UKRAINE and HIV/AIDS: Time to act

United Nations
Development Programme
Kyiv, Ukraine
Ukraine is a young nation on the move. The national response to HIV/AIDS is also gathering pace. It is bringing together fresh coalitions of people, leaders and institutions who want to stop the further spread of this virus and to ensure care for those who are in need. The good news for all is that there are now known ways of preventing the spread of the virus and treatment is increasingly available.

The challenge remains immense – to some overwhelming. The insidious nature of the virus is that it attacks men and women in the prime of their life – between the ages of 15 and 40. It robs children of their parents, and society of its productive citizens.

Limited budgets and ungrounded stigma have severely hampered a scaled-up nationwide response. Positive rhetoric is helpful, but it needs to be matched by personal commitment and concrete actions.

With the infusion of new resources, now is the time to remove the log jams and unleash a broad-based national effort to change the current course of the epidemic. As the Secretary General of the United Nations Kofi Annan recently said, “We have come a long way, but not far enough. Clearly, we will have to work harder to ensure that our commitment is matched by the necessary resources and action.”

In the face of the situation, this special national Human Development Report has been prepared to highlight the extraordinary threat to Ukraine’s security posed by HIV/AIDS – as well as the opportunity to act now to head off a full-scale epidemic, while at the same time addressing related issues in gender, poverty, and governance. This document attempts to provide a perspective on the present situation and suggests the key levers needed to achieve a successful outcome. We hope this will serve as a springboard for Ukraine to overcome a number of challenges and protect its most valuable resource – its people.

We are grateful to the many contributors who have made this document possible. As in many aspects of the HIV/AIDS response, the solidarity and commitment of the various players gives us hope that this clear and present danger will be handled effectively.

We pay special tribute to the Network of People Living with HIV/AIDS who, through their courage and leadership, serve as a continuing source of inspiration to us all.
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**To the reader**

This report is a Special Edition of the National Human Development Report series which look at various transition issues and their impact on human development in Ukraine. The serious nature of HIV/AIDS as a threat to this development has prompted the publication of this separate report. It is intended for policy-makers, elected officials, donor organizations, HIV/AIDS-service NGOs, and all others interested in understanding the situation in Ukraine. This report was a joint effort by Ukrainian and international professionals who brought together existing research and data to offer a set of urgent actions that can change the course of the HIV/AIDS epidemic in Ukraine.

This report is divided into five sections, each of which contains thematic information and analysis on the HIV/AIDS situation in Ukraine. Here is a mini-guide to the document:

- **Chapter 1** describes the current situation in Ukraine with HIV/AIDS and its implications for the entire country and for all Ukrainians.
- **Chapter 2** provides the background against which Ukraine became so vulnerable.
- **Chapter 3** reviews the Ukrainian government’s response to HIV/AIDS since 1987.
- **Chapter 4** considers public and private capacity in Ukraine to deal with HIV/AIDS now.
- **Chapter 5** indicates the most important steps needed to stem the HIV/AIDS epidemic.
EXECUTIVE SUMMARY

The Human Immunodeficiency Virus is well-entrenched among certain vulnerable groups in Ukraine, notably the country’s large and growing number of injecting drug users. Critically, it shows signs of spreading among the general population, especially young people.

1. Today's threat to tomorrow's well-being

As many as 250,000 Ukrainians may already be living with HIV/AIDS. With prevalence approaching 1% among those aged 15-49, Ukraine has the highest rate of infection in Europe and the CIS, with cases registered in every oblast or province. Officially registered new cases of HIV infection have fallen among injecting drug users and risen in other groups in Ukraine. Still, IDUs continue to be the key source of infection. Transmission through heterosexual sex with non-IDUs is increasingly a route of infection, which means the general population is at ever-greater risk. An estimated 40% of people living with HIV/AIDS in Ukraine today are women. Increased infection among pregnant women has led to more and more HIV-positive children since 1999.

If a comprehensive response is delayed, the growing epidemic will strain the country’s entire health care system, costing 20-50% of the Health Ministry's budget by 2010: 43,000-95,000 Ukrainians will likely die from AIDS during that year; and the cumulative number of children orphaned by the disease will be between 46,000 and 77,000.

2. HIV/AIDS in a transition economy

The HIV/AIDS epidemic is growing at a time when Ukraine is struggling economically. This has increased vulnerability to HIV/AIDS and reduced response capacity in several ways:

• widespread poverty and unemployment, a growing income gap;
• increased high risk behaviours among young people;
• weakening family and community ties;
• growing legal and illegal migration patterns;
• a growing illegal drug trade that drives the epidemic.

3. Public response: Catching up

HIV/AIDS was recognized in Ukraine when the first cases were registered in 1987. By 1995, there was an extremely rapid spread of HIV among IDUs, and the challenge outweighed the capacity and the resources of the country to respond. Now, Ukraine is the worst affected country in the region. In 2001, a new national strategy was introduced and new funding came in 2002 from the Global Fund for AIDS, TB and Malaria. A key TB and HIV/AIDS loan agreement with the World Bank was recently signed.

4. From planning to reality: A question of capacity

Budgets and spending. National budget commitments for HIV/AIDS Programmes have been consistently underspent and the gap between assessed needs and available funds is growing. The capacity to ensure effective usage of funds is unclear.

Obstacles to a multi-sectoral approach. Neither the Health Ministry nor the Government Commission to Fight HIV/AIDS have a proper mandate to coordinate allocation of funds or to monitor and evaluate their efficient use. A legal framework and set of procedures for state structures to enter into social service contracts is needed.

Costs and benefits of comprehensive care. As growing numbers of HIV-positive people begin to fall ill with AIDS, increasing demands are being placed on the national health system. Providing comprehensive care, including antiretroviral therapy, to all citizens in need will be costly. However, such care can reduce the long-term burden by averting hospitalization and by virtually eliminating infection of newborns.

5. Moving forward

As HIV/AIDS begins to threaten the general population of Ukraine, the risk of infection must be minimized and access to effective treatment maximized. The roadmap is clear:

• National commitments must be put into action.
• Budget allocations should be reflected in the disbursement of funds.
• Better procedures for monitoring and evaluation are needed for better results.
• Local and sectoral partnerships must be strengthened and new partners engaged.
• Improved mechanisms are needed to foster non-state involvement and delivery.
• The human rights of vulnerable groups and people living with HIV/AIDS must be entrenched.
• Injecting drug use needs to be tackled on all sides as the driving force behind the epidemic.
• The increasing vulnerability of women, and thus of newborns, must be addressed.
• The school system must be involved, to promote risk prevention among the young.
• Mass media have a key role in raising awareness and reducing discrimination.
• Comprehensive care must become a cornerstone of the national response.
1. TODAY’S THREAT TO TOMORROW’S WELL-BEING

Ukraine today teeters on the edge of a generalised HIV/AIDS epidemic. The virus is well-entrenched among certain vulnerable groups, notably the country’s large and growing population of injecting drug users. However, patterns of infection are shifting and the virus shows signs of spreading among the general population, with more women and newborns becoming infected.

№1 in the region

Some basic data shows the seriousness of the situation with HIV/AIDS in Ukraine:

• An estimated 250,000 Ukrainians are living with HIV/AIDS.¹

• Every day, between 150 and 200 persons are newly infected with HIV.

• As many as 11,000 people may have died because of AIDS in 2001 (see Chart 2 in Supplement).

• Among those age 15-49, Ukraine has the highest prevalence in Europe, followed by Russia and Estonia.

According to the best epidemiological estimates, Ukraine has the highest HIV prevalence among the adult population, defined as age 15-49, in Europe and the CIS. In Table 1, the country is shown to have an estimated prevalence, among adults, of 1% at the beginning of 2002, a figure comparable to Estonia and slightly higher than Russia. In absolute numbers, Ukraine is second on the list, behind the 700,000 estimated to be living with the virus in neighbouring Russia.

The number of officially registered HIV/AIDS cases in Ukraine, about 55,000 at this time, may represent only 20% of the real number of infected people. Official data does, however, make it possible to trace some of the epidemic’s dynamics and trends over time, both nationally and in the region.

№1 in Europe and the CIS (estimated, adults 15-49)

Table 1. HIV prevalence, 2002

<table>
<thead>
<tr>
<th>Country</th>
<th>% infected</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ukraine</td>
<td>1.0</td>
</tr>
<tr>
<td>Estonia</td>
<td>1.0</td>
</tr>
<tr>
<td>Russia</td>
<td>0.9</td>
</tr>
<tr>
<td>Spain</td>
<td>0.5</td>
</tr>
<tr>
<td>Portugal</td>
<td>0.5</td>
</tr>
<tr>
<td>Switzerland</td>
<td>0.5</td>
</tr>
<tr>
<td>Italy</td>
<td>0.4</td>
</tr>
<tr>
<td>Latvia</td>
<td>0.4</td>
</tr>
<tr>
<td>France</td>
<td>0.3</td>
</tr>
<tr>
<td>Belarus</td>
<td>0.3</td>
</tr>
<tr>
<td>Armenia</td>
<td>0.2</td>
</tr>
<tr>
<td>Moldova</td>
<td>0.2</td>
</tr>
<tr>
<td>Poland</td>
<td>&gt;0.1</td>
</tr>
</tbody>
</table>


The history of HIV/AIDS in three stages

Ukraine’s HIV/AIDS epidemic has undergone three distinctive stages:

• The first stage (1987–1994) was characterized by sporadic registration of new HIV infections. Mass-scale testing identified about 400 cases of HIV, two thirds of which were transmitted via heterosexual relations. The ratio between registered HIV-positive men and women was 1:1. More than half the cases were foreigners.

• The second stage (1995-1998) saw a massive outburst of infection among injecting drug users, identified first in 1995 in the cities of Mykolayiv and Odesa. Within two years, HIV-positive IDUs were registered in all oblasts of Ukraine and accounted for 84% of all officially registered HIV cases. Transmission was mostly through sharing contaminated needles and syringes. About 70% of the infected were 15-30 years old and the ratio of HIV-positive men to women was now 4:1.

• The third stage (1999-present) is showing higher rates of new HIV infections and possible signs of the fourth stage: a generalized epidemic driven by sexual transmission among people who do not inject drugs. More than 99% of HIV-positive cases in the country today are Ukrainian citizens, the great majority of them IDUs and their sexual partners. The number of HIV-positive women, and children born to them, is also rising.

What’s an epidemic?

HIV epidemics are characterised as “low-level,” “concentrated” or “generalised,” based on a set of quantitative measures. A “concentrated” epidemic is when HIV infection is over 5% in at least one vulnerable group. A “generalised” epidemic is when HIV prevalence among pregnant women is steadily higher than 1% in both urban and rural areas. National statistics, backed by estimates from international agencies and researchers, suggest that the HIV epidemic in Ukraine is currently “concentrated,” but in some urban areas – specifically Odesa and Mykolayiv – prevalence among pregnant women has steadily exceeded 1%.²

Why “undercounted”?

In 1987, HIV/AIDS was first detected in Ukraine when an official surveillance programme was started. National legislation to this day specifies that people are only registered as HIV-positive if they have undergone both clinical and laboratory testing and if their data are “personified.” This conservative approach has been superseded by more advanced techniques in other countries because it generally leads to a serious gap between the official count and the harsher reality.

Table 2. Living with HIV/AIDS, 2002

<table>
<thead>
<tr>
<th>Country</th>
<th>Estimate</th>
</tr>
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<tbody>
<tr>
<td>Russia</td>
<td>700,000</td>
</tr>
<tr>
<td>Ukraine</td>
<td>250,000</td>
</tr>
<tr>
<td>Spain</td>
<td>130,000</td>
</tr>
<tr>
<td>Italy</td>
<td>100,000</td>
</tr>
<tr>
<td>France</td>
<td>100,000</td>
</tr>
<tr>
<td>Germany</td>
<td>41,000</td>
</tr>
<tr>
<td>Portugal</td>
<td>27,000</td>
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<tr>
<td>Belarus</td>
<td>15,000</td>
</tr>
<tr>
<td>Poland</td>
<td>14,000</td>
</tr>
<tr>
<td>Estonia</td>
<td>7,000</td>
</tr>
<tr>
<td>Kazakhstan</td>
<td>6,000</td>
</tr>
<tr>
<td>Moldova</td>
<td>5,500</td>
</tr>
<tr>
<td>Armenia</td>
<td>2,400</td>
</tr>
<tr>
<td>Lithuania</td>
<td>1,300</td>
</tr>
</tbody>
</table>

The trajectory of HIV/AIDS in Ukraine has shown a shift in the predominant means of transmission. The main source began with predominantly heterosexual sex in 1987-1994, then moved to injecting drug use in 1995-1998. IDU has remained predominant, but heterosexual and mother-to-child transmission have both been growing since 1999.

