HVADS POLICY IN



A Civil Society Perspective

A series of reports on HIV/AIDS policy in Nicaragua, Senegal, Ukraine, the United States, and Vietnam

PUBLIC HEALTH WATCH



HIV/AIDS Policy in Ukraine

A Civil Society Perspective

Andriy Bega, International Centre for Policy Studies

A series of reports on HIV/AIDS policy in Nicaragua, Senegal, Ukraine, the United States, and Vietnam

PUBLIC HEALTH WATCH



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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 signed the Declaration of Commitment on HIV/AIDS. The document commits signatory governments to improve their 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. Towards 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.

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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Lidia Andrushchak, UNAIDS

Inna Banakh, "Povernennya Do Zhyttya" Kirovograd Oblast Fund

Tetyana Bilyk, Transatlantic Partners Against AIDS

Tetyana Bordunis, All-Ukrainian Network of People Living with HIV/AIDS

Oleksiy Daschenko, All-Ukrainian Council for Patients' Rights and Security

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Roman Drozd, Poltava Regional Office of All-Ukrainian Network of People Living with HIV/ AIDS

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Lesya Kostiyuk, "Vertical" Charity Foundation

Nataliya Kovnir, All-Ukrainian Network of People Living with HIV/AIDS

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Volodymyr Misyuitin, Poltava HIV/AIDS Center

Olena Nechesina, Coalition of HIV-Service NGOs

Oleksandr Ostapov, All-Ukrainian Harm Reduction Network

Artur Ovsepyan, All-Ukrainian Network of People Living with HIV/AIDS

Zhanna Parkhomenko, Medicines Sans Frontiers

Nataliya Pidlisna, Coalition of HIV-Service NGOs

Denys Poltavets, International Renaissance Foundation

Stanislav Pokutniy, "Club Eney" Charity Organization

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Olena Sabinina, Poltava HIV/AIDS Center

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Oleg Tymoshenko, Poltava Regional Office of All-Ukrainian Network of People Living with

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Terry White, European Coalition of Positive People

Oleksander Yurchenko, Kyiv HIV/AIDS Center

Serhij Zhuk, "Svitlo Nadii" Charitable Organization, Poltava

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-Kóvàcîc, 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 political leaders in Ukraine have declared their commitment to controlling HIV/ AIDS and to protecting the rights of people living with HIV/AIDS. The government's efforts have not been wholly successful, however, and the epidemic continues to spread rapidly. The government's failure to distribute donor funds and provide sufficient funding for HIV/AIDS programs, and its frequent violations of human rights, are among the major obstacles to controlling the HIV/AIDS epidemic.

The AIDS Epidemic in Ukraine

Ukraine has the highest prevalence of HIV/AIDS and the fastest-growing AIDS epidemic in Europe. An estimated 410,000 people (1.4 percent of the population) are living with HIV/ AIDS. Injection drug use continues to drive the epidemic and is responsible for more than 60 percent of the cases of HIV/AIDS to date. Approximately 70 percent of each year's new HIV infections are directly or indirectly attributable to drug use. HIV/AIDS tends to afflict the young in Ukraine: Approximately 80 percent of all registered HIV cases are in people between the ages of 15 and 39. This trend has long-term socioeconomic implications.

There are alarming signs that the AIDS epidemic is spreading to Ukraine's general population through sexual contact. From 1997 to 2005, the percentage of new cases resulting from heterosexual transmission has tripled—from 11 to 34 percent. Eighteen percent of the HIV cases registered in 2004 were in children born to HIV-positive mothers, despite recent success in decreasing mother-to-child transmission.

National political leaders have declared their commitment to control HIV/AIDS and to protect the rights of people living with HIV/AIDS. Ukraine was among the first governments to call for the United Nations General Assembly Special Session (UNGASS) on HIV/AIDS in June 2001. It is also one of 191 countries that have adopted the Declaration of Commitment on HIV/AIDS (DoC). In addition, the Ukrainian parliament (Verkhovna Rada) has developed an "AIDS law," which guarantees access to confidential HIV testing and counseling, social protection, and medical care for people living with HIV/AIDS. The government has also adopted a series of national HIV/AIDS programs—the latest (running from 2004 through 2008) includes provisions to expand voluntary counseling and testing (VCT) sites and ensure care and support for people living with HIV/AIDS.

One important step forward was the creation of the Ukrainian National Coordinating Council on HIV/AIDS (NCC) in May 2005. The NCC helps implement HIV/AIDS policies in a more coordinated manner, with input from a broad range of stakeholders, including civil society organizations. In October 2006, however, high-level officials challenged the NCC's authority and legitimacy, and the council was relegated to the status of an advisory body, which may limit meaningful civil society participation in policymaking processes.

Major Obstacles

Many consider the lack of administrative capacity and the lack of coordination of donors and across ministries to be major hurdles in implementing HIV/AIDS programs. For example, the persecution of drug users by law enforcement agents complicates the delivery of prevention, treatment services, and harm reduction measures (such as needle-exchange programs and substitution therapy).

There is a yawning gap between AIDS-related law and actual practice in Ukraine. For instance, the AIDS law stipulates that treatment with antiretroviral (ARV) drugs and other medical care should be accessible to all, free of charge. In practice, this is far from the case. People living with HIV/AIDS reportedly are requested to pay for diagnostic tests and treatment of opportunistic infections. Those in marginalized groups indicate that they are charged for "free" services as much as 70 percent of the time.

International financial donors and other organizations are frustrated by the lack of policy coordination regarding substitution therapy and other issues and also by the government's ineffectiveness in disbursing donor funds. For example, in April 2006, the World Bank announced that it would suspend a \$60 million, four-year project to stop the spread of HIV and tuberculosis (TB) due to the government's failure to distribute funds and implement programs. The suspension was lifted in November 2006 under the condition that Ukraine improve project management and accelerate implementation of its programs. In 2004, the Global Fund withdrew the government's two-year grant of \$25 million and transferred it to the management of the International HIV/AIDS Alliance in Ukraine (IHAU).

Insufficient funding is also responsible for the ineffective response to HIV/AIDS to date, and there are significant gaps in resources despite the considerable support of international donors. With the support of the Global Fund, by September 2006, more than 4,100 people had received ARV treatment—compared to 135 people in early 2004. An estimated 17,000 people are still in need of treatment, however. Because the policy-formulation process does not take budgets into account, many proposed HIV/AIDS programs are little more than items on "wish lists." The government has also been reluctant to make financial commitments to continue treatment beyond 2008, when the Global Fund grant period will end. The new Global Fund grant, which focuses on prevention, is expected to cover only 24 percent of the overall financial gap for the 2007–2011 period, so the Ukraine government must be prepared to increase funding for treatment and other programs.

Discrimination against People Living with HIV/AIDS

Efforts to control HIV/AIDS are also compromised by frequent violations of human rights. Seventy-five percent of the country's HIV-positive people are unaware of their HIV status, and most of the population has limited knowledge about HIV and how to protect against its transmission. Due to low levels of public awareness, many people harbor fears and misconceptions about HIV/AIDS. Years of negative propaganda about HIV/AIDS during the 1980s and early 1990s have had a lasting effect and continue to influence popular attitudes toward those living with the disease today. All of these factors contribute to an atmosphere in which people living with HIV/AIDS are stigmatized and subjected to discrimination.

HIV tests are often administered without consent, particularly in TB hospitals and drug clinics. Despite a confidentiality clause in Ukraine's national HIV/AIDS law, medical staff members often disclose a patient's HIV-positive status to relatives or employers without the patient's consent. People living with HIV/AIDS are often denied or dismissed from their employment, are refused care, or receive substandard care in health care settings. A survey of HIV-positive pregnant women revealed that medical personnel pressured the majority to abort their pregnancies.

Former drug users who are HIV-positive frequently report experiencing discrimination by police. In some cases, police have confiscated ARV drugs at the time of arrest, forcing patients to interrupt their treatment. According to a recent Human Rights Watch report, drug users and sex workers also face other forms of police abuse, including severe beatings, torture, and arrests, which hinder and complicate their access to services.

Recommendations

The national government can respond to the HIV/AIDS epidemic more comprehensively and effectively by improving the design and implementation of HIV/AIDS policy in the following ways:

- Prioritize and increase financial support for HIV/AIDS to close the anticipated funding gap of more than \$464 million for the years 2007 through 2011 and ensure effective use and management of resources.
- Significantly expand the involvement of civil society in planning, implementing, and monitoring HIV/AIDS programs—for example, engage nongovernmental organizations (NGOs) in the provision of testing and other services.

- Ensure equal access to prevention, treatment, care, and support services for members of marginalized populations, such as injecting drug users, sex workers, prisoners, and men who have sex with men.
- Facilitate an effective scale-up of ARV treatment and treatment of opportunistic infections—for example, by recruiting and training more HIV/AIDS specialists.
- Ensure access to substitution therapy for the estimated 60,000 to 238,000 drug users in need of it in order to prevent the spread of HIV and to maximize the effectiveness of ARV treatment and treatment of opportunistic infections.
- Encourage more people to test for HIV, particularly high-risk groups such as injecting drug users and sex workers.
- Launch a communications campaign to inform people about HIV transmission, access to testing and services, and the importance of battling stigma and discrimination.

Background

After claiming independence in 1991, Ukraine underwent a decade of economic crisis, and the annual gross domestic product (GDP) declined by as much as 23 percent in the mid-1990s. The economy has experienced steady growth since 2000, with a 50 percent increase in GDP between 1999 and 2004. The 2004 growth rate was 12.1 percent, the highest in Europe. Despite increases in real income, however, more than 57 percent of families were living below the official minimum living wage in 2004.2,3

The transition period has also had a negative impact on the country's demographics. Between 1991 and 2005, the total population declined from 52 million to 47 million.4 Demographic indicators in Ukraine are far below European averages. In 2003, the death rate in Ukraine was 16.1 per 1,000, compared to 9.8 per 1,000 in the European Union (EU).5 In Ukraine, life expectancy was 62.3 years for men and 73.6 years for women, compared to life expectancy in the EU of 75.1 and 81.4 years, respectively.6

HIV/AIDS is expected to have a negative impact on the economy in the coming years. One recent study suggests that expenditures for AIDS treatment, unpaid taxes, and productivity losses could cost up to 418 million UAH (Ukrainian hryvnia) by 2014 (approximately \$82 million) and cause an overall reduction in economic growth.7

Incidence and Prevalence of HIV/AIDS

The first case of HIV in Ukraine was registered in 1987. The epidemic has spread rapidly since 1994, when the first HIV case was identified in an injecting drug user in Mykolayiv. Today, Ukraine has the fastest-growing epidemic and the highest prevalence rate in Europe. The number of registered cases of HIV rose by 36 percent between 2003 and 2005, and estimates indicate that there are approximately 410,000 people (1.4 percent of the population) living with HIV/AIDS.^{8, 9} In 2005, the World Health Organization (WHO) estimated that 17,000 people were in need of ARV treatment.10 Without intervention, the total number of HIV cases could reach 820,000 (3.5 percent of the adult population) by 2014, and AIDS will be the cause of death for one out of three male adults between the ages of 15 and 49.11

As of February 2006, there had been 103,572 officially registered cases of HIV (89,819 adults and 13,753 children), 17,692 reported cases of AIDS, and 9,910 deaths since the beginning of the epidemic.12 According to some sources, however, the official death rate may represent only a fraction of the actual number of deaths. The nongovernmental organization IHAU estimates that for every person who dies of AIDS, three times as many HIV-positive people—mostly young injecting drug users—die of secondary causes ranging from overdose to suicide.¹³

Injecting drug users are the primary risk group for HIV infection, accounting for 60 percent of all cumulative HIV cases as of January 2005, although their ratio to the total number of new HIV infections has declined from 84 percent in 1997 to 46 percent in 2004. ¹⁴ This decline reflects the fact that an increasing number of HIV infections are acquired through sexual contact. Between 1997 and 2005, the incidence of heterosexual transmission tripled from 11 to 34 percent. One HIV/AIDS expert has noted, however, that although the number of infections caused by needle sharing is declining, the number of infections among the sexual partners of drug users is rising. As a result, drug use is still directly or indirectly at the root of more than 70 percent of new infections. ¹⁵

Due to increases in HIV infection among women, the number of HIV-positive children born to HIV-positive mothers has risen steadily. In 2004, 18 percent of new registered cases of HIV were in children born to HIV-positive women, despite Ukraine's success in decreasing mother-to-child transmission from 30 to 10 percent. Estimated HIV prevalence among pregnant women is below 1 percent in all but two oblasts (Mykolayiv and Odessa), but the recent trend leads to concern that HIV prevalence rate among pregnant women may soon reach a "generalized" level of more than 1 percent at the national level.

