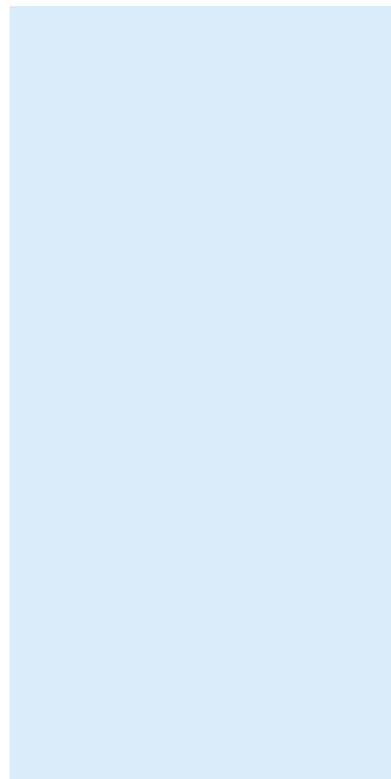


A Nongovernmental Organization's National Response to HIV: the Work of the All-Ukrainian Network of People Living with HIV

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About this publication

Primary research, including interviews, was conducted in Ukraine from 26 September through 13 October 2006. The author visited Network branches and affiliated organizations in the following cities: Cherkassy, Chernigiv, Kyiv, Odesa and Simferopol. He also attended the Network's annual General Assembly meeting in Foros, Crimea, from 26–29 September. Dates and locations of interviews are included in citations throughout this report.

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Executive summary

More than 100 000 HIV cases have been officially registered in Ukraine, but UNAIDS estimates that perhaps four times as many people are living with the virus (2006 estimate 410 000 [range 250 000–680 000]). That represents adult HIV prevalence of nearly 1.5%, the highest in Europe. The HIV situation in Ukraine is characterized by: a lack of prevention services for drug users; insufficient funding for HIV transmission prevention and treatment services; lack of respect for medical confidentiality; persistent stigma and discrimination; and lack of integrated health-care delivery.

The Network was formed in the late 1990s by people living with HIV alarmed at the rapidly growing HIV epidemic in their country and the lack of resources and support for themselves and others living with HIV. Since then, the Network has grown rapidly and steadily. In 2006, it provided services and support to more than 14 000 people living with HIV. Its roots are in a self-help ethos coupled with the Greater Involvement of People Living with HIV/AIDS (GIPA) principle that people living with HIV should always be involved in and able to influence debates about health and social policy at all levels; and have the right to the same amount of information and level of support and health care available to all members of society.

The Network's four key strategy components are:

- increasing access to non-medical care, treatment and support;
- lobbying and advocating to protect the rights of people living with HIV;
- seeking to increase acceptance towards people living with HIV throughout society; and
- enhancing the organizational capacity of the Network.

The Network was formally registered in May 2001. Just one month later, it was included in the Ukrainian delegation to the United Nations General Assembly Special Session (UNGASS) on HIV/AIDS in New York. The Network also reached out to international donors and consultants for assistance in creating a viable structure, business plan and advocacy strategy. Over the next two years, it solidified its advocacy credentials and helped its leaders create a professional structure enabling rapid growth through the establishment of local branches and affiliations with other nongovernmental organizations across most of Ukraine.

The Network's efforts to date and the structure it has developed may offer important lessons for similar organizations in other countries. Recommendations and lessons learnt based on the Network's experience to date include:

- an efficient internal structure requires clear job descriptions and responsibilities;
- hire the best, regardless of HIV status;
- do not be afraid to seek outside help and support from allies;
- a 'one size fits all' approach to local groups is impractical, unworkable and unwise;
- always have a mastery of relevant issues; and
- accept local groups' autonomy and work as a team to resolve problems.

Challenges facing the Network currently, and potentially in the future include:

- lack of expertise among people living with HIV;
- limited resources and growing demand leading to rationing of services, fewer full-time staff than required to deliver services comprehensively, and restrictions on expansion;
- retaining close relations with (and ensuring quality control among) individual local groups as their number increases; and
- lack of consistency in the national government.