A country-wide problem

Since 1997, new HIV infections have been registered all over Ukraine. The most affected oblasts are in the south and east, including Donetsk, Dnipropetrovsk, Odesa, Mykolayiv oblasts and Crimea. At the end of 2002, these five areas had about 70% of all people living with HIV/AIDS, compared to about 30% of the total population.

The Western region of Ukraine, which includes eight oblasts, remains the least affected, with just 6% of all officially registered HIV-positives. The maps in Figures 1 and 2 show the dramatic change in the geographic spread of the virus between 1997 and 2002. The maps illustrate only officially registered cases of HIV: the actual number is estimated to be five times greater.

A disease of the Twenty-somethings

The HIV epidemic is most widespread among younger people, for a variety of social and economic reasons. Although worldwide around 50% of all new HIV infections occur among those aged 15-24, in Ukraine, official statistics show that almost 50% of new cases are in the 20-29 group, followed by those aged 30-39. The relatively large number of under-13’s is almost entirely the result of mother-to-child transmission. (Fig. 3)

The epidemic does not affect women and men equally, for a variety of reasons discussed in Chapter 2. Official AIDS mortality figures (see Chart 3) show that, cumulatively, the largest numbers of deaths among men have been concentrated in the 30-34 age group, while the peak in mortality for women is in the 25-29 age group.

Figure 1 & 2: Registered cases of HIV in oblast centers (at January 1, per 100,000)

Growing up with HIV/AIDS

More and more women are infected with HIV every year. It is estimated that today about 40% of people in Ukraine living with HIV/AIDS are women and two thirds of registered HIV-positive women are 20-29, at the height of their reproductive years. In fact, 60% of pregnant HIV-positive women were under 25. Not surprisingly, rising numbers of infected pregnant women have resulted in a significant growth in the numbers of HIV-positive children since 1999 (Fig. 5). 97% of HIV-positive children (those 14 years and under in the Ukraine HIV/AIDS context) have been born to HIV-positive mothers.

Figure 3: Age distribution of registered HIV cases (%, cumulative to 2002)

Figure 4: Gender/age distribution

Figure 5: Proportion of women and children among HIV-positive (%, 1996-2002)

Because the HIV epidemic has been concentrated so far in marginalized groups, most HIV-positive children are born to socially disadvantaged families in Ukraine. They grow up lacking adequate nutrition, housing, clothing, toys, school supplies – all the living conditions that constitute a good quality of life.13

- 70% of HIV-positive children are born into families where one or both parents are using drugs, are vagrants, or are in prison, etc;
- 20% have been abandoned to the state’s care and live in orphanages or medical facilities;
- 85% of their parents are under 30; and
- 0% are ever likely to be taken in by foster parents or adopted.

Meanwhile, the number of officially registered HIV-positive children who inject drugs themselves has been growing since 2000, although it is only slightly over 2%. However, the real number is believed to be much larger, as many are street children age 10-13 who have been exposed to both drugs and sexual activity.14

Risks to the general population

To gain a more realistic estimate of the HIV/AIDS situation, Ukraine introduced a new monitoring tool, second generation surveillance, in 2002. This includes “sentinel surveillance” for HIV infection and sexually transmitted infections (STI), and behavioral monitoring of vulnerable groups.15

In Ukraine, this kind of surveillance was carried out in seven cities in oblasts with high, medium and low HIV incidence.16 Sentinel groups included injecting drug users, commercial sex-workers (female and male), and STI patients. The results confirmed that most HIV-related risk factors are indeed concentrated in these groups and that the course the epidemic follows will largely be determined by the actions and interactions of these populations.

The highest HIV prevalence continues to be among injecting drug users, ranging from 20% to 60%, with southern and eastern cities like Donetsk, Odesa and Mykolayiv the worst. In 2002, a western city, Lutsk, first showed a high HIV infection rate among IDUs: over 30%. This means that Western Ukraine, long considered a low HIV incidence region,17 is not immune to the risks of HIV and could also witness a significant increase in infections. (See Figs. 1 and 2)

While HIV prevalence among female sex-workers ranges from 4% to 12% in Lutsk, Simferopol and Kharkiv, it is as high as 17% to 31% in Donetsk, Odesa, Mykolayiv and Poltava. Critically, over 35% of HIV-positive FSWs also inject drugs, a statistic that is comparable to most of Europe and North America. In other countries, a sudden increase in HIV-positive FSWs to 50-80% is considered a warning signal that the epidemic is spreading to the population at large.18 The fact that the sex trade is illegal complicates the task of estimating the number of people involved in it and hampers the introduction of effective efforts to limit the spread of HIV, because FSWs operate largely underground and out of view.

Mother-to-child transmission

HIV can be transmitted from an infected mother to her baby during pregnancy, delivery or breast-feeding. How often this happens varies geographically. The European average is around 25-30%.19 The first data on mother-to-child transmission in Ukraine, collected in 2001, fell within this range at 27.6%.20

Without preventive treatment, 14% of HIV-positive children develop AIDS within the first year of life. An additional 12% develop it each year of life. The great majority of such children die before reaching five.21

Preventive activities such as anti-retroviral treatment for pregnant women, delivery by caesarian, and alternatives to breast-feeding can reduce the frequency of MTCT to 2-5%.22 Ukraine started to implement a programme of ARV treatment for infected pregnant women with the assistance of international donors and NGOs.

What is sentinel surveillance?

Sentinel surveillance studies HIV prevalence rates at regular intervals among selected groups known as “sentinel groups.” It is used to monitor trends in infection over time, by group, and by place. This information is useful for planning and providing HIV/AIDS prevention and care services, and to make projections about HIV/AIDS for the entire country.23
How aware are different vulnerable groups?

In 2002, self-identified Ukrainian MSM were specifically targeted for HIV testing for the first time, in a project carried out by Liga, an NGO in Mykolayiv. The project offered free testing and collected behavioral information. 12 gay men aged 20–47 participated. None were drug users or practiced commercial sex, though all were sexually active. Three of the 12 tested HIV positive. The study indicated very low awareness of preventive methods, insufficient supply of condoms, and lack of access to professional counseling by psychologists or health care workers able to address their needs.23

Although Ukraine decriminalised consensual sex between adult men in 1991 – the first former Soviet republic to do so –, men who have sex with men are also largely inaccessible to sentinel research due to stigmatization.24 Thus, there are few reliable estimates of the total number of MSM in the country. Since HIV/AIDS appeared in Ukraine, only 43 homosexual and bisexual HIV-positive men have been officially registered,25 a number that is far too small to be statistically useful.

Although official figures show a decline in the incidence of sexually transmitted infections since the mid-1990s, this may partly reflect the growing use of private clinics, which do not necessarily report on their diagnoses. In 2001, 13.3% of male STI sufferers at urban clinics in Ukraine were diagnosed as HIV-positive.26 The presence of an STI increases the risk of HIV transmission through unprotected sex by as much as 10 times, either by creating more opportunities for the virus to spread, or by contributing to its reproduction. Many STIs can be treated by antibiotics, but inadequate services, lack of medications, and limited access to diagnostics make effective identification and treatment difficult. This creates yet another obstacle to preventing the spread of HIV/AIDS in Ukraine.27

Among prisoners,28 HIV spreads quickly, mainly through unprotected sex and shared needles. In studied countries, its prevalence is considerably higher in prisons than in the larger community. Although HIV has not been comprehensively studied in Ukraine’s prison system, official statistics showed a 6.7% incidence among the 11,841 prisoners in a 6-month period. The number for 1995 was 455; in 1996 it was 2,937 and for the first 9 months of 1997 there were over 1,300… 83% were injecting drug users.29

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“...The rapid increase [of HIV in Ukraine] has affected the number of HIV cases in our prisons. Between 1987 and 1994, only 11 HIV-infected persons entered remand institutions. The number for 1995 was 455; in 1996 it was 2,937 and for the first 9 months of 1997 there were over 1,300… 83% were injecting drug users.”

Shifting paths to infection

The distribution of HIV transmission routes in Ukraine for 2002 can be seen in Fig. 6. While the use of injected drugs continues to predominate, since 1997 the proportion of IDUs among all officially registered HIV-positive Ukrainians has dropped, from a peak of 84% to only 52%.30 However, injecting drug users continue to be the key vulnerable group in the spread of HIV in Ukraine, and the problem is becoming more global as their non-IDU sexual partners become a bridge for spreading HIV to the general population.

Clearly, once it has entered a given vulnerable group, HIV does not remain isolated there, and the role of unprotected sex in the spread of HIV from drug users to their partners is critical. Research in Odesa

How can HIV be transmitted?

A person can be infected with HIV in three ways, through:

- unprotected sex with an HIV-positive partner;
- the blood, from contaminated needles or syringes during drug injection, medical procedures, piercing and tattooing, or through contaminated blood during a transfusion;
- pregnancy, delivery or breastfeeding if the baby’s mother is infected.25

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HIV testing: a critical policy gap

From a peak of 7.2 million tests in 1993, HIV testing has declined to some 2-3 million tests per year. Today, although the State guarantees voluntary confidential testing, such services are still severely limited. Obstacles include price, location, and limited testing centers. In addition, the public is inadequately informed about such services, pre- and post-test counselling procedures are inconsistent, and the supply of testing kits is inadequate.

The national testing programme is currently giving the highest priority to pregnant women and blood donors, and lower priority to IDUs and STI patients (Fig. 9). This could, however, result in significant under-identification of new HIV infections. Curbing the spread of HIV among IDUs and STI patients is the most effective way of preventing HIV from spreading among pregnant women and blood donors.

The worst-case scenario exceeded best-case figures by 2-2.5 times. The best-case scenario suggests that in 2010:

- 582,000 Ukrainians will be living with HIV/AIDS, including those sick with AIDS. This is more than double the current figure of 250,000.
- 43,000 will likely die of AIDS during 2010.
- More than 46,000 children will have been orphaned by AIDS by 2010.

Under the worst-case scenario:

- 1,440,000 Ukrainians may be living with HIV/AIDS.
- More than 95,000 will likely die of AIDS during 2010.
- More than 77,000 children will have been orphaned by AIDS by 2010.

Between a low birth rate and other health factors, Ukraine’s population is already expected to decline, from 47.28 million in 2005 to 45.48 million in 2010. The impact of HIV/AIDS will further reduce the population to between 45.09 and 44.89 million in 2010. In both scenarios, the largest number of AIDS cases will be in the 25-29 year age group.

It is clear, without even hazarding a guess as to the impact of HIV/AIDS on the overall economy, that Ukraine’s health system will be heavily and increasingly burdened by this epidemic. The costs of diagnostics, treatment and care for people living with HIV/AIDS, and of preventing mother-to-child transmission will grow. There will also be rising ancillary costs such as for training specialised health care staff, labs and test kits, hospitals, hospices, etc. Since access to treatment is a right guaranteed by the Ukrainian Constitution, the lack of access to antiretroviral drugs will become ever more unacceptable politically, especially if Ukraine aspires to enter the European Union.

The forecast included an estimate of budget funding needed to respond to the HIV/AIDS epidemic (Table 3). Even in the best case, the cost of treatment to the health care system will grow sharply and could, by 2010, exceed one fifth of the total Health Ministry budget. In the worst case scenario, responding to the epidemic will take almost half the Ministry’s budget.

Yet neither of these scenarios is inevitable. Firstly, a great number of HIV-related deaths and illness can be averted if ARV treatment is provided.

Two scenarios for 2010

In 2001, a forecast was prepared by an international team including representatives of the Ukrainian Institute for Social Research, the British Council, UNAIDS, the Ukrainian AIDS Prevention Centre, and the Ukrainian Institute of Economy. The team looked at possible trends in the HIV/AIDS epidemic in Ukraine, including its effect on the population and the economy. The forecast provided two scenarios with differing rates of HIV spread, based on a national response that was “little or none” and on a response that involved the necessary levels of scaling up.