Table 1. HIV transmission routes in Ukraine¹⁸

Transmission routes	1997	1998	1999	2000	2001	2002	2003	2004	200519
Drug injection	7,448	6,516	3,771	3,881	3,964	4,587	4,815	5,778	6,103
Heterosexual contact	1,007	1,385	1,323	1,427	1,885	2,499	3,043	4,041	4,652
Mother to child	196	378	527	727	914	1,371	1,830	2,273	2,524
Undetermined	260	294	202	173	231	295	314	389	355
Other	2	2	4	4	6	4	7	IO	8
Total:	8,913	8,575	5,827	6,212	7,000	8,756	10,009	12,491	13,642

There are reported cases of HIV in all regions of Ukraine. The highest HIV incidence was recorded in the Odessa oblast, with 432 cases per 100,000 as of January 2005. Other areas with high incidence include the Mykolayiv, Dnipropetrovsk, Donetsk, and Cherkasy oblasts; Crimea; and the cities of Sevastopol and Kyiv. In these areas, injecting drug users represent approximately 75 percent of those with HIV infections. Historically, western Ukraine has had lower rates of HIV/AIDS than other regions. For example, in Zakarpatia, HIV incidence was 13 cases per 100,000 in 2005. In 2005, however, the national

UNGASS report indicated that HIV prevalence among drug users had reached 26 percent in Lutsk (in western Ukraine)—an alarming sign that HIV is spreading to all areas of the country.20

High-Risk Populations

The HIV/AIDS epidemic in Ukraine has coincided with an epidemic of injection drug use. As of 1990, the state narcotics service had registered approximately 20,000 drug addicts; by 2005, this number had risen to 116,231 (247 cases per 100,000 people). Some experts estimate that the total number of drug users is as high as 560,000, although the more widely accepted number is closer to 397,000.22,23 According to one profile of injecting drug users, about 74 percent are male, 46 percent are under 24 years of age, and 73 percent are unemployed or partly employed.24

Injecting drug users run an extremely high risk of HIV infection in Ukraine. Studies show that HIV prevalence rates among drug users have been steadily increasing. In 1995, 2 percent of the injecting drug users surveyed were infected with HIV. By 1999, nearly 7 percent were HIV-positive and, by 2003, close to 15 percent.²⁵ These statistics may not accurately reflect reality, however. The State Institute for Family and Youth Affairs reports that many seropositive drug users who undergo HIV tests often do not return to clinics to get their results. They may miss appointments with doctors or fail to provide samples for the retesting of an initially positive result. As a result, a large number of cases are not reflected in the official register.26 This uncertainty about the reliability of the data is reflected in the government's 2005 estimate of the HIV prevalence rate among injecting drug users as "between 10 and 59 percent."27

Sex workers are also at high risk of HIV infection. A Global Fund-supported study in seven regions revealed that HIV prevalence among this group averaged 19 percent, ranging between 4 and 31 percent.28 In addition, the study indicated that 60 percent of sex workers admitted drug use and that the rate of HIV infection among sex workers who injected drugs was five times higher than the HIV rates among sex workers who did not.

HIV and Tuberculosis

The spread of the HIV/AIDS epidemic in Ukraine has occurred simultaneously with a resurgence of TB. According to the Academy of Medical Science of Ukraine, the number of cases of HIV-associated TB has been increasing by approximately 23 percent annually over the past several years (Table 2). In 2004, TB was diagnosed in 55 percent of all AIDS cases. TB is the leading cause of death among AIDS patients, accounting for more than 1,300 (60 percent) of AIDS-related deaths in 2005.29,30

Table 2. HIV-associated TB

Year	2000	2001	2002	2003	2004
Number of cases of HIV-associated TB ³¹	233	313	414	955	1,218
Total number of TB cases (notified) ³²	32,945	36,784	40,175	37,043	38,403

A study of newly diagnosed TB patients in Kyiv found that the main risk factor for TB/HIV coinfection was injection drug use. The percentage of TB patients infected with HIV who reported injection drug use increased from 62.5 percent in 2002 to 66.7 percent in 2004.33 Data from the Ministry of Health in 2004 suggest that approximately 700,000 people have TB.34 As with HIV/AIDS, the highest incidence of TB is found in the southern and eastern regions of Ukraine.

Despite evidence of increased TB/HIV coinfection and the clear linkage between drug use and HIV/AIDS, there is little interaction or coordination between HIV/AIDS, TB, and drug-dependency treatment programs. In a structure that is a remnant of the Sovietstyle health system, separate vertical institutions and programs deal with these individual issues, although all entities are under the umbrella of the Ministry of Health. Specialists who are reluctant either to relinquish control over their areas of expertise or to cooperate with other sectors develop and manage the programs.

The Coalition of HIV-Service NGOs has been struggling to introduce a TB component into the NCC to improve coordination of TB and HIV/AIDS programs, but without notable success.35 As one HIV/AIDS activist said, "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."36 The integration between TB and HIV/ AIDS programs is expected to improve with the implementation of the Global Fund Round 6 grant. The recently approved proposal addresses several barriers to effective management of TB/HIV coinfection, outlining the need for unified protocols, trained specialists, and access to TB services for injecting drug users and people living with HIV/AIDS.37

There is still a lack of consensus among Ukrainian specialists on the applicability of DOTS, the internationally recommended strategy for TB control, the five components of which include: political commitment with increased and sustained financing; case detection through quality-assured bacteriology; standardized treatment with supervision and patient support; effective drug supply and management system; and monitoring and evaluation system. Many TB doctors, public-health experts, and officials within the Ministry of Health of Ukraine point to the success of the post-World War II Soviet TB control system of X-ray diagnoses and mandatory in-patient treatment as the more appropriate model.³⁸ In fact, TB treatment (which is free of charge throughout Ukraine) is largely administered through a national network of 124 TB clinics, which are staffed by 3,147 specialists and equipped with 25,251 beds.39

As a result, DOTS has only been piloted in select oblasts. Moreover, the Academy of Medical Science of Ukraine reported that the pilot program in Donetsk showed poor results compared to the national average, including higher TB mortality rates and higher incidence of TB among children. It concluded that these poor results were due to the fact that the DOTS strategy requires little or no hospital stay for patients. Academic researchers and other proponents of Soviet-style TB treatment assert that longer hospital stays are required to ensure treatment adherence, especially because a large proportion of Ukrainian TB patients (43 percent in 2004) are jobless and without sufficient food and money, making travel to clinics for daily treatment difficult.40 The poor results of the DOTS pilot have reinforced the opinion of many Ukrainian specialists that DOTS must be adapted to the national context in order to be effective.

Even without the full support of TB specialists, the government plans to endorse DOTS more widely, in part due to negotiations with the World Bank to reinstate a \$60 million loan. 41 The National TB Program for 2007–2011, adopted by the Cabinet of Ministers of Ukraine in June 2006, indicates that the "optimal option for resolving the [TB] problem is implementing the DOTS strategy, adapted to Ukrainian specifics."42

A recent study also revealed that the current TB treatment system is not effective with the marginalized and difficult-to-reach groups who are most likely to become infected. Individuals who are homeless, jobless, or who abuse alcohol are much more likely to visit TB clinics and hospitals only when they have reached an advanced stage of the disease, so they are at risk of a high mortality rate. These patients frequently explain that they "thought the symptoms would go away" or that they didn't consider the symptoms serious enough to seek treatment.43 Some NGO representatives have suggested that TB patients could be treated more effectively in shelters, which cost less to maintain and could provide more comprehensive, personal care (including provision of food) than hospitals. Some doctors, however, believe that state funding should be used to strengthen the existing TB system rather than creating new and untested alternatives.44

Budget Allocation and Spending in the Health Sector

Health care spending has increased from 5.4 billion UAH (approximately \$1.1 billion) in 2001 to 11.6 billion UAH (approximately \$2.3 billion) in 2005, although the relative share of GDP allocated to health care on a percentage basis was lower in 2004 and 2005 than in 2003 (Table 3). In general, however, increased spending has not led to better-quality or more-accessible services.

Table 3. Spending on health care⁴⁵

Year	2001	2002	2003	2004	2005
Healt hcare spending (in billion UAHs)	5-4	6.5	8.5	9.4	11.6
Per capita health care spending (UAH)	109.3	131.1	174.7	196.8	251.0
Health care spending as % of GDP	2.6	2.8	3.2	2.7	2.8
Total new HIV infections (registered) ⁴⁶	7,000	8,756	10,009	12,491	13,642

The health care system has retained the Soviet-era emphasis on in-patient treatment. Rather than on the basis of services provided, health care financing is determined on the basis of facilities expenses (the salaries paid to health care workers plus the cost of building and equipment maintenance). To maximize financing, hospitals request more beds for in-patient services, regardless of need. Ukraine has far more hospitals and hospital beds than the European average (Table 4). As a result, a large percentage of health care spending is devoted to the maintenance of hospitals and clinics, leaving only negligible amounts for prevention, diagnosis, and treatment of disease.

Table 4. Health care indicators: Ukraine and European averages⁴⁷

Indicator	Ukraine	EU average
Hospitals per 100 000 (2004)	5.64	3.11
Hospital beds per 100 000 (2004)	872.85	591.56
Nurses per 100 000 (2004)	777-47	731.15
Physicians per 100 000 (2003)	300.64	347.13

Also due to Soviet tradition, Ukraine has no shortage of physicians or nurses. As of July 2005, the health care system employed 194,597 doctors and 464,752 trained support personnel. Many do not wish to work in rural areas, however, which limits people's

access to health services in nonurban centers. According to Volodymyr Bondarenko in the Ministry of Health, "residents of many villages cannot get elementary advice or support from paramedics because [they] are simply not there."48 The government requires medical school graduates who receive public scholarships to either work for several years in rural areas or pay back the tuition in full. These efforts have met with considerable controversy, but also a measure of success. In 2005, approximately 1,300 young specialists went to work in rural areas compared to 400 who went in 2004.49

Political Commitment

Strong leadership at all levels of society is essential for an effective response to the epidemic

—UNGASS Declaration of Commitment on HIV/AIDS, preamble to "Leadership"

HIV/AIDS [is] one of the fundamental threats to both health and prosperity for humanity and the overall security of our world.