1. Introduction

Summary: The All-Ukrainian Network of People Living with HIV/AIDS (the 'Network') was formed in the late 1990s by HIV-positive individuals alarmed at the surging HIV epidemic in their country and the lack of resources and support for themselves and others living with the virus. It has grown rapidly and steadily since then, providing services and support to more than 14 000 people living with HIV. Its roots are in the self-help ethos, based on the belief that people living with HIV must be directly involved in leading national and local responses to HIV. The Network's four key strategy components are:

- increasing access to non-medical care, treatment and support;
- lobbying and advocating to protect the rights of people living with HIV;
- seeking to increase acceptance towards people living with HIV throughout society; and
- enhancing the organizational capacity of the Network.

HIV came to Eastern Europe and the Commonwealth of Independent States (CIS) relatively late. But driven by an explosion in drug use, it had become a serious public health problem by the late 1990s in several of the region's countries. Ukraine was hit particularly hard. HIV began spreading quickly as the country struggled with numerous post-transition difficulties, including a steep economic decline in the wake of the collapse of the Soviet Union. For several years after Ukraine became independent in 1991, living standards plunged, public health and education structures became increasingly frayed, and the seeds were planted for a demographic decline that has already reduced the Ukrainian population from a high of 52 million in 1993¹ to less than 47 million in 2005.²

All of these factors contributed to creating an environment in which HIV, once established, was able to flourish. As the first signs of a burgeoning HIV epidemic became clear, the government was neither capable of responding nor willing to do so. HIV was seen as a disease that affected lawbreakers and social and moral outcasts; moreover, the country faced innumerable other problems that demanded policy-makers' attention. As a result, HIV was not a priority, and neither were the growing number of people living with—and beginning to die from—AIDS-related illnesses.

As the new millennium dawned, the lives of people living with HIV in many parts of the world, notably neighbouring countries to Ukraine's west, were greatly improving as antiretroviral treatment became available. Long-running and comprehensive prevention programmes had helped stabilize or even lower HIV prevalence throughout much of Europe. Special services were geared towards reducing potentially risky behaviour among individuals considered to be particularly vulnerable to HIV transmission, including injecting drug users and men who have sex with men.

In comparison, meanwhile, people living with HIV in Ukraine had nothing. They had no access to diagnostics, treatment, or support services of any kind. Doctors and other

¹ See www.ukrweekly.com/Archive/1999/029903.shtml.

² See http://encarta.msn.com/fact_631504885/Ukraine_Facts_and_Figures.html. Most projections do not expect the demographic decline to abate in the near future. According to one recent projection, Ukraine's population will decline by 43% between 2005 and 2050. Unless addressed forcefully, HIV will likely exacerbate that decline. See *The Economist*, 'Incredible Shrinking Countries', 5 January 2006. Online: www.economist.com/opinion/displaystory.cfm?story_id=5358255.

health-care providers knew little if anything about HIV or many of its opportunistic infections. HIV-related stigma and discrimination were rife, at least partly because the majority of the population remained ignorant about every aspect of the virus, including how it is transmitted. A nearly complete lack of prevention information and services kept awareness low and risk-taking high throughout society.

In 1999, a handful of people living with HIV in Ukraine decided that it was up to them to initiate change in their own country. They realized that their lives and the lives of tens of thousands of others living with HIV, both now and in the future, could only be saved and improved through their own efforts. With support from, among others, the United Nations Development Programme (UNDP) and the Counterpart Alliance for Partnership, a project funded by the USA Agency for International Development (USAID), the pioneers created a framework for grassroots-based citizens' advocacy and self-support, led by people living with HIV. Thus was born the All-Ukrainian Network of People Living with HIV/AIDS (the 'Network'), one of the purest examples of the GIPA Principle put into action.³

Seven years later, the Network has grown from an all-volunteer group of 10 or so individuals to a registered nongovernmental organization with an annual budget approaching US\$ 3 million a year. It now has local branches and affiliated organizations throughout the country, and each year the number continues to increase. By mid-2006, more than 14 000 people living with HIV across Ukraine (known as 'clients') were receiving a wide range of services through the Network, including self-help groups, vital assistance in obtaining access to and adhering to antiretroviral treatment regimens, food and nutrition support, and legal and psychological assistance. Furthermore, at both the national and local levels the Network has been instrumental in identifying, pushing for, and implementing programmes and strategies designed to improve the lives and well-being of all people living with HIV in the country. It has been at the forefront of successful advocacy efforts leading to the introduction of antiretroviral treatment in Ukraine and greater government commitment to meet its responsibilities under law to care for people living with HIV and protect their rights.