Table 3: The cost of HIV/AIDS to the national health system, 2005-2010

<table>
<thead>
<tr>
<th></th>
<th>Best-case scenario</th>
<th>Worst-case scenario</th>
</tr>
</thead>
<tbody>
<tr>
<td>% of total hospital beds required for HIV/AIDS patients</td>
<td>2005: 0.9</td>
<td>2010: 1.3</td>
</tr>
</tbody>
</table>

Secondly, ARVs are no longer a luxury reserved for only the wealthiest countries. Brazil has demonstrated that providing such treatment results in a dramatic reduction of HIV-related illnesses and in mortality due to AIDS. Brazil’s 1996 decision to guarantee universal access to free treatment has helped over 100,000 HIV-positive people, with dramatic results. By 2000, Brazil’s AIDS mortality was three times lower than in 1996 (see sidebar p. 20). The saving in budget funds that would otherwise have been spent on medical care and other services far exceeded the annual cost of treatment.35

### Millennium Development Goals at risk?

Among the Millennium Development Goals Ukraine has committed itself to, there is an overall target of reducing the rate of the spread of HIV/AIDS by 13% between 2001 and 2015 according to three key indicators (Table 4):

- the number of new HIV-infections per 100,000
- the number of AIDS-related deaths per 100,000
- the proportion of HIV-positive children born to HIV-positive mothers.

These goals are within the ability of Ukraine to achieve, but only if the level of response in prevention and care (in particular a serious scaling-up of access to ARV therapy) is greatly expanded. Delaying this will be fatal for tens of thousands of Ukrainians in the coming years. According to a recent study, a delay of just three years in implementing comprehensive prevention measures can “reduce by 50% the total number of new infections averted by 2010. Any delay also results in a much smaller benefit for each year of implementation.” 37

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<tr>
<td>new HIV-infection cases/100,000</td>
<td>14.2</td>
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<td>14.1</td>
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<td>AIDS-related deaths/100,000</td>
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<td>1.2</td>
<td>0.7</td>
<td>0.6</td>
<td>0.5</td>
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<tr>
<td>HIV-positive infants (% of all births)</td>
<td>35.0</td>
<td>30.0</td>
<td>25.0</td>
<td>15.0</td>
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Table 4: Schedule for HIV-related Ukraine Millennium Development Goals
2. HIV/AIDS IN A TIME OF TRANSITION

Economic transition has contributed the HIV/AIDS epidemic in Ukraine, giving rise to a number of key factors that increased the vulnerability of this society.

The economic situation in Ukraine has been improving since the late 1990s, and Ukrainians are seeing real improvements in key indicators, such as average household incomes. Still, the effects of transition have increased the susceptibility of the population to HIV/AIDS and reduced the capacities of the society to respond effectively. The set of specific social problems has eight key characteristics:

- socio-economic decline due to widespread poverty, unemployment, and growing income inequality;
- disintegration of families and communities, with increasing numbers of orphans, state wards and street children;
- increasing frequency of HIV-related risk behaviors among young people, principally unprotected sex and sharing injecting drug equipment;
- deterioration in the educational system, reducing its capacity to helping youth develop skills to protect themselves from infection;
- gender inequalities that reduce women’s ability to protect themselves from HIV infection and increase the burden of care that falls on them;
- population instability reflected in both legal and illegal migration patterns;
- a growing illegal drug trade, the most directly-linked “driver” of the epidemic;
- stigma and discrimination against people living with HIV/AIDS.

While not all of these factors are direct results of transition, they are part of the overall context that fosters the spread of HIV in Ukraine.

The growth of poverty

The economic drop in Ukraine between 1990 and 1998 led to widespread poverty, burgeoning unemployment, and rapid growing income gap. Each of these has had a powerful impact on the spread of HIV by increasing the vulnerability of different segments of the population. The situation started to improve by 2000, in part due to government reforms, but the benefits are spread unequally according to region, gender, age and employment sector.

According to the State Statistics Committee of Ukraine, in 2000 around 26% of Ukrainians lived in poverty, with a further 14% in extreme poverty.

Moreover, poverty in Ukraine has become significantly deeper for those disadvantaged by market conditions or lacking a social safety net. In 1996 survey, more than two-thirds of the poorest households in Ukraine were comprised of pensioners. The remainder were largely families with many children, and households that have a disabled or unemployed relative.

Moreover, the labor market shows a deepening lag in the supply of jobs, a decreasing number of salaried employees, significant levels of hidden and official unemployment, and a growing illegal labor market. The total number of unemployed in 2001, based on ILO methodology rather than the much smaller “officially registered unemployed persons,” was over 2.5 million people, an unemployment rate of 11.1%. About one-third of all unemployed are young people aged 20-29, for a level of 15.4%. Moreover, with the manufacturing sector showing only slow signs of recovery, unemployment will not go down soon. The longer they are unemployed, the more vulnerable young people become. Average duration of unemployment in 2001 was 23 months, indicating that it is becoming an intractable feature of society.

Experience from other countries shows an integral relationship between income inequality and HIV infection. According to the World Bank, of 96 countries, Ukraine has the 71st most unequal distribution of income as measured by the Gini Index. The margin of inequality continues to grow. Ukraine’s severely skewed distribution is based on factors such as salary differentiation by industry, unequal ability to receive revenues from privatized property, and exploitation of communal and state property by special interests.

Families fall apart, communities cannot hold

Ukrainian families are under enormous stress today, much of it related to economic upheaval. As unemployment rose and living standards declined, many families destabilized, losing the ability to form and maintain moral and ethical guidelines. No state or social institutions can replace the family in providing security and stability in a quickly changing world. The trend has been to postpone marriage and there was a large decline in childbirth in all oblasts of the country, including rural areas. Meanwhile, the proportion of divorces to marriages continues to grow.

Communities have traditionally played a significant role in personal development and socialization, but in recent years they have gradually lost their influence. Ukrainian society is orienting more towards individualism – to the detriment of traditional public spirit, many say. Without doubt, this contributes to the vulnerability of young people to HIV/AIDS.

The number of state wards and street children has continued to grow significantly in Ukraine. The number of wards rose from 1,800 in 1991 to 6,000 in 2000 and the number of children abandoned at birth went from 12,300 to 19,800. Officially, there are at least 40,000 homeless and uncared-for children, a figure that is rising. In 2001, during the “Street
How do kids learn about sex and drugs?

I got my education on the street, like practically all my friends. I get the impression my parents are afraid of the words “sex” and “drugs.” They stutter and blush like first-graders when they hear these words, so what can I discuss with them? If I say anything, they won’t let me take a step on my own – they’ll even lead me to school by the hand. Today, the average six-year-old knows more about sex and drugs than my Mom and Dad.

Children of the transition

Young people aged 15-24 are children of the transition period, having spent most of their lives in a shifting social, cultural and economic environment. While this has certainly opened new opportunities for them, it has also increased key risk factors: unprotected sex and substance abuse, both drugs and alcohol.

Changes in the sexual behaviour of young Ukrainians include a lower age of the onset of sexual relations. A study carried out by the Ukrainian Institute for Social Research and the Social Monitoring Center in 1998 found that 6% of teenagers have their first sexual experience at 11-13 years, and 11% at 14. This is especially typical for the Central and Western regions of Ukraine and could result in an upward change in their currently low incidence of HIV/AIDS. According to a 2001 survey among young people, almost two thirds of those aged 15-22 have already had sexual relations. Only 55% of sexually active young people use condoms, while 10-20% say they cannot afford them. Between 1989 and 2002, syphilis among girls aged 15-17 increased from 5.5 to 73.1 per 100,000, and from 2.6 to 21.5 among boys. This significantly increases the risk of HIV infection, either by creating more opportunities for the virus to spread, or by contributing to its reproduction.

Official statistics show that the overwhelming majority of Ukrainians diagnosed as drug dependent are aged 15-17 (83%). At the same time, the age of registered drug addicts continues to fall. Many young people already consider drugs a part of their everyday lives, closely linked to friends, clubs and discos. However, attitudes may be gradually changing. In a 2002 survey of young people, many respondents believed that the spread of drug use (36%) and HIV/AIDS (14%) constituted the greatest threat to their health. As well, young people appear to be more critical towards injected drugs than to “soft drugs” such as marijuana and hashish.

A struggling school system

The educational system is crucial in any country’s response to HIV/AIDS, as well as to drug abuse. With access to children and teens on an almost daily basis, schools have the opportunity to provide young people with information about HIV/AIDS. However, the educational system in Ukraine has experienced reduced enrollment, partly because of declining numbers of children nationwide and a growing number of street children. User-pay educational institutions have arisen, effectively excluding growing numbers from the educational process:

- The pre-school network shrank 36% between 1991 and 2001, reducing access to pre-school education and socialization to 45%. Public schools have not much changed in number, but paid institutions have doubled.
- Vocational institutions and enrollments declined over 21% between 1991 and 2001.
- Enrollment in higher education is rising, as is the number of students at top-ranking institutions – and the cost of a higher education. In 1995-1996 only 18% paid for their education; in 2001-2002 it was 59%. This reduces accessibility to poorer children.

The quality of education in Ukraine has also been damaged, with both curriculum problems and inadequate material conditions. Most activities specific to HIV/AIDS and drug use prevention are now in a planned or start-up stage. International donors such as UNDP and the European Commission have funded projects to introduce HIV/AIDS education in the school system and in orphanages. These need to be scaled up rapidly so that much larger numbers of young people can get the information necessary to make effective decisions.

A growing gender gap

“Gender,” the widely-shared expectations and norms within a society about “appropriate” male and female behaviour, characteristics and roles, significantly affects a person’s vulnerability to HIV infection. Rigid gender roles can discourage individuals from taking positive decisions to regard their own health and well-being. Although Ukraine has relatively high gender equality as measured by the UNDP Gender Development Index, such measures reflect legal and institutional equality rather than the attitudes and behaviours of everyday life.

Currently, about 80% of HIV-positive Ukrainians are male, reflecting the greater number of men who are injecting drug users. This is consistent with the wider context of gender differences in Ukraine regarding risky behaviour and life expectancy. Among Ukrainians between the ages of 20 and 40, the probability of death among men is 3-3.5 times greater than for women, largely due to unhealthy life-styles, working conditions, and alcohol and tobacco consumption.

While extramarital relations are considered a norm for men, women are expected to be faithful wives and responsible mothers. Ironically, a woman’s risk of HIV infection depends less on her lifestyle, moral principles or number of sexual partners than on her ability to insist on condom use by her partner.

Female sex workers and IDUs are at a heightened risk of HIV infection. In addition to having little...
leverage to oblige their clients or partners to use condoms, there are no official prevention activities which might support these women. They also have little access to medical services, although they have reportedly been forced to undergo testing. Research by the State Institute for Family and Youth indicates that, for many women, sex work has become the only adequate source of income: more than 50% of them support their children and parents.

Female IDUs are more vulnerable to HIV infection than their male counterparts, partly because the men tend to purchase raw materials and prepare their own drugs, while the women much more frequently inject with a dealer’s or partner’s syringe. Moreover, female IDUs are more likely to have sexual partners who also inject drugs, especially since a significant proportion of these women provide sexual services to get their drugs.

A population on the move

Epidemiological research from around the world shows that migration processes – both internal and external – play an important role in the growth of an HIV/AIDS epidemic. There was a great deal of official migratory flow in and out of Ukraine between 1991 and 2002 (Fig. 10), although the overall numbers have stabilized. However, official data reflects only the tip of the iceberg because illegal migration continues to be substantial.

Figure 10. Migration balance: immigrants minus emigrants (1989-2000)

Ever since exit procedures for citizens were simplified in 1994, more and more Ukrainians are going abroad in search of work. The HIV risk for external labor migration stems from the fact that most workers are young men aged 20-40, at the most sexually active stage of their lives. The unsettled life far from their families fosters casual sexual relations and commercial sex, heightening the risk of infection. When HIV-positive migrants return home, they may spread the infection to their spouses and/or their local sexual partners. Meanwhile, tens of thousands of young Ukrainian women have become involved in sex trade networks abroad, voluntarily and involuntarily. As sex workers, illegal migrants and women, they are at a triple risk abroad and upon returning they may not seek psychological and medical services and thus transmit the virus further.

While many people confuse refugees and illegal immigrants, both groups elicit negative attitudes. One of the chief differences between these groups is their sheer numbers. While some estimates suggest there are as many as 550,000 illegal migrants in Ukraine at the moment, only 2,942 people have refugee status in Ukraine as of July 1, 2003. 60% of refugees come from Asian countries with relatively low HIV incidence. African refugees constitute only 11%, mostly from the Congo.

One of the factors contributing to the large numbers of migrants from the east is that Ukraine’s eastern borders are relatively open but the western ones closed. Most illegal migrants originally intended to pass through on their way to Western Europe.

