- Emphasize the particular importance of civil society input in the National Composite Policy Index (NCPI) component of the UNGASS review report, and provide technical support to civil society organizations—including people living with HIV/AIDS and those representing marginalized populations, in particular—to ensure they understand the reporting process, indicators, and ways to collect, analyze, and submit data;
- Establish and widely disseminate concrete plans to consult with civil society regarding their participation in the UNGASS reporting process at the national level and in submitting shadow reports directly to UNAIDS as stipulated in the *Guidelines on Construction of Core Indicators*, including designation of a primary point person responsible for liaising with civil society; and
- Ensure the accuracy and validity of national UNGASS progress reports by encouraging integration of civil society perspectives into national reporting processes, and suggesting national level discussions where alternative perspectives in civil society shadow reports differ significantly from official national reports.

To civil society:

- Take full advantage of representation opportunities, such as positions on the Global Fund Country Coordinating Mechanisms or national AIDS committees, by representing the concerns of broader constituencies and maintaining consistent contact with these groups;
- Learn about the UNGASS and universal access processes and share information with other civil society organizations about these initiatives and the right of civil society to participate in them;
- Seek technical assistance from UNAIDS and others, as appropriate, to ensure civil society perspectives are adequately represented in national UNGASS review processes and in implementing policies and programs to achieve universal access by 2010; and
- Advocate for universal access to prevention, treatment, care and support for all, particularly marginalized, high-risk populations.

Notes

1. The UN General Assembly adopted a resolution in December 2005 requesting UNAIDS and its cosponsors to “scale up HIV prevention, treatment, care and support with the aim of coming as close to possible to the goal of universal access to treatment by 2010...” Per the Political Declaration adopted at the UN high-level meeting on HIV/AIDS in June 2006, countries around the world are in the process of scaling up their response to AIDS toward achieving universal access to HIV prevention, treatment, care and support by 2010. For more information, please see: <http://www.unaids.org/en/Coordination/Initiatives/default.asp>.
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3. Declaration of Commitment, Article 37.
4. Declaration of Commitment, Articles 47–57.
5. Declaration of Commitment, Articles 58–61.
6. Declaration of Commitment, Articles 62–67.
7. Declaration of Commitment, Article 94.
8. For a full text of the joint proposal and the list of more than 50 signatories, please see www.ungasshiv.org
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11. The exact original language was “YES” in response to a question on whether substitution therapy was available.
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20. See Article 49 in the Political Declaration on HIV/AIDS adopted by the UN General Assembly on June 2, 2006. Available at: http://data.unaids.org/pub/Report/2006/20060615_HLM_PoliticalDeclaration_ARES60262_en.pdf

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[We] acknowledg[e] the particular role and significant contribution of people living with HIV/AIDS, young people and civil society actors in addressing the problem of HIV/AIDS in all its aspects, and recogniz[e] that their full involvement and participation in the design, planning, implementation and evaluation of programmes is crucial to the development of effective responses to the HIV/AIDS epidemic.

—UNGASS Declaration of Commitment
on HIV/AIDS, Article 33

Public Health Watch promotes informed civil society engagement in policymaking on tuberculosis and HIV/AIDS. The project's monitoring reports offer a civil society perspective on the extent to which government policies comply with international commitments such as the Amsterdam Declaration to Stop Tuberculosis and the Declaration of Commitment on HIV/AIDS—and on the extent to which those policies have been implemented. HIV/AIDS monitoring reports include assessments of policies in Nicaragua, Senegal, Ukraine, the United States, and Vietnam.