- Ukraine Foreign Minister Kostiantyn Hryschchenko

Ukraine was among the first of the former Soviet republics to draw international attention to the issue of HIV/AIDS. Shortly after the adoption of the UNGASS Declaration of Commitment on HIV/AIDS in June 2001, the president and the Cabinet of Ministers of Ukraine took several measures to strengthen the national campaign against HIV/AIDS. A presidential decree declared 2002 the "Year Against AIDS." High-level Ukrainian leaders publicly have asserted the importance they place on the fight against HIV/AIDS. In 2004, during the 59th session of the United Nations General Assembly, Foreign Minister Kostiantyn Hryshchenko declared that HIV/AIDS was "one of the fundamental threats to both health and prosperity for humanity and the overall security of our world." In April 2005, Health Minister Mykola Polishchuk noted in his progress report on the government action plan that "the uncontrolled spread of the TB and HIV/AIDS epidemics is one of the top-priority issues" in the health care sector. ⁵²

Although political leaders have spoken out about their commitment to controlling HIV/AIDS, a recent survey of top officials and politicians suggests that there is still insufficient understanding of the possible impact of the epidemic.³³ For example, fewer than 25 percent of respondents agreed that HIV/AIDS could require a significant transfer of funds from other sectors for the treatment and care of people living with HIV/AIDS, and only II percent agreed that the epidemic could contribute to increased poverty levels.

The National Program and HIV Legislation

In 1991, the Ukrainian parliament adopted a law on the prevention of AIDS and the social protection of the population (the AIDS law). In 1998 and in 2001, the AIDS law was amended to incorporate provisions on voluntary testing, the concept of confidentiality, and mandatory pre- and post-test consultations. Specifically, the AIDS law obligates the government to ensure the following:

- access to free, voluntary, and confidential HIV testing and counseling;
- the right to regular and comprehensive information about HIV/AIDS to foster greater public awareness, education for young people, and the development of models of safer behavior;
- broad-based access to measures to prevent heterosexual transmission of HIV;
- favorable conditions for needle and syringe exchange to prevent the spread of HIV among injecting drug users; and
- social protection for people living with HIV/AIDS, including compensation if wrongful disclosure of HIV-status results in financial loss; provision of free medical treatment and psychosocial support; free transportation to and from treatment centers; and special provisions for HIV-positive children, such as subsidies and parental leave.

The AIDS law is implemented through the national HIV/AIDS program, which is reviewed and amended every three to five years to respond to the current situation and to prevailing trends in the HIV/AIDS epidemic. The national program for 2004-2008, the fifth of its kind, was adopted in March 2004.⁵⁴ The national program is intended to provide a mechanism for coordinating government and donor efforts at the national level.

The national program and the AIDS law recognize specific marginalized groups and groups at high risk of HIV infection, including drug users, young people, school-aged children, students, and military personnel. They do not, however, address the needs of other risk groups, such as sex workers and men who have sex with men.

Control of the HIV/AIDS epidemic is also a component of Ukraine's socioeconomic development program for 2005 and 2006. The EU-Ukraine Action Plan forms the basis for a partnership between the EU and Ukraine to combat HIV/AIDS by strengthening human-resource capacity and implementing joint projects.⁵⁵

The Need for a National Communications Strategy

The national HIV/AIDS program lacks a strategy both to increase awareness of HIV/AIDS among the general public and government officials and to combat discrimination against people living with HIV/AIDS. As a result, many people living with HIV/AIDS are unaware of their rights or of the services available to them. For example, one person living with HIV/AIDS said that he had not received any information in school or elsewhere about how to prevent HIV transmission, although he had learned the meaning of the acronym, AIDS. Only when he was admitted to a drug rehabilitation center did he receive information about HIV/AIDS prevention and the services and treatment available for drug users and people living with HIV/AIDS.⁵⁶

Global Fund monies have financed occasional campaigns to promote public awareness, encourage positive behavioral changes, and promote greater tolerance of people living with HIV/AIDS. For example, a national media campaign was launched on World AIDS Day in 2004 to disseminate video and audio materials and brochures to help reduce discrimination against people living with HIV/AIDS. The government reported that Ukrainian national television aired 5,820 hours of public service announcements (PSAs) and 676 hours of programming on HIV/AIDS. In 2005, the national radio aired 1,500 hours of HIV/AIDS programming.⁵⁷ There has been little attempt to assess the impact of such efforts or to follow up on them, however, so it is difficult to determine whether or not they have been effective.

Some NGOs have also attempted to place HIV/AIDS-related programming on national television and radio, relying on legislation that requires media outlets to set aside no less than 5 percent of their advertising time for PSAs. There is no mechanism to enforce implementation of this legislative provision, however, and NGOs reportedly have faced difficulties obtaining airtime, particularly when competing for it with government-sponsored programming.⁵⁸

Moreover, there has been little coordination among the organizations that produce HIV/AIDS-related PSAs. In the absence of a national communications strategy, the potential hazard is that audiences will receive mixed or even contradictory messages from different groups.

Public Awareness and Action

Within Ukraine, there is little awareness of the basic facts about HIV and AIDS, both among members of the general public and among individuals and groups at greatest risk of infection. In addition, the negative propaganda of the 1980s and early 1990s continues to influence public attitudes toward people living with the disease.

Few people—including some health care workers whose job is to implement key aspects of the AIDS law-are aware of the measures the government has taken to fight HIV/AIDS. According to a recent survey by the All-Ukrainian Network of People Living with HIV/AIDS (the Network) and the International HIV/AIDS Alliance in Ukraine (IHAU), only 7.3 percent of those people surveyed were well acquainted with the AIDS law; 28.9 percent knew something about it. Others either had heard about it but were not familiar with its content or had not heard of it at all.59

Ignorance of the ways in which HIV infection is transmitted is also widespread. One recent survey found that only 14 percent of people 15 to 24 years old were fully informed about modes of HIV transmission; 70 percent thought they could get the disease from an insect bite. 60 The same survey indicated that only 21 percent of injecting drug users correctly identified ways to prevent sexual transmission of HIV and rejected major misconceptions about HIV transmission.61

Low levels of awareness about HIV/AIDS fuel the public's fears and misconceptions about the disease. In this environment, people living with HIV/AIDS claim that they frequently experience discriminatory and even illegal treatment in a variety of settings, including schools, hospitals, clinics, and prisons—but they lack the public support, information, and legal tools to challenge these violations of their rights effectively.

Discrimination against People Living with HIV/AIDS

By 2003, enact, strengthen or enforce, as appropriate, legislation, regulations and other measures to eliminate all forms of discrimination against and to ensure the full enjoyment of human rights and fundamental freedoms by people living with HIV/AIDS and members of vulnerable groups...and develop strategies to combat stigma and social exclusion connected with the epidemic.

—UNGASS Declaration of Commitment on HIV/AIDS, Article 58

An HIV-positive person with pneumonia was forced to leave an Odessa hospital because doctors were afraid he would infect other people.

— Human Rights Watch, "Rhetoric and Risk: Human Rights Abuses Impeding Ukraine's Fight against HIV/AIDS."

Some Ukrainian legislation reinforces the stigma often associated with HIV/AIDS. Under Article 130 of the Criminal Code of Ukraine, it is a crime to infect another person with HIV or to endanger another person with infection—therefore, any sexual relationship between a person living with HIV and a person who is not infected can be classified as a crime. People who are HIV-positive can be prosecuted even if their HIV status was unknown at the time their partners were infected, or even if their partners were aware of the HIV-positive status and the risks involved in unprotected sexual activity.

The legislation also requires people who are HIV-positive to sign a written acknowledgement of criminal liability as soon as they are diagnosed with HIV.⁶² According to one AIDS expert, this requirement violates the United Nation's international guidelines on HIV/ AIDS and the protection of human rights. ^{63, 64} The Network believes that this requirement is one of the principal reasons why many people do not voluntarily undergo HIV testing and refuse to repeat testing when necessary to verify a result.

People living with HIV/AIDS have provided numerous testimonies of abusive treatment, particularly in health care settings. According to Tetyana Bordunis, a former lawyer for the Network, approximately two-thirds of all reported cases of discrimination against people living with HIV/AIDS occur in hospitals and other medical facilities.⁶⁵ Bordunis recalled a 2004 case in which local doctors refused to operate on a HIV-positive man. The patient was transferred to Kyiv, where doctors again refused to operate. He was only able to receive medical attention after the Network arranged media coverage of the case.⁶⁶

An HIV-positive person who had pneumonia claimed that he was forced to leave an Odessa hospital because doctors were afraid that he would infect other people. The man had to pay \$60 to stay overnight at a hotel while his mother tried to find another hospital that would treat him.⁶⁷ In addition to refusal of treatment, many people living with HIV/AIDS experienced other unpleasant situations—for example, one nurse fainted after hearing a patient was HIV-positive; a doctor wore plastic gloves over heavy gardening gloves while performing a gynecological exam.⁶⁸

In addition, people living with HIV/AIDS reported that health care workers often request payment to deliver services, despite existing legislation that guarantees free treatment and care. 69 According to a 2004 survey, drug users were charged fees for services at medical or drug-treatment centers about 60 to 70 percent of the time. The highest reported official payment for an overnight hospital stay was 5,000 UAH (approximately \$1,000).7°

In a 2003 survey of 40 pregnant HIV-positive women, the majority reported that they had been pressured by medical personnel to have an abortion.71 Most noted that they felt stigmatized and discriminated against due to their HIV status; that health personnel were slow to respond to their requests for help; and that they were often separated from other patients.

HIV-positive children whose status has been disclosed reportedly suffer from discrimination at school. For example, an HIV-positive child in Kyiv was forced to leave school after a protest by teachers and parents of other students. With no recourse at their disposal, children have little choice but to change schools.72

Injecting drug users report particularly severe treatment in health care facilities and police stations. Many facilities refuse to admit or treat active drug users, and doctors frequently call the police to report patients if they suspect drug use. As a result, drug users often avoid seeking treatment or administer their own home remedies.73 The police, who are often uninformed about the requirements of AIDS treatment, have been known to confiscate ARV drugs at time of arrest, forcing patients to interrupt their treatment.74 HIV-positive prison inmates report being denied access to ARV treatment and being required to perform hard manual labor, despite their health status.75

There have been minimal efforts to provide clear and accessible information about methods that can protect people living with HIV/AIDS against discrimination. As a result, legal provisions that provide some measure of protection are often violated. For example, in many cases, the AIDS law's provisions for voluntary testing and counseling and for confidentiality are not observed. HIV tests are often given without consent, particularly in TB hospitals and drug clinics.⁷⁶ According to a public opinion poll by the Network in 2004, 39 percent of HIV-positive respondents reported that they were tested without consent.77

The Network poll also indicated that, among those who tested voluntarily, only 30 percent had both pre- and post-test consultations. More than 41 percent of respondents reported that medical staff had disclosed their HIV-positive status to relatives or employers without their consent.⁷⁸ These disclosures have serious consequences. Although Ukrainian law clearly prohibits discriminatory denial or dismissal from employment, one of the most common complaints of people living with HIV/AIDS is loss of employment after their HIV status is revealed.⁷⁹ Moreover, people living with HIV/AIDS (and the general population) often avoid reaching out for assistance because they lack trust in government agencies and institutions.80

The Role of Civil Society in Policymaking

Recently, the government has solicited input from civil society in developing HIV/AIDS policy. Through an official order, the Ministry of Health established a working group to develop the concept for the national HIV/AIDS policy.⁸¹ Among those in the working group were representatives of the Network, the IHAU, and other local NGOs, the WHO, the Joint United Nations Program on HIV/AIDS (UNAIDS), and government agencies. Civil society representatives say they welcome the opportunity to debate HIV/AIDS-related issues with government officials, even if the officials maintain their stance. Each Civil society organizations and people living with HIV/AIDS were also included in the drafting of a proposal for continued support from the Global Fund in April and May 2005. They also participated in a series of national consultations on the universal access process from December 2005 to February 2006, which established concrete targets to increase access to HIV/AIDS prevention, treatment, and care by 2010. Each

The collaboration has already had positive impact. Civil society organizations compiled an annex for the national UNGASS report, assessing the government's progress in fighting stigmatization and discrimination and ensuring equal access to prevention, treatment, and care for all people living with HIV/AIDS. Also, largely due to pressure from civil society, Ukraine's 2004–2008 national HIV/AIDS program specifically states that the government will provide needle exchange and substitution therapy for injecting drug users.