Among the Network's core beliefs—heavily influenced by the GIPA Principle—are that people living with HIV should:

- always be involved in and able to influence debates about health and social policy at all levels; and
- have the right to the same amount of information and level of support and health care available to all members of society.

The Network's four key strategy components centre on⁴:

- increasing access to non-medical care, treatment and support;
- lobbying and advocating to protect the rights of people living with HIV;
- seeking to increase tolerance towards people living with HIV throughout society; and
- enhancing the organizational capacity of the Network.

³ GIPA represents the 'Greater Involvement of People with HIV/AIDS', and derives from a principle embedded in the Paris AIDS Summit Declaration of 1994. The principle was formalized when 42 countries agreed to "support a greater involvement of people living with HIV at all...levels...and to...stimulate the creation of supportive political, legal and social environments".

⁴ These four components are listed in the Network's most recent policy document (June 2006). Additional information is available on the Network's website: www.network.org.ua

The Network was founded on the principles of self-help. From the beginning, people living with HIV have been responsible for the Network's phenomenal growth and strategic importance in the country's HIV response. People living with HIV organized the local branches themselves and their engagement and leadership remain at the core of the Network's efforts and activities. Although not all Network members are HIV-positive, the organization's bylaws stipulate that its primary oversight body, the Coordination Council, comprise only people living with HIV. Other requirements, such as one mandating that all potential members spend at least six months volunteering for their local branch before being eligible for membership, serve to create a committed corps of advocates and service providers knit closely together by a common vision and standards.

The Network's vital role in mobilizing HIV-related services in Ukraine is undisputed by most observers and partners, including the government, other civil society groups and international donors. In August 2006, for example, it was one from more than 500 community organizations from around the world presented with a Red Ribbon Award from UNDP at the XVI International AIDS Conference in Toronto. The awards recognize "outstanding contribution(s) to the frontline response to HIV and AIDS"; the Network was cited for its work in addressing HIV-related stigma and discrimination.⁵

The challenges facing the Network and its country remain daunting, however. For one thing, the epidemic shows little sign of slowing down in Ukraine, and government leadership continues to lag (although it is improving). The significant progress made in recent years is limited: tens of thousands of people living with HIV still cannot obtain the services they urgently need. The demands placed on the fragile, underfunded and unprepared public health sector will only increase in the foreseeable future. The Network will be one of many entities struggling to provide adequate treatment and prevention assistance to a growing number of desperate people.

At the same time, the Network is embarking on a journey that will dramatically change its size, scope and focus. In November 2006, the Board of the Global Fund to Fight AIDS, Tuberculosis and Malaria (the 'Global Fund') approved Ukraine's Round Six proposal for up to US\$ 29.6 million for the first two years, with a maximum of up to US\$ 151 million over five years. The Network is indicated in the proposal as the co-Principal Recipient for this grant, subject to approval from the Global Fund. The Network will have major administrative responsibilities and its annual budget is expected to quadruple. Staff, members and volunteers all vow to retain its grassroots-oriented structure and emphasis; administering Global Fund money, they say, will only enhance the Network's ability to engage more closely with those most in need at the local level. Some outside observers wonder, however, if the Network has the capacity to handle such massive responsibilities while also continuing to advocate effectively on behalf of people living with HIV—and to do so with its customary independence.

Such challenges will undoubtedly redefine the Network to some extent. Yet whatever happens in the future cannot alter the impact it has had over the past several years in Ukraine. Its innovative structure, high-profile and successful advocacy campaigns at both the national and local levels, and strong track record in delivering an ever-expanding array of services to people living with HIV are worthy of close attention. For these reasons, the

⁵ See <http://content.undp.org/go/newsroom/august-2006/ukraine-redribbon-20060817.en.jsessionid=aT2LkWUsSmB8>. Accessed 19 September 2006.

Network would seem to offer a worthy model for similarly led advocacy and service efforts by people living with HIV in many other countries.⁶ This report seeks to provide useful information for potential adaptation by outlining the Network's background, structure and focus in the context of the HIV epidemic in Ukraine. It concludes with an overview of current and future challenges as well as lessons learnt from this important and evolving experiment.