Several key problems encountered by these two groups increase their risk of becoming infected with HIV/AIDS:

- few prevention services are targeted to different needs and cultural values;
- the reorganisation of the State Migration Service has left applicants for refugee status in limbo;
- even with official status, many refugees face unemployment and financial difficulties;
- since Ukraine cannot return illegal migrants and refused applicants to their home countries, they continue living here without status. Some resort to petty trading, others survive through riskier activities, such as drug dealing and commercial sex;
- since there is no compulsory HIV/AIDS testing for refugee applicants, they can be tested only on a paid basis, which most cannot afford.

The illicit drug trade

Injected drugs, a huge and growing problem in their own right in Ukraine, are deeply linked with the country’s HIV epidemic. Of a total 83,888 Ukrainians registered as drug addicts as of Jan. 1, 2003, the Health Ministry reports, 96% were injecting drug users. The numbers continue to grow by 11-12% per year, with most drug users young people – and getting younger. Some evaluate the real number of injecting drug users in Ukraine as close to 560,000.

The most affected areas are Donetsk, Dnipropetrovsk, Odesa, Mykolayiv, Crimea, and the city of Kyiv. The variety of illicit substances has also been expanding significantly. Certain aspects of drug use in Ukraine make users more vulnerable to HIV infection. Research among users in Kyiv and Kharkiv showed that more than half barter their drugs for different “services” such as producing drugs and sexual favors, compounding their already-high risk. Another character-
In my experience, medical staff behave very unethically. They’ve come to me and threatened to “denounce” me to the police. I get the impression their job isn’t to treat HIV-positive people, but to keep track of them – and not just our behaviour, even our thoughts. As if we are all terrorist maniacs. But when it comes to getting a doctor’s help, nobody wants to even listen…

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Living with the stigma of HIV/AIDS

Public attitudes towards HIV/AIDS and the people personally affected by it are one of the largest obstacles to an effective response to the epidemic in any country. PLHA face many kinds of discrimination when their status becomes public:

- isolation and ostracism from family and friends;
- dismissal from a job, or conditions that force them to leave their work;
- discrimination by neighbors, including demands to move away.

Stigma is also a likely factor in both the low number of officially registered HIV/AIDS cases in Ukraine and the under-use of HIV/AIDS facilities such as government AIDS Centers. Recently, international organizations have been calling attention to the human rights of those living with HIV/AIDS, which may have an increasing impact on how they are treated in Ukraine.

Prejudice is partly due to public misinformation regarding HIV/AIDS from the start. A consistent information policy has yet to be put together to cover the problem. Even today, Ukraine has no advocacy and public education strategy to improve awareness. Sensationalist reports by newspapers and TV often make little mention that public health actions could do much to stem the epidemic. Surveys continue to show that the general population is intolerant of people with HIV/AIDS.

Most disturbing, however, is discrimination by health care workers. In violation both of professional ethics and Ukrainian law, medical staff frequently violate confidentiality and anonymity of information about HIV status. Some staff even refuse to provide any medical services, whether HIV-related or not, to infected patients. Such practices appear to be relatively common. For instance, while HIV prevention and opportunities for women to take HIV tests before pregnancy were until recently almost non-existent, testing is now widespread for pregnant women. If a woman is found to be positive, medical staff typically recommend an abortion without informing her about medical options for preventing mother-to-child transmission. Worse, such prevention is still not available in all parts of Ukraine, although it is now a government priority.

For the most part, public opinion does differentiate between HIV-positive children and the children of HIV-positive parents. But such parents often have to remove their children from childcare or school and bring them up at home, or to transfer them to another facility just to avoid confrontation and give their child a chance to study under more conducive conditions. Children orphaned by AIDS or abandoned by HIV-positive parents are often brought up in state orphanages, mostly in separate groups or at hospitals for infectious disease until they reach school age. Very little social or psychological support is provided to such children and public schools are generally not willing to admit them. There is an ongoing debate about special arrangements, including home schooling.
3. PUBLIC RESPONSE: CATCHING UP

After a rapid initial response, it became clear that public capacity was lacking in Ukraine. Huge gaps between allocated and disbursed budget funds continued. Renewed efforts since 2001 are moving in the right direction and need to be scaled up substantially. The latest National Programme addresses key areas more.

Reaction to the spread of HIV in Ukraine in the late 1980s and the early 1990s was rapid: the government set up bodies and structures to fight HIV/AIDS and adopted the first regulatory directive. In 1995, there began an extremely rapid spread of HIV among injecting drug users, a test year for the country’s response system. The challenge outweighed both capacity and resources. By the end of the decade, Ukraine was the worst affected country in the region.

In 2001, the President signaled a renewed effort by setting up a top-level body responsible for policy direction and for coordinating the national response: the Government Commission on HIV/AIDS, chaired by the Vice Premier. The new national strategic plan for HIV/AIDS provided for a more multi-sectoral and multi-partner approach.

New funding for the response was secured with Ukraine’s successful application to the Global Fund for AIDS, TB and Malaria in 2002.\(^7\) The country now appears to have in place the most crucial elements for reversing the spread of HIV/AIDS: significant financial resources, an action plan, and the institutional arrangement for a multi-sectoral and multi-partner response.

A history of National Programmes

The first National AIDS Prevention Programme for 1992-1994\(^4\) focused on implementing activities to prevent HIV transmission through the nation’s blood supply. This was during a very difficult period, when the country faced a serious lack of disposable medical equipment, disinfectants, sterilization equipment, quality test-kits, condoms, and medications for the treatment of HIV/AIDS patients.

The Second Programme (1995-1997) continued the focus and also provided for scientific research on HIV/AIDS, establishing a network of specialised facilities to care for persons living with HIV/AIDS. The Third Programme (1999-2000) occurred in a time of reorganisation, including the dissolution of the National AIDS Prevention Committee.

In retrospect, these Programmes failed to provide for activities, except repressive ones, to prevent HIV transmission among the very groups where the epidemic was most serious: injecting drug users, sex workers and others. They also failed to mobilize civil society to fight the epidemic, despite the lessons learned in other parts of the world.

The 1998 law provided for more government obligations and guarantees in accordance with international standards, in particular, provisions for public information, healthy lifestyle promotion, and improved safety in health and related services. It emphasized multi-sectoral approaches and decentralized prevention activities, correcting some human rights violations, such as compulsory testing of certain social groups. Procedures for testing and confidentiality were more clearly established, and provisions for expelling HIV-positive foreigners relaxed. Notably, this law was the first in the region to guarantee state support for needle exchanges, which paved the way for developing and implementing harm-reduction projects.

Meanwhile, public concern was gradually formalized into networks, associations and organizations. By 2000, 36 HIV prevention projects for IDUs had been established on the initiative of NGOs in 18 oblasts, and 17 projects for female sex workers in 12 oblasts, offering information and education activities; training for specialists and target groups; condom promotion and distribution; harm reduction for IDUs; counseling, treatment and a supportive environment.

Financing came from a range of international agencies, governments and NGOs.\(^7\) In 1999-2000, the first HIV-positive activists appeared on the political arena. The first national conference of persons living with HIV/AIDS from different oblasts of Ukraine took place in November 2000 and the All-Ukrainian Network of PLHA was formed.

In this way, Ukraine gained experience working with vulnerable groups. Without serious financial backing from national and oblast governments, however, the coverage of these projects remained between 5% to 20%.\(^7\) Having created a favourable legal environment for carrying out prevention programmes, the state did not have economic or political leverage – or the political will – to control and coordinate them.

Budget financing during 1995-1997 was insufficient due to the economic crisis and sharply reduced tax revenues. In 1996 and 1997, less than 50% of planned expenditures were disbursed (Table 5). Only
in 2000 did actual funding match planned levels – which were about a tenth of 1996 and 1997. Financial data is not available for 1998 or 1999.

Funds from international donors make a significant contribution to Ukraine’s HIV/AIDS efforts. From mid-1990s, the UN agencies in Ukraine, the EU and the US, the German government, the British Council, the International Renaissance Foundation and other organizations provided organizational and technical assistance to the Ukrainian Government and NGOs in HIV/AIDS prevention activities. A joint UN programme called ACT NOW supported several activity areas that lacked national programming or sufficient funding:

- developing leadership and political support through an intensive programme for representatives from government, NGOs, religious groups and media, and through informational and policy support to the Government AIDS Commission (UNDP, UNAIDS);
- prevention of mother-to-child transmission through a national programme to access trained medical professionals and transmission reduction medications (UNICEF);
- prevention activities among highly vulnerable groups, including support for harm reduction activities among IDUs, outreach and expanded services to sex workers, and educational programmes for the armed forces and the prison system (UNDP, UNAIDS, UNFPA, UNICEF);
- developing and improving the epidemic monitoring system (UNAIDS, UNICEF).

The total financial resources provided by international donors in 1995–1997 was $928,120. Figures are unavailable for 1998–2000, but calculating the actual value of external contributions is difficult anyhow, since there is no state body monitoring external funding for HIV/AIDS. Almost all leading international agencies and foreign organizations provided financial data for this report, but only an estimate is possible for two reasons:

- funding is often channeled through several international projects or organizations, who can be both donors and implementers;
- reporting frameworks and methods of different agencies and organizations vary and are largely incompatible for analysis.

Nevertheless, the National Programmes accomplished some important goals, in particular:

- setting up domestic manufacturing capacity for disposable syringes, medical instruments and latex goods such as condoms and surgical gloves. Today, domestic production of contemporary diagnostic tools fully satisfies the country’s demand for testing kits to detect HIV antibodies and infectious agents that cause opportunistic infections;
- organizing a network of diagnostic labs to control donor blood quality at blood transfusion points and to test people in vulnerable groups;
- establishing a network of 27 oblast HIV/AIDS prevention centers;
- opening 127 centers for confidential HIV testing;
- assigning 224 hospital beds in 7 centers to provide specialized in-patient care for PLHA.

With technical support from UNAIDS, rigorous strategic planning of the national response began and the Fourth Programme was developed.

2000–2001: The turning point

By the beginning of the new millennium, the need to revitalise and re-focus the national response drew the attention of the President and Verkhovna Rada. In September 2000, Ukraine signed on to the Millennium Development Goals, of which the sixth goal is to halt and begin to reverse the spread of HIV/AIDS by 2015.

In less than a year, the President issued three Decrees: Urgent Measures to Prevent HIV/AIDS (Nov. 1, 2000); Declaring 2002 the Year to Fight AIDS in Ukraine (June 22, 2001); and Additional Measures to Strengthen the Response to HIV/AIDS (Aug. 28, 2001). In broad terms, these directed the Ukrainian government to:

- inform the general public about HIV/AIDS;
- introduce modern medical technologies and maintain the safety of donor blood supplies;
- improve specialized medical assistance to people living with HIV/AIDS;
- promote activities of community and charitable organizations in preventing HIV/AIDS;
- study and introduce global best practices on the care and support of PLHA.

To keep things moving, a Commission to Fight HIV/AIDS was mandated to coordinate AIDS activities among ministries and the Fourth National Programme on HIV/AIDS was approved in 2001. This was consistent with the goals of the Declaration of Commitment made at the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) in June 2001.44

On the legal front, some key changes were made in 2001. The law on HIV/AIDS introduced changes covering blood transfusions and indemnification for harm. In response to continuing doubt over the safety of the country’s blood supply system, the Law specifically states that a blood transfusion can only be given when there is no other way to save a life. Transfusion of untested blood is absolutely prohibited and transfusion of blood tested with rapid tests is allowed only when there is no other way to save a life. Transfusion of tested blood is absolutely prohibited and transfusion of blood tested with rapid tests is allowed only when there is an immediate threat to life and lab testing is nonetheless performed subsequently. Finally, people infected with HIV through blood transfusions are guaranteed compensation for harm, even if the transfusion was performed with their consent.

The first day I injected

I remember the day I first injected a drug very well. A friend showed me how to do it behind the front door of a neighboring building. I don’t blame anyone because I pumped my vein myself, but my life changed dramatically after the first thrill. I struggled to control it, but soon I was trying to get drugs at any cost...

Then my parents pressured me to begin treatment. When doctors offered me an HIV test, I agreed. The result was supposed to come in two weeks, but when no answer came I became scared. I had a repeat test. A month later, I learned I was HIV-positive. It was terrifying. I stopped caring about anything. I took up drugs again... until I understood one day that they would kill me sooner than AIDS.
UKRAINE and HIV/AIDS: Time to act

A COMMITMENT TO PREVENTION AND CARE

Taken together, the commitments made by the Government of Ukraine to HIV/AIDS provide a set of clear yardsticks by which the national response to the epidemic can be measured.

HIV/AIDS-related Goals of the Millennium Summit (September 2000)

- reduce the spread of HIV/AIDS by 2015;
- establish universal access to safe/reliable contraceptive methods by 2015;
- reduce the under-5 mortality rate by two-thirds by 2015.