The process of preparing the Global Fund Round 6 proposal is another example of civil society's positive role in policy development and implementation. The open and transparent process involved a working group of representatives from all sectors, ranging from faith-based organizations and trade unions to people living with HIV/AIDS. There was a public stakeholders meeting, a public call for proposals, and a technical review panel and proposal development group, who were responsible for review and consolidation of submitted proposals. Two civil society organizations—the Network and the IHAU—will be principal recipients of the grant, which will focus on enhancing access to prevention, treatment, care, and support for vulnerable populations.

Civil society was also instrumental in helping to lower the price of ARVs. The government had been paying 24 to 27 times more for ARVs than the Global Fund-supported project was paying. Through repeated protests and demands for more transparent tender procedures, the purchase prices declined by almost twentyfold by July 2006. Civil society still is not represented on the tender committee, however, despite representatives' multiple requests to the government.

Although civil society organizations are strong at the national level, organizations at the regional and local levels are not as well mobilized. National organizations, such as the Network and the Ukrainian Harm Reduction Association, have conducted training through their regional branches, but still need more resources and training events in order for regional and local actors to participate more fully and effectively in policymaking processes.

Policy Administration and Financing

By 2003, ensure the development and implementation of multisectoral national strategies and financing plans for combating HIV/AIDS that address the epidemic in forthright terms....

-UNGASS Declaration of Commitment, Article 37

The Ukrainian government has committed to a strong, strategic, national response to the HIV/AIDS epidemic and has adopted progressive legislation and a series of national programs to frame its activities in this area. Implementation of AIDS legislation and programming has fallen far short of stated goals and aspirations, however.

Several different entities coordinate HIV/AIDS policy at the national level—chiefly the Ministry of Health and the NCC. As stipulated in the AIDS law, the Ministry of Health is the central executive office responsible for the management and coordination of HIV/AIDS policies and programming.

In May 2005, the government established the NCC to facilitate HIV/AIDS policy implementation with input from a broad range of stakeholders.85 The government's earlier attempts at creating a multisectoral coordinating body in 1999 and in 2001 had involved only government officials.^{86,87} In accordance with Global Fund requirements that a national coordinating body include representatives from civil society, the NCC is made up of nine government officials and eight civil society representatives, including a person living with HIV/AIDS. The organization's main objectives are to coordinate the work of ministries and other executive bodies (central and local) and international and domestic NGOs in implementing the national HIV/AIDS policy; to track spending on HIV/AIDS; and to improve monitoring and evaluation of HIV/AIDS interventions.

The NCC consists of six committees, which address several aspects of HIV/AIDS policy: strategic planning; budgeting; monitoring and evaluating; educating and communicating to effect behavioral change; providing treatment, care, and support; working with marginalized groups; shaping regional policy; and protecting the rights of people living with HIV/AIDS. Each committee is chaired by an NCC member and invites additional representatives from the government, international organizations, and NGOs to discuss policy issues and to submit recommendations to the NCC secretariat, which then reports to the Cabinet of Ministers.

Similar coordinating councils were created at the regional level, allowing NGOs and people living with HIV/AIDS to participate in coordinating and implementing HIV/ AIDS activities in their local areas. According to Nataliya Kovnir, the regional coordinator of the Network, the capacity and effectiveness of local coordination councils varies greatly from

region to region.⁸⁸ Some councils operate effectively and allow for active participation of civil society organizations in such tasks as developing local programs and budgets. The budget for the Chernigiv oblast, for example, allocates funds to HIV service organizations based on input from NGOs. In Lugansk, the local coordination council established a special working group to address HIV prevention among drug users as a result of a local NGO initiative.⁸⁹

Some local coordination councils have benefited from technical assistance provided by international donors. For example, the POLICY Project has helped the Odessa council set up multisectoral working groups, perform local situation analyses, and develop recommendations for improving the effectiveness of local programs. ⁹⁰ As a result, the local coordination council in Odessa has been able to plan its HIV/AIDS programs with a better understanding of the available resources and more effectively coordinate government agencies and NGOs in allocating them.

The NCC's innovative structure creates a unique opportunity for broader civil society participation in policymaking. Its effectiveness as a coordinating body has been severely limited, however, both by the lack of clear lines of authority and reporting requirements and by the absence of mechanisms to ensure accountability for its work. The NCC does not meet quarterly, as required by the 2005 resolution; in fact, no meetings were held from June 2005 to April 2006. The organization's primary function to date has been to submit proposals to the Global Fund, and it convenes on an ad hoc basis, just before the submission deadline. From May 2006, when the Global Fund called for Round 6 proposals, to the completion of Ukraine's proposal in August that year, the NCC met four times.⁹¹

Challenges to the NCC's legitimacy from high-ranking officials have led to uncertainty about its status. In February 2006, during a stakeholders' meeting organized by the IHAU, Deputy Minister of Health Valeriy Ivasiuk questioned the legality of the NCC on the grounds that one government body cannot order another to implement its decisions (only the Cabinet of Ministers' decisions are mandatory for implementation), and he recommended reform and reevaluation. ^{92, 93} In reaction, representatives of civil society mobilized to advocate for the NCC's preservation; organizations sent letters to the president and to the Global Fund and met with the Minister of Health to support the NCC. ^{94, 95, 96} To some extent, these efforts succeeded. In May 2006, the NCC convened to review the government's UNGASS progress report and led the process of developing and submitting the Round 6 proposal to the Global Fund. ⁹⁷

The NCC is not fully operational, however. The NCC's Secretariat was terminated when donor support expired in April 2006, and its website also ceased operation. In October 2006, the NCC was relegated to an advisory role, and it can no longer propose policies for mandatory adoption by the government. This change in status may impact the NCC's effectiveness and, in turn, the extent to which civil society is engaged in policymaking processes.

In May 2006, while the problems with the NCC were being discussed, the government established the Committee on HIV/AIDS under the Ministry of Health. The committee's purpose is to help coordinate the efforts of HIV/AIDS, TB, and drug-dependency treatment services and to increase the overall effectiveness of the health system in fighting HIV/AIDS and other diseases. 100 On July 5, 2006, Deputy Minister of Health Valeriy Ivasiuk was appointed as the head of the committee. As a department within the Ministry of Health, the committee will have a dedicated, permanent staff, an infrastructure, and financial resources. The committee has not publicly announced its key objectives or accomplished any tasks, however, and so its effectiveness cannot yet be determined.

The committee's mandate is limited to the health sector; it is the NCC's responsibility to coordinate across all ministries, agencies, and donors at the national level. Considering the NCC's ineffectiveness to date and the recent amendment in its statute that precludes policymaking authority, national coordination is very weak and exists, for the most part, only on paper. If the committee emerges as the dominant force in HIV/AIDS coordination, Ukraine's response to HIV/AIDS will primarily be in the health sector, without the muchneeded interaction with the prison system, law enforcement agencies, and social services sector.

Coordination with Donors

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

> —Denys Poltavets, consultant for the International Renaissance Foundation

The government's difficulties in managing and coordinating its HIV/AIDS programs have led some multilateral donors to reconsider their funding support. In April 2006, for example, due to the government's failure to distribute funds and implement programs, the World Bank announced that it would suspend a \$60 million, four-year project to stop the spread of HIV and TB in Ukraine. Since the inception of the grant in January 2004, the government had spent only 2 percent of the funding that had been made available to purchase medicines, support prevention services, and train health care workers in methods of reaching out to high-risk groups, such as injecting drug users, sex workers, and prisoners. 101

According to Paul Bermingham, the director for the region, the World Bank decided on this course of action because the project "had failed to make any significant impact on

the growing threat of TB and HIV/AIDS in Ukraine and the neighboring countries." Countering accusations of corruption, Minister of Health Yuriy Polyachenko said that "there was no corruption in the use of funds because there was no use of funds. That is why the loan was stopped." Polyachenko went on to explain the reasons why the money had not been used for three years: the level of bureaucracy both in the Ministry of Health and the World Bank and the lack of synchronization between the World Bank's complicated procedures and Ukrainian legislation. After the suspension of the loan, the World Bank announced that it was ready "to discuss how the recently suspended project may be restructured and relaunched." A working group was established to negotiate for the relaunch of the loan, which was formally reinstated in November 2006, under the condition that the government follow through on its recommendations to adopt a new TB-control strategy (including further rollout of DOTS programs), accept alternative procurement procedures to accelerate project implementation, and improve project management."

In 2004, the Global Fund withdrew a two-year grant of \$25 million, citing similar difficulties as those that interfered with distribution of the World Bank loan: bureaucratic barriers and an inability to align Ukraine's legislative requirements and donor procedures.

When Ukraine signed an agreement with the Global Fund in early 2003, there were three grant recipients: the Ukrainian Fund to Fight HIV/AIDS (a government agency created specifically to manage Global Fund grants), to manage the dissemination of information; the Ministry of Health, to administer treatment, care, and support; and the United Nations Development Programme (UNDP), to work with marginalized populations. In January 2004, almost a year into the grant period, a Global Fund mission to Ukraine discovered that the grant to the Ministry of Health was being implemented very slowly: out of \$7.5 million allocated, only \$740,000 had been utilized. ¹⁰⁶ Shortly afterward, the Global Fund withdrew the grant due to its "concerns with the slow progress of the HIV/AIDS prevention and care programs in Ukraine."