⁶ The Network's example is likely to be of particular interest to people living with HIV and their allies in other Commonwealth of Independent States countries. HIV epidemics in many of those nations share certain key characteristics with Ukraine's, notably the role of drug use in the spread of the HIV, ongoing and often destabilizing political and economic transitions, and relatively weak civil society engagement. The Network has already begun to work closely with people living with HIV organizations in 14 other countries of the region through the Eastern European and Central Asian Union of PLWH organizations (ECUO), which it helped to establish in September 2005. (See box on ECUO for additional information.)

2. History of the Network

Summary: A small group of people living with HIV, many of whom had experience in self-help groups, came together in 1999 and decided to take steps towards creating a self-support and advocacy group led by and for HIV-positive individuals. They reached out to international donors and consultants for assistance in creating a viable structure, business plan and advocacy strategy. The Network was registered in May 2001. Just one month later, it was included in the Ukrainian delegation to the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) meeting in New York. Several other developments over the next two years solidified its advocacy credentials and helped its leaders create a professional structure enabling rapid growth through the establishment of local branches and affiliations with other nongovernmental organizations across most of Ukraine.

The first steps towards the formation of the All-Ukrainian Network for People Living with HIV/AIDS occurred in 1999. At that time, HIV was still a relatively new problem but already a big one, especially among communities of injecting drug users. Some HIV service organizations already existed, but they were limited in scope and reach and none had been organized with the direct participation of HIV-positive individuals.

An emerging group of activists, many of whom had experience in self-help groups, were increasingly dissatisfied with the nearly complete lack of services available for them and other HIV-positive people. Most of the rapidly growing number of people living with HIV were isolated and alone, vulnerable to legal, social and economic discrimination. Ignorance about HIV was widespread and treatment was a distant dream.

Initial discussions among a small group of activists, initially numbering no more than seven, preceded the Second All Ukrainian Conference of HIV-Service Organizations and People Living with HIV/AIDS, which took place in November 1999. At the meeting they formed a working group and decided to take steps towards creating a movement. The people living with HIV activists believed that they were best positioned to identify the specific needs and most effective advocacy strategies to protect their legal rights, lobby for access to treatment, and improve the quality of life of all people living with HIV in the country. As one individual involved in the early days noted, "For us to survive, we knew we needed to build a network. We thought, 'Our lives depend on how quickly we do this.'"⁷

It would take another 18 months until the Network was officially registered, with the Ministry of Justice, as a nongovernmental organization under Ukrainian law. During that time, the initial organizers sought to identify other people living with HIV across the country who were interested in helping shape the group, both at the national and local levels. They also reached out to existing local groups, many of which had just begun coalescing on their own in response to lack of services. Among the methods used to find others were networking among self-help groups for drug users and placing newspaper ads with telephone numbers for interested people to call.⁸

⁷ Interview with Konstantin Lezhentsev in Kyiv on 5 October 2006. Lezhentsev has been an early and active supporter of the Network through work and personal contacts.

⁸ As noted by Sergei Fedorov, an initial Network member and one of the founders of its affiliated group in Odesa, Life Plus. Interview in Odesa on 10 October 2006.

Initial activities

One very important original priority was to provide support to people in the “worst conditions”.⁹ In 2000, for example, people living with HIV in Odesa initiated what they described as the first project in Ukraine and the Commonwealth of Independent States to provide non-medical care to HIV-positive individuals. This consisted of basic yet important services such as providing food packages, transporting people to medical facilities (usually for treatment for TB and other opportunistic infections, because antiretroviral drugs were not available), and even updating and organizing key documents such as medical cards. In many cases these early clients became organizers themselves, a development that has continued throughout the life of the Network and is considered one of its most important and effective outcomes.¹⁰

The early months were marked by a scramble for money and in-kind support for even these basic services. (As one early organizer, Artur Ovsepyan, said, “We were just looking for friends with cars so we could help people get places”.¹¹) The visits to the clinics and hospitals had an important impact on Network organizers as well. “We knew then that we had to be an advocacy group too,” Ovsepyan said. “There was a total absence [in the health-care facilities] of what people needed in terms of care and a complete lack of understanding of the situation. It was obvious to us then that we had to depend on ourselves to take care of ourselves.”¹² One early notable achievement in Odesa, for example, was arranging for antiretroviral drugs to be brought into the country illegally for a sick woman with five children.¹³