Key Commitments in the UNGASS Declaration (June 2001)

- By 2003, develop and/or strengthen national strategies, policies and programmes, supported by regional and international initiatives, as appropriate, through a participatory approach, to promote and protect the health of those identifiable groups which currently have high or increasing rates of HIV infection or which public health information indicates are at greatest risk of and most vulnerable to new infection;
- By 2003, have national strategies to address the spread of HIV among national uniformed services, including the armed forces and the police;
- By 2003, have in place nationwide strategies, policies and programmes that identify and begin to address factors that make people particularly vulnerable to HIV infection, to complement prevention programmes that address activities which place people at risk of HIV infection;
- By 2005, develop and make significant progress in implementing comprehensive care strategies;
- By 2005, strengthen the response to HIV/AIDS in the workplace by establishing and implementing prevention and care programmes in public, private and informal job sectors, and take steps to provide a supportive work environment for those living with HIV/AIDS;
- By 2005, ensure that at least 90%, and by 2010, at least 95% of young men and women aged 15 to 24 have access to the information, education (including peer education and youth-specific HIV education), and services necessary to develop life skills to reduce vulnerability to HIV infection;
- By 2005, reduce the proportion of infants infected with HIV by 20%, and by 2010 – 50%.

The Law still has some drawbacks with regards to human rights. The main difference between the Law and international legal instruments is in the Preamble, which does not emphasize the protection of human rights, and Art. 22, which does not mention human rights protection as a priority policy area.

The new Criminal Code brought changes to provisions for criminal responsibility in cases of violating confidentiality regarding HIV infection. Art. 132, regarding “disclosure of information derived from medical examination,” now covers a narrower range of persons who may have obtained information without permission or medical staff and it is impossible to apply it to other officials who may have access to information about persons living with HIV/AIDS. Art. 130 has equally serious human rights implications for PLHA and vulnerable groups, especially where it establishes responsibility for “conscious exposure of other persons to the threat of infection.” According to this article, even if PLHA take precautionary measures, they are liable to criminal prosecution for any activity that even hypothetically could result in transmission.

Better coordination, wider representation

Since coordination and true multi-sectoral representation have been an obstacle to the national response, the new Commission to Fight HIV/AIDS can play a key role. Established on Feb. 7, 2001, the Commission is an autonomous body reporting to the Cabinet of Ministers and headed by the Vice Premier. All 27 members are government officials and their key tasks are to:

- determine priority directions of HIV/AIDS response;
- oversee implementation of respective government programmes;
- coordinate activities of central and local executive bodies, enterprises, institutions and organisations in response to HIV/AIDS;
- update the Government, international community and general population about the HIV/AIDS situation in the country.

Coordinating councils have also been established in each oblast, generally headed by the deputy state administrator. In some oblasts, these exist only nominally, unsupported by organisational or financial provisions to implement any decisions made. This situation must change to develop a consistent nationwide response to HIV/AIDS.

The Health Ministry has been directed to develop joint programmes and instructions in cooperation with other central bodies, and to coordinate assistance, both financial and technical, from international organizations.
The Fourth National Plan, 2001-2003

The Fourth National Programme for 2001-2003 was developed on the basis of strategic planning by the Ministry of Health in 1999-2000 with the support of UNAIDS. Its main areas of activity are:

- information/education programmes for children and teenagers;
- media campaigns to inform the general public on HIV/AIDS prevention;
- reducing risk of infection among specific groups (IDUs, female sex-workers, MSM, prisoners, others);
- activities to ensure donor blood safety;
- mitigating negative consequences of HIV/AIDS in the country (treatment and care for people living with HIV/AIDS);
- monitoring the HIV/AIDS situation, its impact, and preventive interventions.

Unlike previous Programmes, special attention is focused on support to community organizations involved in prevention, care and support, and mitigation.

The Programme anticipates multi-channel funding from public budgets, international donors and others. Data suggests that external contributions amounted to $8 million in 2000-2002, significantly greater than cumulative amounts in previous years. They were concentrated in these areas:

- information/education programmes for children and teenagers (over $5 million);
- HIV/AIDS and STI prevention among vulnerable groups (over $1 million);
- prevention of mother-to-child transmission (over $500,000);
- care and treatment for PLHA, especially social and legal support (up to $200,000);
- epidemiological and behavioral monitoring (up to $100,000)

Funding was also allocated for policy development and capacity-building for NGOs, activity areas in which the Ukrainian government invested little funding. A joint European Union-United States programme was signed on Dec. 1, 2000.

The EC-US HIV/AIDS Prevention and Awareness Programme for Ukraine received a European grant of Euro 1.8 million and a US grant of $2 million. Its activities, which end in 2003, are being carried out by the International HIV/AIDS Alliance and the British Council. The Alliance currently supports 25 NGOs in 20 oblasts, for awareness activities with IDUs, FSWs, MSMs, PLHA and STI patients. The Alliance also supports an Information and Resource Centre which regularly publishes materials based on international best practice and local experience of Ukrainian HIV/AIDS service organisations.

The British Council has instituted a pilot project for prevention among youth in five oblasts and one city, focused on life skills. It has also financed a media awareness campaign and an all-Ukraine media contest on HIV/AIDS.

The Global Fund to Fight AIDS, TB and Malaria

The Global Fund to Fight AIDS, TB and Malaria was established in 2001 to strengthen the response to HIV/AIDS. One of the first countries to sign an agreement with the Fund to receive financing, Ukraine currently represents the interests of 24 countries of the region on the Fund’s Board. The Fund is providing two-year grants for:

- the Ministry of Health to reduce morbidity and mortality rates from HIV/AIDS and to improve the quality of life of PLHA ($16.9 million);
- UNDP to reduce vulnerability to HIV infection among IDUs, FSWs, prisoners and people in uniform (police force, prison staff and military personnel) ($1.9 million);
- the Ukrainian Foundation to Fight HIV/AIDS to encourage safe behaviour and healthy lifestyle skills by informing and educating teenagers and young adults, reducing the risk of HIV and other STIs, as well as stigmatization of and discrimination against PLHA ($6.1 million).

The Country Coordinating Mechanism of the Global Fund in Ukraine is responsible for overall supervision of grant implementation and involves the participation of representatives from government, international organisations, the private sector, and Ukrainian NGOs. Of its 45 members, the CCM reserves three seats for people living with HIV/AIDS, five for community and charity organisations, two for representatives of the private sector, five for the education sector, 10 for international organisations and the remaining 20 for the government sector.

World Bank loan

Ukraine recently negotiated a $60 million World Bank loan to fund a project entitled “Control over TB and HIV/AIDS” which was ratified by the legislature Nov. 18, 2003. While the loan will finance work on both TB and HIV/AIDS, a significant part covers activities to reduce harm and prevent the spread of HIV/AIDS. According to an agreed-upon plan, a good part of the funds will be earmarked for providing material and technical resources to harm reduction programmes ($10 million), awareness activities ($6.7 million), material and technical resources for medical facilities ($3.8 million) and medicine ($3.9 million). Another chunk of the loan ($1.1 million) is for monitoring project performance, public opinion surveys, and quality control of drugs, goods and services. There is also an HIV/AIDS in prisons component.

Reaching out

A large number of HIV/AIDS prevention activities are now underway in Ukraine. Although few are at a truly national scale, they show what is possible and are offering valuable experience to many individuals and organizations.
The first project aimed at FSWs was implemented in 1997 by an Odesa NGO called Faith, Hope, and Love, with the support of UNDP and UNAIDS, and became the basis for a sex workers’ self-support organization called Maria Magdalena. In 1999, a one-year project “FSW Network Initiative with NGOs in Ukraine” was coordinated by the Ukrainian Institute of Social Research and implemented in 11 cities, with technical assistance from UNAIDS and the British Council. Funded by the Federal Republic of Germany, the project served as a springboard for other initiatives with sex workers, including a second phase in 2002-03 supported by UNDP in 18 cities in 18 oblasts.

In 1996, Ukraine’s first Harm Reduction programme among IDUs was initiated, also in Odesa. Today, some 36 HIV prevention projects for IDUs have been launched in 18 oblasts, mostly with the support of the International Renaissance Foundation, International HIV/AIDS Alliance and UN agencies. Standard harm-reduction services include providing drug users with IEC materials, needle exchanges and distribution, distribution of condoms and disinfectants, information on safer behaviour, and referrals to medical services for treatment. Such projects have yielded concrete results and a wealth of experience to build on. Behavioral surveillance of participants shows that the tendency to share syringes and buy ready-made drugs in filled syringes has been reduced substantially in these projects, and consistent condom use has increased dramatically. However, such programmes cover only about 15% of IDUs in Ukraine. Expert opinion generally suggests that at least 60% of IDUs must be supported by such activities to have a substantial impact on the HIV infection rate.

Proposals put forth by the All-Ukrainian Network of People Living with HIV/AIDS were influential in the inclusion of provisions to mitigate the negative impact of the epidemic through comprehensive assistance, care and support to those living with HIV/AIDS in the National HIV/AIDS Prevention Programme for 2001-2003. These provisions supported a number of concrete initiatives. In the summer of 2002, the country’s first project for non-medical care to HIV-positive people was started in Odesa with the support of the International HIV/AIDS Alliance. The pilot project is implemented by one of the Network’s partner organizations, the “Life+” Self-Support Club. Since its start-up, the project has provided assistance and support to dozens of HIV-positive people and has helped families support their HIV-positive relatives.

**Reaching kids**

Supported by UNDP and UNAIDS, a peer education project has been set up by the Ministry of Education and Science in collaboration with the Ukrainian Association of Teachers and Trainers, to promote healthy lifestyles. It aims to prevent HIV and STI transmission among youth, as well as prevent drug, tobacco and alcohol abuse.

The programme plans to train 1,500 teacher-trainers, who in their turn will train 50,000 teenage trainers to work among their peers. In all, peer education activities will cover 5,000 general secondary schools and extracurricular institutions that make up 25% of public schools in Ukraine. To date, 600 have been trained in all 27 oblasts and regions, and training teenage trainers has been initiated in 10 oblasts.

A national programme to prevent mother-to-child transmission of HIV started up at the end of 2000 and now covers almost all oblasts of Ukraine. The Health Ministry has been assisted by a large number of international donors and NGOs, including UNAIDS, UNICEF, USAID, Medicins Sans Frontieres (MSF), the American International Health Alliance (AIHA), and a large number of Ukrainian counterparts, such as hospitals and medical faculties. For example, MSF provides a variety of MTCT services in the southern cities of Odesa, Mykolayiv, and Simferopol, including voluntary counselling and testing, information materials for HIV-positive pregnant women, ARV treatment to prevent mother-to-child transmission, infant formula, and psychosocial support.
4. FROM PLANNING TO REALITY: A QUESTION OF CAPACITY

Ukraine has turned a corner in its approach to HIV/AIDS. Clear political will has been expressed, new coordinating mechanisms are in place, and significant additional funds have been secured. The challenges ahead, as in other important areas of Ukraine’s development efforts, depend on the extent to which the new institutional mechanisms are real or simply a dressing-up of old and demonstrably ineffective structures, whether stated programme objectives are supported by real allocations of funding, and whether the country has the capacity to put the new funds to work.

Planned vs. actual funding

The Fourth National HIV/AIDS Prevention Programme in Ukraine for 2001-2003 prioritizes multi-sectoral coordination for the distribution and usage of funding. Now, there is considerable emphasis on implementing prevention activities among vulnerable groups, providing medical and social assistance to people living with HIV/AIDS, and conducting awareness work targeted at youth. A major part (49%) of the Programme is to be funded from local budgets and 22% from the national one (Table 6). Aside from the Ministry of Health, national funding is coming from:

- the State Committee for Youth and Sports (UAH 6,020,000 over the three years),
- the Ministry of Education and Science (UAH 1,934,000),
- the State Committee for Information Policy (UAH 467,200), and
- the State Directorate for the Execution of Sentences (UAH 125,000).

The government plans to receive almost one third of the necessary funds from external sources such as international organizations, funds, etc.

Despite the emphasis on multi-sectoral coordination, efforts to organize a proper financial monitoring system have been made only recently. Data analysis of allocations from central and regional budgets is disappointingly similar to those of earlier Programmes. In 2001 and 2002, national commitments were only 62% fulfilled.