According to the Country Coordinating Mechanism (CCM), the Ministry of Health had arranged to purchase ARV drugs for 2,000 adults and 100 children in November 2003, at a total price of \$3.9 million based on an open tender. (The Ministry of Health manages the purchase of ARVs and their distribution through the national HIV/AIDS center to regional HIV/AIDS centers.) Although the government was prepared to go with a lower price for the tender, the Global Fund was concerned about the government's questionable management and slow implementation of treatment programs and ARV drug purchases. The Global Fund recommended that the government purchase the drugs at slightly higher cost through an established UN entity, the United Nations Children's Fund. The Ministry of Health contended it could not comply because of the higher cost and that Ukraine was not bound to adhere to Global Fund recommendations because the fund is a nongovernmental entity. (109)

In February 2004, the Global Fund transferred management of the grant to the IHAU, which now acts as the principal recipient and has responsibility for disbursing funds. The IHAU convenes regular meetings for stakeholders to better coordinate grant-implementation efforts. According to stakeholders, the IHAU has been more transparent than any government institution about its operation, financial management, and reporting. All information regarding the Global Fund is available on the IHAU website (www.aidsalliance.org/sw7229.asp), including summaries of past activities and detailed future plans, including specific targets and budget allocations.

Ukraine's Global Fund Round 6 proposal for \$151 million for the period 2007–2011 has recently been approved, but in order to finalize the grant agreement, the government must meet several of the Global Fund's conditions: the increase of budget allocations for HIV/AIDS; successful negotiation for the reinstatement of the World Bank loan; and support for substitution therapy for drug users. Major steps have already been taken to fulfill the Global Fund requirements. Vice Prime Minister Dmytro Tabachnyk announced that in 2007 the government would increase the national budget for HIV/AIDS to \$100 million. The World Bank reinstated its loan in November 2006, and methadone was officially registered on December 1, 2006, allowing for expansion of substitution therapy.

In addition to frustration over ineffective funding-disbursement processes, donors have expressed dissatisfaction about the coordination of policies. According to Denys Poltavets, a consultant for the International Renaissance Foundation, "Donors and the government do not have a single, common paradigm on substitution therapy. There is no consensus among donors or within the government."

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Even though substitution therapy is not prohibited by law, the Ministry of Internal Affairs has refused the requests of NGOs and international organizations to buy methadone abroad for use in Ukraine.¹¹⁴ International organizations cannot provide substitution therapy for injecting drug users without the consent of the government, which maintains tight control of the legal circulation of narcotic drugs.

There are currently approximately 436 drug users on substitution therapy, of whom 283 are HIV-positive. ¹¹⁵ Although a request to purchase the drug buprenorphine was recently approved, there has been stronger resistance to methadone. Drug-control officials claim that methadone will never be allowed in Ukraine because it is too dangerous and because "methadone does not treat drug dependence." They claim that "legalization of consumption and distribution of [methadone] will increase the probability of illegal circulation of the drug, creation of illegal laboratories, and will form so-called 'methadone-mania.'" At the same time, buprenorphine's higher cost poses challenges in scaling up substitution therapy.

Despite these obstacles, many domestic and international NGOs persisted in pushing for the availability of methadone and have recently achieved significant success. On November 30, 2006, the deputy minister of health finally agreed to register methadone.

The next day, World AIDS Day, Vice Prime Minister Dmytro Tabachnyk confirmed that methadone was registered and announced that an NCC working group would study the benefits and risks of a wide-scale increase of methadone for substitution therapy.¹⁷ The recent addition of methadone to the WHO Model List of Essential Medicines likely helped persuade Ukrainian officials to legalize the drug.¹⁸

The Clinton Foundation HIV/AIDS Initiative (CHAI) recently announced a partnership with two private Ukrainian foundations to increase access to rapid testing, improve laboratory capacity, train health care workers, introduce HIV treatment, and improve drug-procurement processes in the Dnipropetrovsk region. During the next several years, CHAI plans to collaborate with the government to expand HIV testing legislation, develop guidelines for rapid HIV tests, and establish new testing sites; increase the number of people on ARV treatment and ensure a reliable drug supply; and register and improve access to methadone-based substitution therapy for injecting drug users.¹¹⁹

Financing

The HIV/AIDS challenge cannot be met without new, additional, and sustained resources.

—UNGASS Declaration of Commitment, preamble to "Resources"

Increase and prioritize national budgetary allocations for HIV/AIDS programmes as required, and ensure that adequate allocations are made by all ministries and other relevant stakeholders.

-UNGASS Declaration of Commitment, Article 82

The financial gap between overall needs for the 2007–2011 period and committed contributions exceeds \$464 million.

—Global Fund Round 6 proposal, August 2006

Government funding for HIV/AIDS programs has increased significantly over the past five years (Table 5), but it still fails to meet the projected need, which is expected to increase from approximately \$103.5 million in 2007 to more than \$175 million in 2011. Because the policy process is decoupled from the budgeting process, programs are proposed without guarantee of funding and often remain little more than items on "wish lists." For example, between 1995 and 1997, only 50 percent of requested funds were allocated to the national HIV/AIDS program. In 2001 and 2002, only 62 percent of the budgeted amount for HIV/

AIDS programs was funded at the national level and 70 percent at the regional level.¹²¹ According to information in the recent Round 6 proposal to the Global Fund, the financial gap between the overall needs and the committed contributions for the 2007–2011 period exceeds \$464 million (24 percent of which will be covered by Round 6 funding if disbursed in full).¹²²

Table 5. State budget funding for HIV/AIDS programs¹²³

Year	2000	2001	2002	2003	2004	2005 (planned)
Funding, in millions UAH	5.4	6.7	9.3	13.6	17.9	34.0
	(\$1.01mn)	(\$1.3mn)	(\$1.75mn)	(\$2.55mn)	(\$3.37mn)	(\$6.7mn)

^{* \$1} is equal to approximately 5.1 UAH.

Information on HIV/AIDS budget allocations and spending is not easily accessible to the public. In fact, even the government does not appear to have a complete picture of how much it spends on HIV/AIDS. Although the national UNGASS progress report provides information on spending by the Ministry of Health, the State Department of Corrections, and local governments, it does not account for other ministries and agencies that are implementing HIV/AIDS programs.

Among the items missing from the national figure are the costs for: operation of the Dovira ("Trust") network of drop-in support centers for drug users; production and placement of public service messaging on television about HIV/AIDS; and implementation of the "positive behaviors" program by the Ministry of Youth, Family, and Sport, which promotes healthy choices for youth through education on the risks of drug and alcohol abuse, unprotected sex, and other issues. In addition, the procedure for reporting local expenditures and program implementation is cumbersome, so it is difficult for a central agency, such as the Ministry of Health, to collect data about local budgets.¹²⁴

In addition to state funding, the government receives considerable financial and technical assistance for HIV/AIDS programming from international, bilateral, and NGO donors. For example, Ukraine's HIV/AIDS treatment budget increased from \$2.6 million in 2003 to \$12.5 million per year in 2004 and 2005, more than a fivefold increase, thanks to the Global Fund grant. Even with international donor support, however, the total funding available is not sufficient to address the scale of the epidemic. Total spending on all HIV/AIDS-related programming and services amounted to approximately \$40 million in 2005. An estimated \$50 million per year is required to provide ARV treatment to all 17,000 people who need it, not including the costs of prevention, palliative care, and other

services.¹²⁸ Civil society representatives contend that this situation could be greatly ameliorated if the government had more open and transparent tendering procedures for the purchase of ARVs, for which government officials have acknowledged paying 22 to 27 times more than market prices in 2004 and 2005.¹²⁹

The planning and implementation of the response to HIV/AIDS suffers from larger and more persistent funding gaps at the subnational level. Oblast governments often do not prioritize HIV/AIDS issues, so planned activities are not backed by adequate financing and, as a result, implementation falters. For example, local governments are responsible for the purchase and distribution of HIV testing kits; in some oblasts, such as Mykolaiv, lack of funding means limited access to HIV tests. ¹³⁰

Ukraine's private sector has made little contribution to funding HIV/AIDS programs. According to the national UNGASS progress report, as of 2005, not one large enterprise or company had an HIV/AIDS workplace policy or program.¹³¹ On the other hand, the government has not established tax breaks or other incentives to encourage the private sector to contribute to public health or social programs.

Prevention

Prevention must be the mainstay of our response.

—UNGASS Declaration of Commitment, preamble to "Prevention"

By 2005, ensure...expanded access to essential commodities, including male and female condoms and sterile injecting equipment; harm reduction efforts related to drug use; expanded access to voluntary and confidential counseling and testing.

-UNGASS Declaration of Commitment, Article 52

The prevention of the spread of HIV/AIDS is specified as one of the key priority areas in the five-year national HIV/AIDS program that was adopted in March 2004. Progress has been made in some areas, but Ukraine has been slow to introduce the full range of prevention services, sometimes due to contradictions between the policies pursued by different government ministries. Meanwhile, those prevention programs that are in place have neither made sufficient impact nor succeeded in reaching out effectively to those groups at greatest risk of HIV infection, such as injecting drug users, sex workers, and men who have sex with men.

The government has registered considerable success in reducing mother-to-child transmission, with rates declining from 27.8 percent in 2001 (when no interventions were available) to 8.2 percent in 2004. 132 According to the national UNGASS progress report, by 2004 all pregnant women had access to HIV tests and received ARV drugs and evaporated milk formula for their babies; 86 percent of HIV-positive pregnant women received ARVs for prevention of mother-to-child transmission. 133

The government has also made considerable progress toward meeting the UNGASS target, which was to reach 90 percent of youth with prevention programs by 2005; the 2005 UNGASS progress report indicated that government programs had reached 83 percent of young people ages 15 to 24. 134 There is little evidence, however, to support the claim that these programs have raised awareness or positively affected behavior. The same report acknowledges that only 14 percent of young people were able to both correctly identify modes of HIV transmission and reject misconceptions. 135 Clearly, prevention programs need to do more than simply "reach" young people; they need to effectively communicate accurate information.

The Global Fund Round 6 grant will likely help strengthen the effectiveness of prevention programs. The proposal prioritizes reducing HIV transmissions, focusing efforts on members of high-risk groups, which currently represent more than 80 percent of all

reported cases of HIV. In line with Ukraine's universal access goals, by 2011, Round 6 funding is expected to provide comprehensive prevention services to 60 percent of injecting drug users; 60 percent of sex workers; 17 percent of men who have sex with men; 100 percent of prison inmates; and 58 percent of street children. 136

Voluntary Counseling and Testing

The 1998 amendment to the AIDS law introduced clear requirements regarding voluntary and confidential testing and counseling, which significantly increased the likelihood of greater participation in prevention services. It has been difficult to implement this portion of the AIDS law, however.

In practice, access to voluntary and confidential testing and counseling is limited to urban areas. Even when testing and counseling centers are available, few people use them, and there have been too few attempts to ensure that communities are aware of their existence and the services they provide. 137

The practice of conducting HIV testing without a patient's consent is widespread, particularly in TB hospitals and clinics for drug users. 138 In many cases, testing is conducted in the absence of pre- or post-test counseling, which makes patients reluctant to return to the testing site to obtain their results. Studies indicate that only 5 percent of young people (ages 15 to 24) who tested for HIV in the past 12 months knew the results; in contrast, 27 percent of injecting drug users and 32 percent of sex workers who received HIV tests knew their results. Many observers believe that the deficiencies in the system are a major factor in preventing people from accessing services.