While initiating such services, Network organizers were also seeking support from donors for both funding and organizational expertise. They focused primarily on international groups with a history of supporting and working with organizations of people living with HIV at the grassroots level, including Médecins Sans Frontières (MSF) and the International HIV/AIDS Alliance, as well as UNDP and the Joint United Nations Programme on HIV/AIDS (UNAIDS).¹⁴ MSF helped fund a crucial meeting, at which Network representatives from 15 regions gathered. At this first general meeting, some 20 participants discussed how to structure the Network as well as how and when to officially register it at the national level. In an unrelated but important development that same month, the Ukrainian Government recognized HIV as an epidemic and a national emergency.

The turning point: developments in 2001 and 2002

Events and strategy decisions over the following two years, 2001 and 2002, helped ensure the Network’s viability and enduring subsequent role in helping shape the HIV response in Ukraine. Among them were the following important developments.

- *Registration.* In May 2001, the Network was officially registered with the Ukrainian Ministry of Justice. This step was vital to increasing its ability and capacity to raise funds and assist its local branches and affiliated organizations to register as well, if

⁹ Interview with Artur Ovsepyan in Kyiv on 2 October 2006.

¹⁰ Ibid.

¹¹ Ibid.

¹² Ibid.

¹³ Ibid. The woman’s need for the antiretroviral drugs in question had been established by her physician. At the time, however, none of them were available in the country.

¹⁴ Support was also provided by USAID through its Counterpart Alliance for Partnership program.

they had not already done so. Registration had an important psychological impact in that it made the Network 'official' in the eyes of its members and clients—not to mention government officials, policy-makers, and funders. This in turn helped reinforce efforts to professionalize the organization.

The registration process was not simple, however. As noted by Iryna Borushek, one of the original Network members, getting approved for registration “required that we have strategies and structures that would help us grow and would be vital to ensuring good management.”¹⁵ Borushek and her colleagues therefore solicited support to prepare for the registration process.¹⁶

- *Solicitation of international and domestic expertise.* White and other international consultants were only part of the expertise outreach effort. Several early Network members and Ukrainian allies had experience working with established nongovernmental organizations in the country, such as MSF. Many of these individuals had relationships with government bureaucrats and politicians and were able to leverage them to increase awareness of the Network and the needs of people living with HIV in general. Their efforts were enhanced by a reliance on hard data and research to bolster advocacy campaigns—an approach that the Network has sought to rigorously maintain over the years.
- *Participation in the United Nations General Assembly Special Session on HIV/AIDS (UNGASS).* Network members worked closely with domestic and international allies in a successful lobbying effort to be included in the official Ukrainian governmental delegations to UNGASS, held in 2001 in New York City. The Network's participation enhanced the credibility of the national delegation by increasing the high-profile involvement of civil society. It also solidified the Network's emerging role as the primary voice for people living with HIV in Ukraine.¹⁷
- *Treatment literacy training.* In August 2002, the Network organized a training session for members on treatment literacy. Some 20 people attended the two-day session in Poltava. The selection of treatment literacy as the topic for its first such session was notable for two reasons. For one thing, it immediately indicated that the Network had more expansive priorities than other HIV service groups in Ukraine, most of which were focusing primarily if not exclusively on prevention. It also signalled a key advocacy emphasis—to make antiretroviral treatment available in the country and, once that occurred, to be prepared to help people living with HIV and the medical establishment utilize all treatment-related services effectively.¹⁸
- *Publicize activities.* From the beginning, Network organizers recognized that a key strategy would be to constantly and comprehensively publicize their activities and advocacy campaigns. For that reason, one of the original staff persons (out of a total of five) focused almost exclusively on public relations.

¹⁵ Interview with Iryna Borushek in Kyiv on 5 October 2006.

¹⁶ White continues to work closely with the Network as a full-time consultant. He maintains an office at the national headquarters in Kyiv.

¹⁷ The Network was also part of the national delegation to the 2006 High Level Meeting on AIDS in New York. The main focus of that meeting was to review progress achieved in realizing the commitments set out in the Declaration of Commitment agreed to in 2001 at UNGASS.