Over the two years, the regional share of funding for the Programme was apparently 77-78% disbursed, but data is incomplete: for each year, information on 3-4 oblasts is missing. Among oblasts that have provided information, funding was disbursed to the fullest extent in Volyn, Donetsk, Poltava, Sumy and Kharkiv oblasts (93%). Data at city and county levels is not available. The lowest implementation was in Ivano-Frankivsk oblast (41% in 2001, 14% in 2002), Crimea (34% in 2002) and Kyiv (57-59%).

The lack of a proper financial monitoring system across the entire Programme makes it impossible to properly analyze all levels of contributions and dis-

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</tr>
<tr>
<td><strong>UAH</strong></td>
</tr>
<tr>
<td>State Budget</td>
</tr>
<tr>
<td>Local budgets</td>
</tr>
<tr>
<td>Other sources</td>
</tr>
<tr>
<td><strong>Total for the year</strong> incl. MoH</td>
</tr>
<tr>
<td>10,437,300</td>
</tr>
<tr>
<td>10,437,300</td>
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<table>
<thead>
<tr>
<th>Table 7. Planned funding for the 2001-2003 HIV/AIDS Prevention Programme (UAH)</th>
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</thead>
<tbody>
<tr>
<td><strong>Total (var. sources)</strong></td>
</tr>
<tr>
<td>--------------------------</td>
</tr>
<tr>
<td>Donor blood safety measures</td>
</tr>
<tr>
<td>Impact reduction of HIV/AIDS epidemic</td>
</tr>
<tr>
<td>Information and education measures, youth-oriented activities</td>
</tr>
<tr>
<td>Monitoring HIV/AIDS situation, epidemic and impact of interventions</td>
</tr>
<tr>
<td>Prevention activities targeting vulnerable groups</td>
</tr>
<tr>
<td><strong>Total</strong></td>
</tr>
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</table>
The challenge: How to maximize funding

Adequate financial resources are not in themselves enough to ensure the effectiveness of prevention and care activities: the implementers must be able to use funds efficiently. This requires appropriate organizational, institutional, human and political resources among the state authorities, Ukrainian NGOs and the international projects operating in Ukraine.

The prospect of receiving substantial donor support through the World Bank Loan and the Global Fund grant highlights longstanding problems with targeted government programmes in Ukraine:

- the capacity of the government and other participants to ensure efficient usage of funds in the absence of appropriate organizational, institutional, human and political resources;
- challenges in multi-sectoral coordination, monitoring, effective resource allocation and efficient resource usage.

All of this becomes increasingly urgent as growing numbers of HIV-positive people begin to fall ill with AIDS and increasing demands are made on the national health system.

The problem with multi-sectoral resource allocation and usage is closely connected with the current practice of budget planning and implementation. Although the national government has officially adopted a programme-oriented approach to budgeting, in reality, the allocation of funds is still largely carried out according to old, line-item-oriented practices. Even though the Health Ministry is the central

Poland: Financing the fight

Although Poland's National Programmes only began in 1996, the total number of registered HIV cases since 1985 amounts only to 8,000, with estimates that there are actually 20,000. First of all, both Programmes (1996-1998 and 1999-2003) had separate budgets and a specialized agency in charge of the funds, originally a Coordination Bureau and now the National AIDS Centre.

The first Programme established the foundation for success thanks to a proactive partnership between the state agency, central and local administrations, and NGOs, who were given as much as 50% of the programme's funding to carry out their work.

The UNDP in Warsaw helped by enabling the inflow of international funds and promoting standards of harm reduction, taking advantage of the latest medical developments, and respect for human rights at an early stage of intervention.

At the same time, the country saw a dynamic growth of NGOs and their national networks, including PLHA organizations, as well as the establishment of training for educators and medical professionals, including doctors, nurses and psychologists.

Ultimately, Poland was fortunate to have a group of open-minded people ready to absorb new approaches, even in the difficult transition period of the 1990s. As a result, the number of registered new HIV cases in Poland has remained stable at about 800 a year for many years now.

Table 8. Ministry of Health 2002 HIV/AIDS-related funding (UAH)

<table>
<thead>
<tr>
<th></th>
<th>Plan</th>
<th>Actual</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Drugs for HIV-positive patients</td>
<td>1,900,000</td>
<td>1,900,000</td>
<td>100.0</td>
</tr>
<tr>
<td>Assistance for HIV-positive children</td>
<td>700,000</td>
<td>641,800</td>
<td>91.7</td>
</tr>
<tr>
<td>Test kit procurement</td>
<td>8,892,300</td>
<td>6,662,800</td>
<td>74.9</td>
</tr>
<tr>
<td>Equipment</td>
<td>3,262,500</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Total</td>
<td>14,754,800</td>
<td>9,204,600</td>
<td>62.4</td>
</tr>
</tbody>
</table>

Table 9. Funding analysis for HIV/AIDS Programme in 2003

<table>
<thead>
<tr>
<th>Expenditure items (UAH)*</th>
<th>Human resources</th>
<th>Logistics and disposables</th>
<th>Training and control</th>
<th>Outreach</th>
<th>Goods and services</th>
<th>Information and IT</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Budget needs</td>
<td>28,112,854</td>
<td>6,173,318</td>
<td>13,677,334</td>
<td>1,886,270</td>
<td>38,077,246</td>
<td>4,756,713</td>
<td>92,683,734</td>
</tr>
<tr>
<td>Government</td>
<td>22,186,066</td>
<td>1,639,062</td>
<td>1,961,154</td>
<td>53,000</td>
<td>319,590</td>
<td>79,500</td>
<td>31,110,560</td>
</tr>
<tr>
<td>NGOs</td>
<td>1,367,400</td>
<td>113,950</td>
<td>53,000</td>
<td>319,590</td>
<td>567,100</td>
<td>0</td>
<td>2,209,040</td>
</tr>
<tr>
<td>Private sector</td>
<td>1,992,164</td>
<td>901,000</td>
<td>3,741,800</td>
<td>533,180</td>
<td>3,243,600</td>
<td>503,500</td>
<td>10,915,244</td>
</tr>
<tr>
<td>Donors</td>
<td>25,546,170</td>
<td>2,654,012</td>
<td>5,755,954</td>
<td>1,335,070</td>
<td>7,824,846</td>
<td>1,685,893</td>
<td>44,801,944</td>
</tr>
<tr>
<td>Available funds</td>
<td>2,566,684</td>
<td>3,519,306</td>
<td>7,921,380</td>
<td>551,200</td>
<td>30,252,400</td>
<td>3,070,820</td>
<td>47,881,790</td>
</tr>
</tbody>
</table>

*Converted from USD at 5.3 exchange rate
executive body responsible for the administration and multi-sectoral coordination of HIV/AIDS efforts, it has neither the authority nor the resources to coordinate the allocation of funds or to monitor and evaluate the efficiency of their usage. Nor does the Government Commission on HIV/AIDS have instruments to exercise control over the financial flows of the Programme. Operative decisions on the disbursement of funds earmarked in the national budget are actually made by the Finance Ministry, and in practice it determines which Programme budget items are to be financed and to what extent. The opposite of transparency, this system is a hold-over from Soviet days.

Last, but not least, more detailed research is needed to examine HIV risk based on ethnic, religious, linguistic and income characteristics. By shedding light on specific populations, more targeted approaches can be developed to deal with the epidemic. Survey models also need to take into account features, such as illiteracy, among certain target groups. The more targeted the response is, the more efficiently funding can be put to use.

Mechanisms for contracting with the community

A number of mechanical obstacles stand in the way of the stated objective of bringing other sectors of society into the national response, one of the most serious being the lack of a legal framework and set of procedures for state structures, such as state and local public hospitals and clinics, health centers, rehabilitation centers, and others, to enter into service contracts with non-state organizations: community groups, businesses, NGOs, religious organizations, charities.

The Law on Purchases of Goods, Works, and Services Using State Funds provides a legislative basis for non-profit organisations to provide a wide range of goods and services relevant to HIV/AIDS work, but it only covers the purchase of goods such as test kits, equipment and so on from private companies. Art. 32 of the socal service contracts law, for instance, stipulates that the lowest possible price is to be set for purchases – with no mention of quality. This is antithetical to many of the services required for HIV/AIDS work: clearly, the most effective outreach service to IDUs or the best counselling service is not likely to be the cheapest one.

Meanwhile, community organizations, including the types of NGOs that provide so much of the effective HIV/AIDS services in other countries, are under-developed in Ukraine. The practice of tendering bids to provide services is almost unknown. A learning process, including a full range of guides and advisory services within government and legal assistance outside it, is also necessary for the state and potential service providers to learn how to work together.

How to maximize human resources

The last point is related to a broader problem: few state officials and leaders of community organizations possess enough skills and knowledge in finance and project management, echoing the findings of UNDP’s 2001 Human Development Report on governance.40 The young NGO sector in Ukraine also demonstrates a relatively low level of organizational skills and lacks coordination. NGOs commonly suffer from distrust, misunderstanding of partner interests, and lack of confidence in their capacities to implement effectively. Mutually beneficial relations between Ukraine’s NGO and private sectors are just beginning to develop.

In general, it is the international organizations who initiate and lobby for modern mechanisms of financial monitoring and efficiency evaluation in managing government programmes at both the national and local levels. Given the importance of efficient use of incoming resources, it is highly desirable to use a share of these resources to raise the skill base of both state officials and NGO leaders in financial and project management, and in the evaluation of cost-effectiveness.

Many necessary technical skills are also in short supply. Although the Ministry of Health, medical facilities and international organizations have been working hard to overcome this, many members of the medical community are ill-prepared to handle these many challenges related to HIV/AIDS. This has ripple effects, such as the lack of medical professionals prepared to work with HIV-positive patients, which in turn hinders the potential of regional AIDS centers to serve their target population.

Cost-benefits of comprehensive care

Antiretroviral treatment and related medical services are available on a severely limited basis in Ukraine today, due both to budget constraints and the lack of capacity to deliver the necessary diagnostic and care services. Comprehensive care, including ARV therapy, needs to be introduced on a far wider scale in Ukraine, as growing numbers of PLHA require treatment. Shouderling this responsibility fits Ukraine’s broader aims in terms of upholding human rights, entrenching constitutional guarantees, and reaching national goals such as joining the European Union.

Antiretroviral therapy is expensive if market prices are paid for the brand-name drugs produced in Western Europe or North America. At this time, the annual cost of ARV therapy in Ukraine varies from $4,247 to $10,467, depending on the combination of drugs used. If even 20,000 HIV-positive Ukrainians are given this treatment at the lowest price, the total annual cost will be about $85 million,41 a huge figure, given that the total annual budget of the HIV/AIDS Prevention Programme in 2002 was only $11 million. Nor does this figure include other necessary components, such as treatment of opportunistic infections and palliative care.

However, other countries have managed to reduce the cost of drugs by several means: using generic drugs that are not covered by patents; negotiating with producers of patented medicines; and establishing domestic production. In India, for example, domestic manufacturers have cut prices to $300-400 for an annual course of ARV. At $400 per
UKRAINE and HIV/AIDS: Time to act

Treatment for life
At one point, I felt really sick. It was so bad that I could barely walk, eat or live. No one could diagnose me, but everything hurt. Finally, I took an HIV test. It was my last hope to make sense of things. Sure enough, the analysis was positive.

But I was lucky – amazingly lucky – that I had my tests done at the AIDS ward of Hromashehsky Hospital for Infectious Diseases. My destiny brought me a present in the person of Svitlana, a wonderful doctor and person. I also was able to receive ARV therapy under a research programme. There weren’t any state treatment programmes back then. It was a real chance, my only chance, because my immune system would have allowed me to live for another week or two (my CD4 count was only 4 cells). I’ve taken ARV for more than 4 years and I feel wonderful. I can work and live like anybody else.

Sometimes I imagine what would have happened to me if I hadn’t been given this chance. I truly hope that every HIV-positive person will be able to receive such treatment. It means life.

Stepan, 41

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Moreover, substantial benefits arise as a result of this approach. In other countries, like Brazil (see sidebar p. 20), universal comprehensive care, including ARV therapy, can reduce the overall health care budget by averting the hospitalization of PLHA and preventing the infection of newborns almost entirely. In other words, comprehensive care is technically possible and financially affordable, and increasing numbers of Ukrainians will need it. Their government has a responsibility to provide it without delay.
5. THE ROAD AHEAD

As the HIV/AIDS epidemic affects increasingly greater numbers of Ukrainians, a new level of energy and determination is called for, to minimize the risk of infection and maximize access to effective treatment. Ukraine has the human resources to do this and has acquired important new financial support. If the gaps and weaknesses discussed in Chapter 4 are dealt with, the way forward is clear.