Collaboration with NGOs

NGOs are limited in providing prevention services due to government restrictions. For example, HIV tests can only be administered in health facilities, so NGOs are prohibited from providing them, even though their organizational expertise and ability to reach marginalized groups more effectively arguably make them better qualified to implement prevention programs. 139. 140 NGOs currently provide information about HIV testing and pre- and posttest counseling, but they must refer clients to designated health centers for actual testing. Many representatives from NGOs have highlighted the importance of "demonopolizing" the government's role in providing testing and other services. As one representative explained, "Currently there are no ways for the state to 'buy' services from NGOs. The state cannot provide all the services...they have difficult procedures for doing things. And they can't work effectively with certain populations that are hard to access."141

Criminal Prosecution of Marginalized Groups

Police frequently wait around legal needle-exchange sites and harass, beat and arrest drug users for possession of syringes or identify them for future arrest.

— Human Rights Watch, "Rhetoric and Risk: Human Rights Abuses

Impeding Ukraine's Fight against HIV/AIDS."

There are several considerable obstacles to the effective implementation of prevention programs: the criminalization of drug use, official ambivalence toward harm reduction measures such as substitution therapy, and a principally punitive approach to dealing with drug users and other high-risk groups.

Attempts to prevent high-risk practices among injecting drug users are hindered and complicated by the fact that possession of drugs is a criminal offense, regardless of whether there is any proof of intent to sell or distribute. For example, possession of o.i grams or more of acetylated opium, one of the most widely used drugs in Ukraine, is punishable by imprisonment. ¹⁴² Of 41,000 drug-related criminal cases in 2005, approximately 80 percent were for the possession of drugs without demonstrated intent to sell or distribute. ¹⁴³ Fear of arrest drives injecting drug users underground; many are afraid to seek assistance or HIV-prevention services for fear of being identified—a justified fear in light of the frequent breach of confidentiality in health care settings. Although there are no legal requirements for health care workers to report drug users to police, many drug users believe they do. ¹⁴⁴

Arrest by the police can, and sometimes does, lead to forced medical treatment or criminal prosecution. Drug users claim that police abuse is rampant, and many have reported undergoing severe beatings or inhumane methods of extracting confessions in detention, sometimes while they are experiencing drug-withdrawal symptoms. ¹⁴⁵ Outreach workers who provide drug users with HIV/AIDS education and prevention services report that police frequently interfere with their efforts, for example, by harassing, beating, and arresting drug users at legal needle-exchange sites for possessing syringes. ¹⁴⁶

Sex workers also report frequent harassment and detention by police. In exchange for release, police allegedly demand payment of fines, information about drug users, or sexual activity. ¹⁴⁷ Sex workers who use drugs are particularly vulnerable to abuse. The situation is also difficult for sex workers who migrate from other regions or countries and lack official registration and identity documents. For these individuals, fear of detainment and deportation adds an additional incentive to avoid any contact with police or with any officials (including health officials) who might report them to the police.

Although efforts are being made to address these issues through partnerships with NGOs on a case-by-case basis, not enough is being done to systematically support harm reduction policies to offset the ill effects of punitive drug-control laws and widespread police abuses.

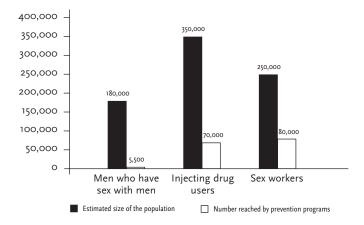
Prevention Efforts Targeting Marginalized Groups

By 2003, develop and/or strengthen national strategies, policies and programmes...to promote and protect the health of those identifiable groups which currently have high or increasing rates of HIV infection.

-UNGASS Declaration of Commitment, Article 64

Official statistics confirm that injecting drug users are the group most vulnerable to HIV infection. They are also the principal path for transmission of HIV to the general population. The government has introduced and supported harm reduction measures, including needle exchange and substitution therapy, on a limited scale, but these programs are not yet reaching sufficient numbers of injecting drug users to halt the epidemic. Programs for other marginalized groups, including sex workers and men who have sex with men, have been even more limited in scope. Figure 1, estimating the numbers of individuals in these marginalized groups and the number of individuals reached by current prevention efforts, illustrates the gap in coverage. In addition, some government policies and practices, particularly in the area of law enforcement, are at cross-purposes with prevention efforts (both governmental and nongovernmental) among marginalized groups, which further limits their scope and effectiveness.

Figure 1. Prevention coverage for marginalized populations



Injecting Drug Users

Methadone does not treat drug dependence.... Legalization of consumption and distribution of [methadone] will increase the probability of illegal circulation of the drug, creation of illegal laboratories, and will form so-called "methadone-mania."

—"Does Methadone Threaten State Security? Heroin Substitute Has Its Supporters and Critics," Segodnya, August 2004

The rapid spread of HIV among drug users can be attributed to high-risk practices, such as the sharing and reusing of needles and the sharing of containers to prepare drug solutions. A recent survey of more than 3,500 injecting drug users indicated that less than one-half (49 percent) of respondents use a new syringe for each injection, and only 26 percent regularly visit needle-exchange sites to get kits with clean needles. Alarmingly, 23 percent of respondents admitted to simply leaving behind their used syringes after they have injected.¹⁴⁸

In 2002, the Dovira network of drop-in centers, managed by the Ministry of Family, Youth, and Sports, developed an organized system for providing services to drug users. The Dovira network's main objectives are to provide information and training on HIV prevention and safe behavior; advice and referral to medical specialists, as appropriate; and needle and syringe exchanges. With support from the Global Fund, by the end of 2005 there were 55 Dovira drop-in centers in operation across the country, and that year they exchanged more than 250,000 syringes. The previously cited survey of injecting drug users, 6 percent of respondents indicated that they had received new syringes at Dovira centers during the previous month. To In addition, a group of NGOs, most of which belong to the Ukrainian Harm Reduction Association, receive international funding to support and staff almost 250 permanent and mobile prevention sites to provide advice, information, and clean injection supplies to drug users.

The combined efforts of the Dovira network and the NGOs demonstrate the effectiveness of harm reduction methods, but they are still not reaching sufficient numbers. Approximately 70,000 injecting drug users (20 percent of the estimated number of injecting drug users in the country) have access to prevention services through these programs. Fee Reporting on its progress on UNGASS implementation, the Ukrainian government acknowledged that prevention programs generally reach only 38 percent of injecting drug users. This result is far below the level required. Recent research suggests that, to have a marked impact on the HIV/AIDS epidemic, at least 60 percent of injecting drug users should have guaranteed access to needle-exchange programs. This would require significant additional investment to support a substantial increase in the number of outreach

centers. ¹⁵⁶ Both the universal access process and the recently approved Global Fund proposal have set the goal of expanding harm reduction services to 60 percent of injecting drug users by 2011.

There is evidence that prevention programs, however limited in scale, do have a positive impact. A survey of drug users found that 24 percent of respondents who had participated in prevention programs had adopted safe injection and sexual practices, compared to only 16 percent of those who had not participated. Moreover, harm reduction programs provide drug users with a centralized source of information about drug dependence, HIV/AIDS, and other services available from government and NGOs, without risk of social exclusion, as they might experience in other types of settings.

In 2001, HIV/AIDS policymakers identified substitution therapy as one of the key measures to prevent the spread of HIV among drug users, but this view met with considerable resistance from the law enforcement agencies that are responsible for formulating and implementing national drug policy. As a result, substitution therapy was not introduced until September 2005, when it began as a pilot project with the drug buprenorphine in seven cities. The therapy is currently available to 436 injecting drug users. There are plans to expand buprenorphine substitution therapy to treat 6,000 patients by the end of 2008, although an estimated 60,000 to 238,000 drug users are in need of substitution therapy. Continued advocacy from domestic and international NGOs has finally succeeded in obtaining government support for treatment with the drug methadone. Substitution therapy with methadone will be provided to 300 injecting drug users in 2007.

The introduction of substitution therapy is a positive step in addressing HIV/AIDS among injecting drug users, but the lack of consensus among government departments on its utility and acceptability and the obstacles to expansion may prevent those on substitution therapy—many of whom are HIV-positive—from receiving ARV treatment due to misconceptions about drug users' ability to adhere to treatment regimen. Although proponents of methadone substitution therapy have gained government endorsement, concerns remain over whether promises made on paper will actually lead to implementation.

Men Who Have Sex with Men

Levels of awareness about modes of HIV transmission are high among the estimated 126,000 to 180,000 men in Ukraine who have sex with men. ^{163,164} Awareness has not, however, had a strong impact on patterns of engagement in high-risk behaviors, such as unprotected sexual intercourse. Recent estimates indicate that the average rate of HIV prevalence among these men ranges between 3 to 15 percent. ¹⁶⁵ Despite these alarming rates, there have been very limited efforts to ensure that men who have sex with men have access to preven-

tion services. Existing programs reach only an estimated 2,300 to 5,500 individuals.^{166,167} By the end of 2011, provision of prevention services to men who have sex with men is anticipated to reach 17 percent.¹⁶⁸

According to a recent survey of 886 men who have sex with men, conducted in seven cities, approximately 89 percent were aware of the risks involved in sharing needles and syringes, and 52 percent knew that HIV could be spread by sharing other drug-related equipment. Although 96 percent knew that condoms safeguard against the transmission of HIV during sexual contact, only 37 percent always used condoms during anal intercourse and only 5 percent during oral intercourse. More than one-half (54 percent) of the respondents were not in long-term, monogamous sexual relationships. Despite their high-risk behaviors, most of the men interviewed in this study estimated their own chances of contracting HIV as average (27 percent of respondents), low (25 percent), or very low (22 percent).

The scarcity of prevention services for men who have sex with men may be due to the prevalence of discriminatory attitudes toward them. Discrimination based on sexual orientation is widespread in Ukraine. According to a 2005 survey of 900 lesbian, gay, bisexual, and transgendered people, 54 percent responded that they had been subject to discrimination because of their sexual orientation, most often in the workplace or in retail establishments. To Discrimination was much more common among those who disclosed their sexual orientation (76 percent) than among those who did not (13 percent).

Sex Workers

The estimated 200,000 and 250,000 sex workers in Ukraine are also at elevated risk of HIV infection.¹⁷¹ The average rate of HIV prevalence among female sex workers is about 19 percent, ranging from 4 percent in Lutsk to 31 percent in Donetsk.¹⁷² According to government estimates, prevention programs reach approximately 34 percent of sex workers.¹⁷³

Sex workers are knowledgeable about HIV/AIDS. A survey of 1,413 sex workers indicated that the majority (90 percent) knew that the consistent use of condoms during sexual activity can decrease the risk of transmitting HIV.¹⁷⁴ According to the survey, sex workers have an average of 12 clients per week, and although 80 percent of sex workers reported using a condom with their most recent clients, only 54 percent claimed to have used condoms consistently during the previous month.

Fewer sex workers are aware of prevention and other services, and even fewer make use of these services. About 40 percent of the survey respondents were unaware that ARV drugs could decrease the risk of mother-to-child transmission. Although 40 percent of respondents knew about the services that governmental or nongovernmental

organizations provide for sex workers and drug users, only 27 percent had actually accessed these services.

Sixty percent of the respondents admitted to drug use, indicating a need for the coordination of the services provided to drug users and sex workers. The connection between sex work and injection drug use is a contributing factor in the rapid increase in sexual transmission of HIV in recent years. The rate of HIV prevalence among sex workers who reported injection drug use ranged from 8.3 to 100 percent, depending on the surveillance site; among sex workers who did not report drug use, the rate ranged from 0 to 21.1 percent.¹⁷⁵

Prison Inmates

As of December 2003, there were nearly 10,000 registered cases of HIV among prisoners—about 15 percent of the total number of those incarcerated. ¹⁷⁶ Despite this statistic, only a limited number of disease-prevention programs have been designed for and implemented in penal institutions.