¹⁸ The Network's second treatment literacy training session was held six months later, in February 2003, in Kyiv. About 20 members attended that session as well.

Key early advocacy efforts

These initial activities and decisions laid the groundwork for subsequent advocacy efforts at the national level that have helped local branches expand services, thereby directly improving the lives of people living with HIV across the country.

Round One Global Fund grant. In 2002, staff and volunteers from the Network's central office were deeply involved in the preparation of Ukraine's application for an HIV grant from the Global Fund. They lobbied for the inclusion of significant funding for services other than prevention, which was the main initial focus of the government and many other civil society groups, and subsequently wrote the non-medical care and support section of the application. As a result of the Network's concerted efforts, a significant portion of grant funds were from the very beginning allocated for treatment—including for purchasing antiretroviral drugs, training medical personnel, enhancing diagnostics capacity—as well as for substitution therapy (including for HIV-positive individuals) and prevention of mother-to-child transmission.¹⁹

The Global Fund ultimately approved US\$ 95 million over five years to Ukraine as part of its Round One funding tranche. However, the Network's lobbying effort vis-à-vis this important source of assistance was not completed once the grant agreement was signed in January 2003. Just one year later, the Network joined several domestic and international organizations seeking the removal of the three original Principal Recipients. That campaign, which was ultimately successful, centred on concerns over poor management and inability to disburse funds quickly and efficiently.²⁰

Suspension of World Bank loan. Similar concerns regarding poor management—and this time coupled with allegations of corruption—prompted Network staff to help mount another successful lobbying campaign just two years later. The Network and many of its allies were concerned that the government was not efficiently administering a US\$ 60 million loan from the World Bank. The funds were to be used primarily to purchase medicines (including antiretrovirals and drugs to treat and prevent TB) and to train health-care workers. In 2006, when the Bank announced it was suspending the loan, the government had spent just 2% of the funds halfway through the four-year grant period.²¹

Antiretroviral drug costs. The Network's direct advocacy regarding pharmaceutical pricing for antiretroviral drugs also began in 2002. Treatment was still not available at that time, but the Global Fund application and pressure from the Network and other organizations were making headway in pushing the government to make antiretroviral treatment access a priority. In May of that year, Volodymyr Zhovtyak, the head of the Network's Coordination Council, participated in negotiations (supported by UNAIDS) involving the government,

¹⁹ For additional details of Ukraine's Round One Global Fund grant for HIV/AIDS, see www.theglobalfund.org/programs/countrysite.aspx?countryid=UKR&lang=en.

²⁰ See www.theglobalfund.org/programs/news_summary.aspx?newsid=37&countryid=UKR&lang=en. In March 2004, the Global Fund appointed a new Principal Recipient, the International HIV/AIDS Alliance in Ukraine, to administer the Round One grant. Nearly all observers, including the Network, agree that the Alliance has been an effective Principal Recipient.

²¹ The suspension of the World Bank loan was particularly wrenching because the funds were targeted towards providing services for individuals considered at high risk for HIV transmission and least likely to have consistent access to help, notably injecting drug users, sex workers, and prison inmates. The suspension appeared to jolt the government into action, however. Just two weeks later, in June 2006, the Ministry of Health announced that it was establishing a working group with the World Bank to work towards resuming the project. The ministry reportedly agreed to meet the Bank's requirements for restructuring the project to have the suspended funds restored.

several UN agencies, and multinational pharmaceutical companies that manufactured antiretroviral drugs. As a result, antiretroviral drug prices eventually dropped by more than 75%.

Although that represented a significant decline, Network staff remain dissatisfied at the relatively high cost of antiretroviral drugs, which finally became available through the public sector for the first time in 2004. More than a year later, the issue of antiretroviral drug price reductions was one of the topics discussed during a landmark meeting in Kyiv between two HIV-positive Network staff members and President Viktor Yushchenko.²²

Nationwide public action. Also in 2002, the Network organized its first country-wide public action, 'Remember to Live', over six days in May. The action took place in 14 cities. It consisted of press conferences about the impact of HIV with members of mass media; distribution of copies of the 'Book of Life', which contains stories of HIV-positive people; and distribution of red ribbons to raise visibility and awareness among the general population.