- **Put all national commitments into action.**

  To date, both the government and the general public in Ukraine have made considerable efforts to fight HIV/AIDS since the epidemic was first detected. Without proper attention to efficiency and compliance with key objectives of the national response, the effect of many actions fell short of the hoped-for results.

  The level of involvement and commitment of much of the government with regards to the HIV/AIDS problem needs raising because HIV/AIDS issues tend to be primarily treated as medical, without considering their social and economic implications. Having committed itself to the Millennium Development Goals and the Declaration of Commitment of the United Nations General Assembly Special Session on HIV/AIDS, Ukraine incorporated the goals into its Fourth National Plan.

  Yet there is considerable evidence that, once again, many of the actions being implemented fall short of reflecting these broad goals and targets. By focusing the bulk of resources on blood safety and procuring diagnostic materials, the lessons of the past decade are being overlooked.

  The goals and targets envisaged by the global commitments must be adapted to the Ukrainian context and vigorously pursued, starting with explicitly referring to them in plans and programmes so that results can be measured against concrete goals and targets – and implementers held accountable for their progress towards meeting them. It also means improving the country’s capacity to monitor and evaluate its national response. There is currently no system in place that can evaluate progress in meeting the UNGASS and MDG indicators.

- **Apply state funding effectively and completely.**

  More capacity, both technical and administrative, is also needed to undertake many necessary actions. This is the result of two gaps: a lack of targeted government funding of non-medical HIV/AIDS response activities, and a lack of responsibility on the part of ministries other than the Health Ministry for contributing to the national response. Even though the HIV/AIDS Prevention Programme is financed on a multi-sectoral basis (i.e., the total funding figure includes money for a number of Ministries and partners), coordination of how funds are allocated between different sectors is minimal, as is monitoring of resource utilization.

  As noted in Chapter 4, planned levels of funding have not been matched by actual spending at both the national and oblast levels. This is serious, in light of the Programme’s emphasis on a greater role for local executive bodies and governments, and the central government’s reluctance in the past to fund important areas of prevention such as information, education and communication.

  To be truly effective, all levels and sectors of national and oblast governments must take on the challenge of response. In practical terms, this means allocating national budget funds to all the main components of the National Programme, and undertaking the coordination of donors, starting with a review of the role and effectiveness of the Government Commission to Fight HIV/AIDS in setting priorities and coordinating efforts.

- **Institute better procedures for monitoring and evaluation.**

  A wide range of information, from the patterns of HIV spread to the effectiveness of specific interventions, is essential to ensure meaningful decision-making and effective response to the HIV/AIDS epidemic. But it is difficult to determine the efficiency of activities when there is no regular monitoring of performance or impact.

  While the situation has improved somewhat, expected results are still not stated and few activities are fully documented to include clear objectives, strategies and resources. Efficiency criteria need to be included, along with reporting requirements that allow an implemented project to be evaluated.

  A national monitoring system needs to be put in place to gather information on:

  - the economic and social impact of HIV/AIDS on the country
  - the efforts of the government, international donors and NGOs in responding.

  In addition, the principles of transparency and accountability must be applied at the front end, when activities are being planned and implemented. As a start, an honest, rigorous and open evaluation of the National HIV/AIDS Prevention Programme for 2001-2003 is needed.

  As the financial resources applied to HIV/AIDS increase, it is critical that these be used effectively and efficiently. Ukraine has made progress, passing legislation to modernise financial and administrative procedures. However, in many cases, the regulations and norms to apply this legislation are either undeveloped or not implemented (see Chapter 4). In particular, the budget process at the national level needs a programme-oriented approach, as opposed to...
to the old line-item orientation, leaving behind the less-than-transparent and accountable methods of resource allocation inherited from past. The benefits of such changes go well beyond the HIV/AIDS response: they are important to most aspects of Ukraine’s development.

- **Strengthen local and sectoral partnerships.**

The brunt of the HIV/AIDS epidemic falls at the local level. Yet, not all oblast governments realise that the spread of HIV/AIDS will become an increasing burden on both the workload and resources of their health and social services. The national government has meanwhile not found a way to strengthen the capacity of and allocate resources to regional authorities. In addition to supporting to the national response, donor support also needs to target the local – oblast, rayon and municipal – level.

One example of support to strengthen local capacities is the UNDP Leadership Development Programme, which has already trained 300 people from around the country. The programme supports NGOs, government structures and the media in developing results-oriented approaches to local responses that can have a sustained impact on the local situation. The success of the local effort has led the mayor of Voznesensk in Mykolayiv oblast to allocate UAH 25,000 to a local initiative of NGOs to prevent the spread of HIV in their community.

The concept of a multi-sectoral response needs to move from paper to action, starting with making different sectors fully aware of HIV/AIDS’ growing scale and its manifestation within their areas of responsibility. Non-health sectors need to be accountable for results in their own spheres, be given resources to do so, and encouraged to integrate or “mainstream” HIV/AIDS into their sectoral plans and budgets. In particular, education, including the post-secondary and vocational systems, has a critical role to play. Alas, the private sector is largely absent from the national response.

Improved mechanisms of multi-sectoral cooperation and coordination are needed. In particular, the Government Commission on HIV/AIDS needs to actively take on the role of coordinating among ministries and advocating within the government as a whole. Currently, the Commission consists only of civil servants, which means it has little ability to coordinate or represent the concerns of different sectors of the community at large. Thought should be given to following the example of the Global Fund’s Country Coordinating Mechanism and opening up to representation from other sectors – including people living with HIV/AIDS.

- **Engage new partners.**

As in other countries, youth organisations, religious organisations, professional associations, women’s groups, sports organisations, trade unions, and political parties all clearly have a considerable role to play in the response to HIV/AIDS. To engage these potential partners, a broad-based debate on HIV/AIDS concerns needs to begin within these institutions and innovative ideas provided as to what they could do. At the same time, the government should consider providing incentives for groups involved in humanitarian support activities, including tax breaks.

The private sector, in particular, has a major role to play, which is so far almost entirely unrealised. In other countries, many initiatives have already been tried, such as workplace programmes, financial support to NGOs, media campaigns, and so on, and they should be promoted here. The ILO Code of Practice on HIV/AIDS can serve as a guide to workplace programmes.

As discussed in the 2001 Ukraine Human Development Report, the issue of government contracts with NGOs as service providers is a serious concern in Ukraine. Community organisations, with their broad potential to contribute to addressing a variety of social problems, have yet to receive funding from either national or local budgets. For government-NGO relations to reach an effective level of partnership, administrative barriers to state financing for prevention and care projects by non-government groups need to be removed.

In particular, this means creating a legal framework and efficient administrative procedures – primarily those within the purview of the Law on social services contracts – for the government to contract with community organisations to provide HIV/AIDS prevention and care services. The current prohibition against provision of HIV/AIDS-related services by private clinics is also troublesome, although improving the state’s ability to procure services from non-state organisations should not undermine the primary responsibility of government for universal and accessible health and social services.

- **Break down barriers to involvement with mechanisms for non-state delivery.**

Relations between the state and community organisations currently hinder the prospects of joint efforts against the spread of HIV. Yet civic organizations, particularly NGOs, faith-based organizations, charities and the private sector, can become powerful allies in the response to HIV/AIDS.

As discussed in the 2001 Ukraine Human Development Report, the issue of government contracts with NGOs as service providers is a serious concern in Ukraine. Community organisations, with their broad potential to contribute to addressing a variety of social problems, have yet to receive funding from either national or local budgets. For government-NGO relations to reach an effective level of partnership, administrative barriers to state financing for prevention and care projects by non-government groups need to be removed.

In particular, this means creating a legal framework and efficient administrative procedures – primarily those within the purview of the Law on social services contracts – for the government to contract with community organisations to provide HIV/AIDS prevention and care services. The current prohibition against provision of HIV/AIDS-related services by private clinics is also troublesome, although improving the state’s ability to procure services from non-state organisations should not undermine the primary responsibility of government for universal and accessible health and social services.

- **Affirm the rights of vulnerable groups and the HIV/AIDS afflicted.**

Ukrainian society, like most, is prejudiced against persons living with HIV/AIDS and vulnerable groups, which leads to abuses of their human rights. Stigma and discrimination can only be surmounted if open, intensive and reasoned debate is carried out on a national scale, and if a concerted effort is made to enshrine human rights for all citizens, both in law and in practice. Moreover, this must be done with the
participation of those living with HIV/AIDS. At the same time, greater efforts need to be made to safeguard the rights of other highly stigmatised groups, such as sex workers and injecting drug users, all of whom are highly vulnerable to HIV/AIDS.

Since government has a moral responsibility to lead on such issues, it can initiate programmes to target discrimination against persons living with HIV/AIDS by government officials and staff at all levels, particularly the police and public health officials. New anti-discrimination legislation is needed, based on the ILO Code of Practice on HIV/AIDS.

Among other options, Ukraine should consider appointing an independent ombudsman or agency to protect citizens against human rights violations. This has been successfully implemented in countries around the world and would provide much-needed support for persons living with HIV/AIDS and members of vulnerable groups.

• **Tackle all sides of the injecting drug problem, including supply.**

It is clear HIV/AIDS prevention and care programming have an important part to play in reducing the impact of illicit drugs on Ukrainian society. This has already been proven on a small scale in a variety of projects, and it is important that these be scaled up.

To be effective, such programmes have to provide a comprehensive package of prevention and care interventions to reach out to IDUs, including those who are in prison, and their partners. Such a package must include information and education, needle and syringe provision, condoms, and treatment of sexually transmitted infections. Since effective treatment of drug addiction is one of the most efficient ways to prevent the spread of HIV/AIDS, more should be done to increase users’ access to treatment and rehabilitation, especially substitution therapy.

Simultaneously, efforts are needed to reduce the vulnerability of young people to the drug trade through both demand and supply reduction. In practice, clear government policy and legislation is necessary to authorise the implementation of all elements of a comprehensive approach – as well as sufficient funding for a large scale effort.

All of this also requires comprehensive training of medical and social services staff to carry out such programmes effectively and in cooperation with – rather than merely being tolerated by – the police and the justice system.

• **Piggyback the school system for risk prevention among the young.**

The education system has unique advantages as a vehicle for influencing the values, attitudes and behaviour of young people from an early age. However, these are not yet being exploited on a wide scale. To take only one example, sex and substance abuse education is a crucial element in any effective HIV/AIDS prevention programme, but is largely lacking in Ukraine.

To maximize the potential of the national educational system, a number of steps can be taken:

• HIV/AIDS-related information can be introduced into approved curricula, in extracurricular activities, and also in teacher/parent education programmes;

• peer education initiatives and leadership courses, applied so far on a small scale and mostly with external funding, should be scaled up in all oblasts and teachers properly trained to supervise or provide them.

• **Take on gender issues to safeguard women and newborns.**

Although more men continue to contract HIV/AIDS, women are far more vulnerable than men in many aspects – physiological, social, economic and cultural – and growing numbers are becoming infected. This, of course, has direct implications for the children they bear. The gender dimensions of the epidemic include specifically addressing women in prevention and care programmes, focusing on their increasing vulnerability to infection, and their difficulty in negotiating safer sex with their partners. Measures are also needed to guarantee financial and social support for women and families affected by HIV/AIDS.

Equally, attention must be focused on men, addressing high-risk behaviours and attitudes that contribute to the vulnerability of women. A big part of this can be tackled through the education system, shaping the attitudes of children and teenagers while they are still being formed. The media have an important function in this.

Programming must also aim to harness the valuable contributions women themselves can make to the response. For example, HIV/AIDS prevention programmes aimed at sex workers have the best results when the women are treated as people capable of protecting both themselves and their clients from HIV transmission. For this to happen, the legal situation of sex workers, and programmes that work with them, has to be modified.

• **Engage the media to raise awareness and reduce discrimination.**

Mass media have a powerful potential for raising awareness about HIV/AIDS, informing people about how to protect themselves, changing attitudes and norms of behaviour, countering stigma, and promoting a healthy and open dialogue about what needs to be done.

In Ukraine, however, there is only a nascent tradition of social advertising, so information about HIV/AIDS prevention is relatively scarce in the media. The government needs to formulate and fund a full-scale national communication strategy for promoting HIV/AIDS prevention goals and tackling stigma against vulnerable groups and persons living with HIV/AIDS.
Past experience shows that, improperly informed, the media can fuel misunderstandings and stigma, undermining any response by the society and the state to fight the spread of the HIV/AIDS epidemic. This makes it urgent that private sector media companies “get it right.” Special attention should be paid to improving the professional skills of journalists who deal with HIV/AIDS issues. The EC-US HIV/AIDS Prevention and Awareness Programme is an example of what can be done to train journalists.