Incarceration rates are particularly high among drug users, due to an aggressive policy of criminal prosecution for possession of even small amounts of drugs or of injection equipment with drug residue. In 2005, nearly 20 percent of all criminal cases were linked to illegal drug use, the majority of which involved personal use, that is, the "possession, transportation, or storage of illegal drugs without purpose of reselling." Drug use in prison is also high. A recent survey revealed that at least 13 percent of prisoners used drugs while incarcerated. Because HIV prevention and drug treatment services are limited, the risk of contracting HIV in prisons is especially high. An estimated 70 percent of HIV-positive inmates are current or former drug users.

The poor living conditions in many Ukrainian prisons also increase the risk of other infections, such as TB. In 2004, the Ukrainian prosecutor general's office acknowledged that I in 20 inmates (II,000 prisoners out of 200,000) had TB—a percentage that is II2 times higher than the percentage of affected people in the general population. The rapid spread of TB is due in part to the fact that in prisons "sick people are held in custody together with healthy inmates." Along with the high rates of both TB and HIV infection, the incidence of TB/HIV coinfection is also on the rise. There is little information available in Ukraine about drug resistance, but there are some indications of increased prevalence. The high risk of interrupted or incomplete TB treatment in prisons, combined with living conditions that are ideal for rapid transmission, create the potential for increasing rates of multidrug-resistant tuberculosis (MDR-TB) among prisoners—and of its transmission to the general population when people return home from prison.

With donor support, NGOs implement most of the HIV-prevention efforts in prisons. As of September 2006, prevention programs reached 29 of the 136 prison facilities. 181, 182 The government plans to allocate \$46,000 of the reinstated World Bank loan for TB- and HIV-prevention programs in prisons. With the implementation of the Round 6 Global Fund grant, prevention services will extend to 5,000 additional inmates in 2007 and to 50,000 by 2011. 183 According to the Ukrainian Network of Drugs and AIDS Services in Prisons, the primary prevention activities in prisons include distribution of condoms and informational materials, the training of prisoners to be peer educators, informational seminars and special radio programs for staff and prisoners, and psychological support and counseling.184

Treatment

Care, support and treatment are fundamental elements of an effective response. —UNGASS Declaration of Commitment, preamble to "Care, Support and Treatment"

Serious challenges must be addressed to expand ARV treatment to 50,000 people by 2010 as declared in the national Universal Access target.

-"Road Map on Scaling-up towards Universal Access to HIV/AIDS Prevention, Treatment, Care and Support in Ukraine by 2010," Ministry of Health and UNAIDS, April 2006

Since 2004, Global Fund resources have allowed for a significant expansion in the availability of ARV treatment, which led to an immediate reduction in the number of AIDS-related deaths. Several serious obstacles, however, stand in the way of further expansion to reach the large and rapidly growing number of people still in need of treatment and care.

Prior to 2004, ARV treatment was available to only 268 patients—137 were treated by the government and the rest (mostly pregnant women) were sponsored by Médecins Sans Frontières.¹⁸⁵ In August 2004, Global Fund resources made it possible to provide ARV treatment in the six regions in which up to 80 percent of the people living with HIV/AIDS reside: Crimea, Dnipropetrovsk, Donetsk, Mykolayiv, Odessa, and the city of Kyiv. 186 By September 2006, more than 4,100 people were receiving ARV treatment, 3,400 of whom were financed by the Global Fund and about 700 by the government. 187 The increased availability of ARV treatment has already had an impact. At a press conference in September 2005, Liudmyla Storozhuk, the deputy director of the Ukrainian Center for AIDS Prevention, stated that the introduction of ARVs had led to a nearly 34 percent reduction in AIDS-related deaths. 188

Each year, as part of the national HIV/AIDS program, the Ministry of Health develops a plan for expanding access to testing, treatment, care, and support for people living with HIV/AIDS. 189 Some of the major components of the 2006 plan included:

- increasing the number of patients on ARVs to 4,400 by the end of 2006 (3,400 from Global Fund resources and 1,000 from government resources);
- expanding ARV treatment into five more oblasts (Volynska, Kirovogradska, Rivnenska, Sumska, and Khmelnytska); and
- improving coordination between TB and HIV/AIDS programs.

As of September 2006, the government was still short of its target goal of providing ARV treatment to 4,400 people (the Global Fund achieved its target of 3,400). The government also has not made significant progress in integrating TB and HIV/AIDS programs, despite a conference held in 2005 to facilitate their coordination. Although Ukraine adopted recommendations on diagnoses of pulmonary and extrapulmonary TB for people living with HIV/AIDS in 2006, a treatment protocol for TB/HIV coinfection still has not been developed or implemented. 190, 191

Obstacles to Universal Access to ARVs

Availability of ARVs has increased dramatically, but UNAIDS and the WHO estimate that as many as 17,000 people are in need of treatment, and demand is likely to increase given the rising incidence of HIV in all 27 regions. According to the universal access targets—determined in consultation with more than 300 representatives from governmental, nongovernmental, and international organizations—ARV treatment will be expanded to reach more than 50,000 people living with HIV/AIDS by 2010. 192 To achieve this goal, several serious challenges must be addressed, including the following:

- Although injecting drug users are among the most vulnerable to HIV infection, law enforcement policies limit their access to information about HIV testing and ARV treatment. Even when they do seek out services, injecting drug users do not have equal access. HIV-positive people suspected of being drug users are often denied treatment, kicked out of hospitals, given inadequate services, or forced to pay for services that should be free. 193 Moreover, because their access to substitution therapy is limited, many HIV-positive drug users find it difficult to stay in hospitals that require full detoxification upon admittance. 194 Reportedly, doctors in the Kyiv HIV/AIDS center keep addicted patients in locked wards to prevent them from taking drugs while they are in the hospital.¹⁹⁵
- Considering the large number of HIV-positive drug users who cycle in and out of Ukraine's prisons, prisoners' access to treatment should expand dramatically. In November 2005, the Ministry of Health and the State Department of Corrections specified how ARV treatment should be organized in prisons. 196 Treatment rollout has been inadequate, however. The Ministry of Health had indicated that ARV treatment for 30 HIV-positive inmates in one prison would be launched in early 2006, but, to date, there is no information available on whether or not this has been implemented.¹⁹⁷ One objective of the Global Fund Round 6 proposal is to expand HIV care and treatment to 4,500 active drug users and 500 prisoners. 198

- Despite the high number of doctors per capita, there is a shortage of HIV/AIDS specialists. The Global Fund has supported some training of doctors on HIV/AIDS care, but the demand far outstrips the supply. The Global Fund has also assisted the Ministry of Health in developing three HIV/AIDS treatment protocols: for adults, for children, and for those with opportunistic infections. There has been no assessment of the degree of adherence to these protocols, however. In addition, a doctor's options for adjusting the combination of ARV drugs according to an individual patient's needs is constrained because of the centralized approach to planning, purchasing, and distributing ARV drugs, which limits the selection of drugs available. Due to the limited budget, the choice is either to treat many patients with a standard drug regimen or to stock a greater variety of drugs that will allow for more tailored treatments of fewer patients.
- Some observers assert that the inefficiency and lack of transparency in the Ministry of Health's drug-procurement procedure limit the budget available for the purchase of ARVs.²⁰³ In 2004, for example, Transatlantic Partners Against AIDS (TPAA) found that the average annual cost of treating one person with ARVs through the Ministry of Health was \$6,322, compared to \$522 for similar treatment offered by Médecins Sans Frontières. The Network reported that the Ministry of Health was paying 24 times more for ARVs than the Global Fund-supported project.

The situation deteriorated in 2005 when the government was about to pay 27 times more for ARVs than the Global Fund-supported project paid for the same drugs. Civil society organizations protested the purchase and demanded that community representatives be included on tender committees in the future.²⁰⁴ By mid-2006, Deputy Minister of Health Valentyn Snisar made assurances that the situation had been resolved and that the government was no longer paying more than market prices for drugs.²⁰⁵ The Coalition of HIV-Service NGOs complained that tender procedures had not been made more transparent and that there were still no civil society representatives on the tender committee.²⁰⁶

• Significant "hidden" costs for HIV/AIDS patients constitute a fifth barrier to treatment. Although the AIDS law and the HIV/AIDS program stipulate free ARV treatment and other medical care, patients often have to pay for diagnostic tests and for treatment of opportunistic infections. Similarly, the AIDS law provides that hospitals that refer patients elsewhere for treatment are responsible for reimbursing the patients' transportation costs to and from the treatment centers. Hospitals, however, do not have a separate budget allocation for transportation and cannot afford to cover these expenses.

Although the Global Fund has approved Round 6 funding for the period 2007-2011, there are concerns about the long-term sustainability of the ARV program. Of the 4,100 people on ARV treatment, 3,400 (nearly 83 percent) are supported through the Global Fund. 207 As indicated previously, a significant funding gap exists between the estimated needs and the committed funds for the next five years— Round 6 funding will cover approximately 24 percent. The priority of Round 6 funding is to provide equitable access to prevention, treatment, care, and support for marginalized and high-risk groups, so the government will have to secure other sources of funding in order to provide treatment to the estimated 50,000 people who will be in need of ARVs by 2011.

Care and Support

In July 2002, the Ministry of Health issued a conceptual framework for the nonmedical care and support of people living with HIV/AIDS. It includes three levels of support: psychological, social, and legal.²⁰⁸ The framework does not, however, address the use of opioid analgesics for pain management. According to the All-Ukrainian Council for Patients' Rights and Security (UCPRS), neither palliative care nor use of opioid analgesics is defined anywhere in the Ukrainian legislation.209 As a result, the UCPRS estimates that less than 10 percent of patients' needs for pain management with opioid analgesics are met. 210 In July 2006, the Ministry of Health established a working group to assess the need for palliative care and opioid analgesics and to draft treatment protocols, but, to date, these have not been made publicly available.

Government-sponsored health facilities face considerable regulatory hurdles in dispensing opioid analysesics and other palliative-care medicines. Because of restrictive licensing requirements, many facilities that would otherwise be capable of providing these services do not have the license to stock narcotics. In a survey of 40 state-run medical facilities—including TB hospitals, drug addiction clinics, and HIV/AIDS centers—only 14 indicated that they had the necessary license for the use of opioid analgesics.²¹¹

In addition, the framework for nonmedical support is too general and fails to establish clear lines of responsibility for implementation. 212 In some instances, government action is precluded by restrictive licensing regulations, as is the case with opioid analgesics. As a consequence, the implementation of care and support services has, for the most part, been left to NGOs rather than government institutions.

In March 2005, the Ministry of Health officially designated several NGOs to deliver nonmedical care and support services, such as counseling. 213 With support from the Global Fund, NGOs and faith-based organizations have started to implement care and support programs, many of which are coordinated and administered by the Network. Services offered include day care for children; self-support groups; peer counseling; counseling for families; consultations for HIV-positive women who are pregnant; home-based care; and legal consultations.²¹⁴ These programs are available only in oblast centers and major cities, however, so rural residents still lack access to adequate care and support services.