• Make access to comprehensive care, including ARVs, part of the response.

No amount of prevention programming can reverse the reality that hundreds of thousands of Ukrainians may already be infected with HIV. With increasing numbers requiring care and support, access to treatment is assuming a rising profile as a political, economic and humanitarian issue. Since the number of persons with AIDS is still relatively low in Ukraine, now is the time for the state to scale up its activities in providing comprehensive care, including antiretroviral therapy. Although this will involve an additional burden on scarce resources – despite considerable support from the Global Fund –, the government needs to explore options for reducing costs: domestic production, preferential terms for registering generic drugs, and negotiated price reductions from major pharmaceutical companies.

At the same time, activities directed at strengthening the infrastructure of medical institutions and improving the professional skills of medical personnel need to be conducted to prepare for the rising use of ARVs. Essential components to comprehensive HIV/AIDS care include:

• ensuring a supply of high quality diagnostic materials and equipment,
• treating opportunistic infections, and
• providing hospice care.

All of these must be built into the next National HIV/AIDS Prevention Programme in ways that ensure that treatment in Ukraine becomes accessible across the country, to all who need it.

A future with HIV/AIDS: not just a fairy tale?

Strangely, when I was healthy, I could not become pregnant. But almost immediately after testing positive for HIV, I realized that I was going to have a baby. I love my husband very much and I wanted very much to have a girl. This baby was really wanted. When my family found out about my pregnancy, however, they turned away from me. Even my husband didn’t want this baby. Of course, I was also afraid the baby would be born sick, but God gave me the strength to carry this pregnancy to term. Until the day I delivered, I kept selling stuff at the market. But I carried the baby well and gave birth incredibly fast – in 5 minutes! Doctors tested her blood for HIV immediately after birth. She was HIV-positive – but it wasn’t final and I had some hope.

A week later, I had to bring the baby back to the hospital: she had a continuous cold, and there was some problem with her lungs. I had to leave her there alone because I had to make some money to pay for medications. After they had treated the bronchitis, I took my baby home. Another week passed and she was sick again and had lost 25% of her weight. Her breathing stopped, and my sister and I took her to the resuscitation department. The doctors told me that she had enterocolitis and bronchial pneumonia. Then they moved us from resuscitation to another department in the isolation hospital, and then to the common ward.

Now there was a new problem: my baby was losing fluids at a tremendous rate. The doctors found spanaemia and suspected TB. While we were outside the ward, a nurse’s aide apparently came into the room and announced to all the other mothers: “You’d better wash your hands with bleach after contact with her and don’t let your children get near. She has AIDS and her baby also has AIDS. Be careful, because you could also be infected by her.”

We were quickly moved to another ward that had separate rooms like boxes. Ours was poorly heated and very drafty. No doctors visited us for an entire day. At one point, the catheter clogged up, and fluid and pus started to ooze from under my baby’s collarbone. I waited day and night for somebody to come from the resuscitation department to change the catheter. I finally asked the staff to call a doctor, but they just closed our door. At last, a doctor arrived, took one look at the baby and didn’t even listen to her lungs. After this visit, the staff barely even brought food for the baby three times a day. The day before we were discharged from the hospital, I asked for boiled water to make a tea for my child. The nurses brought some hot slops with bits of either milk or semolina. I was offended and hurt. Ok, so I’m a sinner and I’m infected because of my own guilt, but what is my baby guilty of? Just the fact that she was born? I insisted on being discharged from the hospital.

Two days later, my child was taken in at another hospital. She was diagnosed with a liver enlarged by four fingers, a spleen by a finger and a half, third-degree rickets, and untreated pneumonia. I liked this hospital better than others: the nurses immediately took her temperature, and referred my baby for a free X-ray. They even gave her nice clothes. I began to hope that someone would be able to treat my child…

After the death of my daughter, I began to really fear HIV. It’s scary to know that I have it inside me. Though I tell myself, Come on, Natasha, all you’re waiting for is medication against this disease. On one hand, I understand that life’s not a fairy tale. On the other hand, I still hope that I will recover from it.

Natasha, 26
A clear roadmap

Around the world, a great deal of experience has been accumulated in responding to the HIV/AIDS epidemic. Ukraine, too, has gained much experience and can point today to many projects and individuals working on the response in various parts of the country. While much of this activity has been financed by external organisations, the hands-on work – the outreach, the advocacy, the caring – has been carried out by Ukrainian professionals and volunteers.

Everywhere, the ultimate objectives in the fight against HIV/AIDS are twofold:

• minimise the number of people getting infected with HIV (prevention);

• and

• maximise access to effective treatment and support for people living with HIV/AIDS (care).

Ukraine has committed itself to these prevention and care objectives. Adapted to the specific conditions of its national epidemic, these commitments have been incorporated into the Fourth National Programme and into agreements such as with the Global Fund to Fight AIDS, TB and Malaria.

In contrast to the 1990s, the correct strategies and much of the necessary resources are in place. The concept of a multi-sectoral approach still needs to be subscribed to among all the institutions who need to get on board to make the response work.

A worrying gap between needs and resources is apparent, as is the perennial gap between planned levels of budgeting and the actual funding disbursed for concrete activities. Contradictory legislation and opaque administrative procedures continue to frustrate innovation and reduce effectiveness.

Although it is widely agreed that community organizations are already an essential part of the multi-sectoral response and should have a much-expanded role, both skills and institutional arrangements need to be upgraded. The potential contribution of people living with HIV/AIDS is largely untapped, partly because of these deficits, but also because of stigma and discrimination.

All these problems are completely surmountable. The input of external resources through the Global Fund and the recently ratified World Bank loan should enable expansion on a scale that would previously have been impossible. On the prevention side, lessons learned in dozens of prevention programmes among various vulnerable groups can now be applied much more widely. On the care side, scaling up can begin on comprehensive care, including ARV therapy.

Even with all the current obstacles, Ukraine clearly can and must move ahead in a massively expanded response to HIV/AIDS. The major question is one of time and political will: how quickly the lessons learned and the new resources can be translated into concrete action. The answer is a matter of life and death – not only for the thousands already ill from AIDS and the hundreds of thousands infected with HIV, but also for all Ukrainians, whoever they are.
ABBREVIATIONS

ARV  Anti-retroviral drug
FSW  Female sex worker
HIV-positive  Person who tests “positive” for HIV, is infected with HIV
IDU  Injecting drug user
IEC  Information, education and communication materials
ILO  International Labour Organisation
MSM  Men who have sex with men
MTCT  Mother-to-child transmission of HIV
NGO  Non-governmental organisation
OSI  Open Society Institute
PLHA  People living with HIV/AIDS
STI  Sexually transmitted infection
TB  Tuberculosis
UNAIDS  United Nations Joint Programme on HIV/AIDS
UNDP  United Nations Development Programme
UNFPA  United Nations Population Fund
UNGASS  United Nations General Assembly Special Session [on HIV/AIDS]
UNICEF  United Nations Children’s Fund
WB  World Bank
WHO  World Health Organisation

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Note: While all the titles of the following papers have been translated, many government documents are available only in the original Ukrainian versions.


DFID/Russian Federal AIDS Centre (2002). Epidemic aftermath. The spread of HIV infection in Russia. (Эпидемические последствия. Распространение ВИЧ-инфекции в России. DFDI, Российский Федеральный центр СПИДа.).


SUPPLEMENT

This appendix contains charts and tables offering more detailed information about some of the statistics and trends in this document.


Source: Ukrainian AIDS Centre, 2003, unpublished. Note. Not all those who die of TB – and other diseases secondary to AIDS – were tested for HIV in their lifetimes, so these numbers do not show the whole picture.
**Chart 3:** AIDS deaths by age along gender lines (1987-2000)

[Chart showing AIDS deaths by age and gender from 1987 to 2000.]


**Chart 4:** Pregnant HIV-positive women by age (2002)

[Chart showing the percentage of pregnant HIV-positive women by age.]


**Chart 5:** Sample international sex worker population rates (2001)

<table>
<thead>
<tr>
<th>Country</th>
<th>Number of female sex workers (FSW)</th>
<th>% 15-49 year-old female population</th>
<th>Total population (UN estimates, 2001 medium variant)</th>
<th>15-49 year-old population (UN estimates 2001 medium variant)</th>
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<td></td>
<td>Low</td>
<td>High</td>
<td>Average</td>
<td>Low</td>
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<tr>
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<td>90,000</td>
<td>1.23</td>
</tr>
</tbody>
</table>

*References*

1. “Mobility in Prostitution in the Netherlands,” 1990-99, EURIPAP
2. Country programme data
3. National AIDS programme, reported to UNAIDS, March 2001
Chart 6: Young people aged 15-19 who had sex before their 15th birthday, 19 countries including the US (1998-2001)


Chart 7: US high school students who have had sexual intercourse
Youth Risk Behaviour Survey, 2001
NOTES

1. UNAIDS (2002). Some estimates are as high as 410,000 (e.g., Balakireva et al (2001).
2. Ukrainian AIDS Centre (2003), unpublished.
3. About 10% of HIV-positive people progress to AIDS within the first two to three years, while up to 5% have no symptoms even after 12 or more years (NIAD, 2001).
5. UNAIDS (2002). The Ukrainian AIDS Centre estimates that 14,000 died of AIDS in 2002.
8. Mortality figures are unreliable due to under-reporting of AIDS.
16. This was carried out by the Ministry of Health, the Ukrainian AIDS Center, and the Ukrainian Institute of Family and Social Issues with UNICEF and UNAIDS assistance (UNICEF/ Ukrainian AIDS Center/Ministry of Health of Ukraine, 2002).
20. In HIV/AIDS programmes, the definition of men who have sex with men includes not only self-identified gay and bisexual men, but also men who engage in same-sex sexual activity but self-identify as heterosexual or don’t self-identify at all. Unprotected anal sex, whether male-male or male-female, is a highly effective route of HIV transmission.
30. Despite popular belief in other routes, HIV cannot be transmitted through handshakes or through contact with objects such as toilets or doorknobs, through sharing food or drink with an HIV-positive person, or through bites of animals or insects.
32. The declining number of tests among blood donors reflects declining donation rates since blood drives became voluntary.
35. UNAIDS (2002).
36. See Chapter 4 for details about the MDG.
40. UNDP (2001), pages 14-17 and 26-28, discuss what indicators of poverty mean in the “real life” of people in different regions and social groups.
43. The Gini index utilizes a single coefficient to summarize the dispersion of the income shares across the whole income distribution. The Gini coefficient may be expressed as a proportion or as a percentage. The Gini coefficient will be equal to 0 when the distribution is completely egalitarian. If the society’s total income accrues to only one person/household unit, leaving the rest with no income at all, then the Gini coefficient will be equal to 1, or 100%. Income distribution in Ukraine is extremely unequal and had the value of 0.46 in 2000.
45. UNAIDS/Ministry of Health of Ukraine (2000).
46. UNDP (2002).
47. UNAIDS/Ministry of Health of Ukraine (2000).
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52. UNDP (2002).
57. UNDP (2001).
58. UNAIDS (2002).
59. See, for example, the gender breakdown in a rapid assessment of drug use in Kharkiv, where the average number of female drug addicts has been 14% of all addicts. Ukrainian Institute For Social Research/WHO (2001).
72. See, for example, the profile of drug users in Institute For Social Research/WHO (2001).
75. Ukraine was one of the first countries in the world to benefit from the Global Fund.
76. Although the word "Programme" is the standard translation for this document, a more accurate description is probably Action Plan since it does not provide the level of detailed objectives and funding allocations that the word “programme” usually implies in English.
80. Ukrainian representatives were active in the preparation of the UN Special Session on HIV/AIDS.
85. UNDP (2001), TRIPS, HIV/AIDS and Access to Drugs.
86. UNDP (2001), op cit.
87. The drugs alone are only a portion of the cost of providing ARV therapy. Diagnostics, counseling, medical monitoring, and a variety of other services must also be budgeted.
88. Under a spring 2002 agreement, the Ukrainian government and several international pharmaceutical companies reduced the price of imported ARV drugs to $1,700 per patient per year. It will be seen whether this is enough to significantly improve access to the therapy for ordinary Ukrainians.
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Production Team:

L. A. Wolanskyj, concept and English edition  
D. Borodayev, design and typesetting  
O. Demydenko and S. Medintsev, Ukrainian edition  
V. Suvorov, photography (p. 3, 4, 7-9, 11-20, 23, 26)  
O. Gladieliev, photography (p. 22, 27)  
Presidential archives, p. 28  
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