NGOs have also started to train families and communities to provide care to people living with HIV/AIDS, but more resources are needed in order to have adequate capacity to support these caregivers. Because hospitals and clinics only treat and care for patients inside the facility and do not offer outreach or home visits, the bulk of the responsibility for nonmedical care falls on NGOs, families, and communities. The various barriers to accessing care in health care settings, ranging from lack of transportation to discrimination, also point to a need to expand home- and community-based care. The government has not allocated any resources for this effort, however, and there is no department or agency overseeing the training and support of nonmedical care providers.

The effective collaborations between HIV/AIDS hospitals and NGOs provide possible models for the delivery of more comprehensive care. As a doctor in an HIV/AIDS center in Poltava explained, the center has agreements with two NGOs—a local branch of the Network and Svitlo Nadii, which provides counseling and psychosocial support to patients. ²¹⁵ The Kyiv HIV/AIDS center works closely with the Vertical Charitable Foundation, which provides clients with information about living with HIV/AIDS; offers pre- and posttest counseling; assists with transportation to and from the hospital; delivers ARV drugs if a patient cannot visit the hospital; and provides information about self-help groups and services available from other governmental or nongovernmental organizations. ²¹⁶

Both in Poltava and Kyiv, these organizations have signed cooperation agreements with their respective HIV/AIDS centers. In both cities, the organizations are housed in the same building as the HIV/AIDS centers and are accessible to all clients. According to Nataliya Kovnir, the regional coordinator of the Network, a similar arrangement is found in all regions.²¹⁷ The Network tries to facilitate partnerships between its local branches and local HIV/AIDS centers by offering technical assistance, training, and advice.

There are some advantages to having NGOs deliver care and support services to people living with HIV/AIDS. NGO workers are reportedly less likely to actively discriminate against drug users and other marginalized groups than are health care workers in state-run hospitals. The reason may be that many care and support organizations are managed and staffed by ex-drug users or individuals that belong to other directly affected communities. Because of their unique perspective, these people may, arguably, be in a better position than doctors, nurses, and other trained medical personnel to provide peer counseling, psychosocial support, and other support services.

Monitoring and Evaluation

Conduct national periodic reviews with the participation of civil society, particularly people living with HIV/AIDS, vulnerable groups and caregivers.

-UNGASS Declaration of Commitment, Article 94

In 2005, the director of the national AIDS center announced plans to develop a comprehensive national monitoring and evaluation (M&E) system to assess the effectiveness of the national HIV/AIDS programs, relative to the goals set forth in the UNGASS Declaration of Commitment. 218 As a first step, the Ministry of Health adopted a list of national M&E indicators on HIV/AIDS, developed operational guidelines, and conducted training seminars at the regional level. 219 The next tasks include establishing a national M&E center and developing a national plan for M&E for the 2007–2011 period.²²⁰ Donors, including the Global Fund, have also offered financial and technical assistance in developing the national M&E system; in fact, 3 percent of the Global Fund grant is earmarked for monitoring and evaluation.²²¹

Various governmental and nongovernmental agencies already collect a considerable amount of data, including epidemiological information, behavioral and socioeconomic surveys, financial management reports, and project-specific impact assessments.²²² There is no central agency to coordinate or amalgamate these efforts, however, and, as a result, they tend to evaluate only individual organizations or programs rather than national-level policy. There are also gaps in information concerning important areas, such as programs that target men who have sex with men.

The most comprehensive monitoring is of the collection of epidemiological data. All medical facilities that provide outpatient care to people living with HIV/AIDS are required to fill out accounting and reporting forms. The national AIDS center within the Ministry of Health is responsible for collecting the forms, summarizing and analyzing them, and publishing the results. There is a parallel system for gathering epidemiological data on sexually transmitted infections (STIs), but because many private clinics do not release data on new cases, the official statistics often do not accurately reflect the actual situation.

To date, international donors have commissioned most of the social and behavioral surveys, often in cooperation with Ukrainian research institutions, such as the Ukrainian Institute of Social Research and the State Institute of Family and Youth Affairs. These collaborations have yielded a considerable number of surveys that assess various aspects of the HIV/AIDS epidemic among marginalized groups, such as sex workers and injecting drug users. The research institutions, in turn, collaborate frequently with NGOs who work closely with these groups, as the NGOs have superior access and are better positioned to ensure

the anonymity and privacy of the individuals surveyed.²²³ NGOs have provided much of the available data regarding access to prevention services among marginalized groups.²²⁴

Civil society organizations have become involved in international monitoring processes at the national level in accordance with UNAIDS guidelines. In comparison, there is little meaningful representation or participation of a broad base of civil society groups in domestic M&E processes.

For example, several organizations participated in strategic meetings to help prepare the 2005 national UNGASS progress report. They jointly compiled an annex for the report, which includes an assessment of government efforts to counter the stigmatization of and discrimination against people living with HIV/AIDS; ensure equal access to prevention, treatment, and care services for at-risk populations; and involve civil society and marginalized populations in HIV/AIDS policy design and implementation. Groups such as the Coalition of HIV-Service NGOs considered this level of participation a major step forward, even though the official UNGASS report reflected the views of government in cases where there were differing views (such as whether to use estimated or actual reported figures).

In addition, the national universal access process included a series of consultations with widely diverse stakeholders, including civil society representatives and people living with HIV/AIDS. The working group developed a series of targets for providing universal access to prevention, treatment and care, and support services by 2010.²²⁷ It is likely that civil society representatives will continue to hold the government accountable for meeting these universal access targets because the targets coincide with objectives established in the Global Fund Round 6 proposal, for which there are specific plans for regular progress reports and oversight by a broad range of stakeholders.

The NCC assumed the role of the Global Fund CCM in 2005 and is supposed to provide a mechanism by which civil society organizations can discuss problematic issues with each other and with government representatives, receive information, and influence policy on HIV/AIDS at the domestic level. In fact, all six committees of the NCC meet regularly, providing a forum for NGOs to discuss relevant issues with government representatives and other stakeholders. The recent amendment in NCC's statute has blunted the organization's potential role as an accountability monitor and a civil society liaison. In order for the committee discussions to lead to action, the NCC needs to hear the issues, make decisions, and offer advice to government for possible implementation. The NCC does not meet regularly, however, except to draft and submit proposals to the Global Fund. Furthermore, there are no guarantees that the government will act upon the NCC's advice.

The government publishes its regulations and decrees in draft form on the Internet, to make them available for discussion by civil society representatives and to invite feedback before adoption. There are currently 18 draft decrees of the Ministry of Health awaiting comments from stakeholders.²²⁸ Unfortunately, the government does not publish the feedback it

receives, nor does it reveal whether they took the remarks into account, so the effectiveness of these electronic consultations is difficult to assess.

In addition, the government created a civil collegium for each ministry, which acts as an advisory council consisting of civil society organizations that meet regularly to discuss and provide feedback on the ministry's draft documents. All NGOs are not guaranteed memberships in these advisory councils, however. Furthermore, the councils operate without set priorities or objectives for engagement and, to date, have not been effective in influencing the ministries' policies or the quality of their work.²²⁹

Recommendations

Ukraine has the highest rate of HIV/AIDS prevalence in Europe and one of the fastestgrowing epidemics in the world. Although the government has demonstrated its political commitment to control the spread of HIV and to provide treatment and support to people living with HIV/AIDS, considerable challenges must be addressed in order to respond to the epidemic more comprehensively and effectively. The following recommendations for the national government, based on research for this report, specify areas for improvement in the design, implementation, and monitoring of HIV/AIDS policy.

- Prioritize and increase financial support for HIV/AIDS to close the anticipated funding gap of more than \$464 million for the period 2007–2011 and ensure effective use and management of resources, including by
 - closely linking policy development and budgeting processes to ensure full financing and implementation of all proposed programs to control HIV/ AIDS:
 - enhancing transparency in drug-procurement processes, for example, through the inclusion of civil society representatives in tender committees;
 - improving administrative capacity and processes to avoid suspension or delays in disbursement of donor funding in the future.
- Significantly expand the involvement of civil society in planning, implementing, and monitoring HIV/AIDS programs, including by
 - strengthening the NCC to assume an effective role in multisectoral coordination to champion participation and transparency;
 - engaging NGOs in provision of HIV testing and other services and in outreach to marginalized populations.
- Ensure equal access to prevention, treatment, care, and support services for marginalized populations, such as injecting drug users, sex workers, prisoners, and men who have sex with men by
 - eliminating police quotas for drug-related arrests that contribute to police interference with HIV/AIDS prevention and treatment centers;
 - addressing discrimination in health care settings by offering regular training for health care providers;

- integrating HIV/AIDS, TB, and drug-dependency treatment more effectively to allow clients to access comprehensive care for all three services in one setting and also offering coordinated treatment and care for active drug users and those who are coinfected with TB/HIV or triply affected;
- improving HIV/AIDS services in prisons, for example, by providing condoms and clean injection supplies and by building capacity for rapid rollout of ARV treatment and treatment for opportunistic infections.
- Facilitate effective scale-up of ARV treatment and treatment of opportunistic infections by
 - ensuring free ARV treatment and other services for people living with HIV/AIDS, as stipulated in the national HIV/AIDS program, by eliminating "hidden" costs of treatment, such as fees for diagnostic tests and treatment of opportunistic infections and transportation costs;
 - coordinating procurement between national and regional governments to avoid the underfinancing of commodities and stock-outs;
 - recruiting and training more HIV/AIDS specialists and ensuring full adherence with HIV/AIDS treatment protocols.
- Scale up substitution therapy to ensure access to the estimated 60,000 to 238,000 drug users in need of substitution therapy, in order to prevent the spread of HIV and to maximize the effectiveness of ARV treatment and treatment of opportunistic infections for drug users, by
 - ensuring that funding of substitution therapy is supported by the overall health budget rather than limited to the HIV/AIDS budget;
 - allowing substitution therapy in hospitals in order to ensure that people can seek the care they need without being subjected to forced detoxification and that they receive the treatment they need without interruption;
 - following through on the rollout of methadone substitution therapy in 2007 and considering plans for this cheaper form of substitution therapy to be made widely available;
 - referring drug users who are in possession of a small amount of drugs, without intention to resell or redistribute them, to substitution therapy or other appropriate treatment programs, rather than incarcerating them.

- Encourage more people to test for HIV, particularly members of high-risk groups, such as injecting drug users and sex workers, by
 - increasing the number of counseling and testing sites, particularly in rural areas, and ensuring that these sites and other institutions, such as drug clinics and TB hospitals, offer voluntary and confidential testing and pre- and posttest counseling;
 - eliminating the current procedure of requiring HIV-positive people to sign a written release acknowledging criminal responsibility;
 - allowing NGOs to play a greater role in testing, for example, by encouraging partnerships with hospitals and testing sites and by repealing legislation that prohibits NGOs from providing testing;
 - establishing and strengthening mechanisms to protect people from all forms of discrimination and breaches of confidentiality and providing outlets to voice complaints, pursue legal action, and receive compensation for damages.
- Launch a communications campaign to inform people about the means of HIV transmission, the availability of testing and services, and the importance of battling stigmatization and discrimination and also ensure wide and effective dissemination of accurate and up-to-date information, including by
 - assessing the impact of efforts on public awareness and behavior;
 - enforcing legislation that requires media outlets to dedicate at least 5 percent of advertising time to public service announcements by NGOs; coordinating HIV/AIDS-related public service announcements to eliminate contradictory messages.

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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.