As these advocacy efforts clearly indicate, by the end of 2002 the Network had become firmly entrenched in the national level response to HIV and was serving as a watchdog on behalf of all people living with HIV. In particular, it had signalled its intention and willingness to both push the government to improve its performance and to work with it at the same time. As one Network member from the early days noted, "We wanted the government to know we were ready and willing to move forward with our goals. We said to them, 'We will be doing these things, so please help by removing barriers. We're serious and want to do it.'"²³

Also at that time, the Network had begun its rapid spread across the country with the establishment of local branches and signing affiliation agreements with existing local groups of people living with HIV. (See Section 4 for additional information about the Network's structure, the number of regions and clients served, and the extent and types of services offered.)

Voices of Network members

Nearly 150 people gathered in Foros, a resort town in Crimea, for the Network's annual General Assembly meeting in September 2006. The following brief snapshots of some of the members' experiences with living with HIV illustrate both the challenges and hope that characterize the HIV response in Ukraine today. The quotes and observations are taken from interviews conducted in Foros from 26–29 September 2006.

Marina Britvenko (Kharkiv):

I was diagnosed with HIV in 1997 after donating blood. A local prosecutor demanded that I go to prison because I didn't mention my HIV status when I went to donate blood. But I didn't know my status before then! I finally convinced the authorities that what I was saying was true. But it was a scary time for me and very stressful.

²² The meeting took place in November 2005. The two Network staff members were members of its Coordination Council: Volodymyr Zhovtyak (who as head of the Coordination Council also serves as chief executive of the Network) and Iryna Borushek. See Section 5.3.1 for more detailed information about this meeting.

²³ Interview with Artur Ovsepyan in Kyiv on 2 October 2006.

Inna Turkova (Krivy Rig):

I wanted to commit suicide when I was first diagnosed. I didn't know anything about the problem, and I thought it meant a quick death. I didn't tell anyone for two months, but then I felt less depressed and began reading literature about HIV and reaching out. Knowledge and information are so important! It's still true that if I tell people about my status they don't always take it well...society is still not ready to tolerate us. I am trying to help change this. In my city, perhaps 8000 of 700 000 residents have HIV, but there is no place to get tested unless you're a pregnant women. People often die from AIDS without knowing their status.

Yuri Kayuda (Khmelnyskyy):

I was a drug user for seven years, but then I went through rehab and stopped about four years ago. I went to get an HIV test and was sure I would be positive because all my friends were. But my test came back negative. I took this as a sign from God and decided to become an activist.

Our local branch is just seven months old, but we already have 130 regular clients. In my opinion one of the biggest problems is that there is no substitution treatment available in the city for drug users.

Zhenya Topchaev (Lugansk):

I was diagnosed with HIV in October 1996, and then a year later my son was born. Around that time I moved to Moscow to find work. While there, I didn't think about my health at all. But in 2004 I became very sick and had to go back home. I had pneumonia and was treated for nine months at the AIDS centre. I started antiretroviral drugs in May 2004, when I had just six CD4 cells. Now I have 345. I heard about the Network while in hospital and I decided to join when I got out. One reason is that three quarters of my friends were dead from AIDS by then and I wanted to do something in memory of them.

Katya (Yalta):

I was diagnosed in 1998 and it was traced to a dentist. After my diagnosis I had no information about HIV or any idea of where to go for any. In 2004 I heard about Network in a newspaper article and went to get some information. Even today I'm still afraid to tell doctors that I have HIV and I don't like to go to the AIDS centre. I'm worried people might see me and then my son, who's only one year old, will face stigma and discrimination. Yalta is [a] small town and everyone will know. I am lucky because my husband supports me. Both he and my son are HIV-negative.

No one can get CD4 tests or antiretroviral drugs in Yalta. We have to go to Simferopol, which is at least 90 minutes away. It's hard to go there when you have a job, especially since you have to go once a month. It would be more convenient [to] get enough pills to last for three months, say. Many poor people find it difficult to go to Simferopol once a month. They don't have cars, buses take a long time, and taxis are too expensive.

3. HIV situation in Ukraine

Summary: Some 100 000 HIV cases have been officially registered in Ukraine, but UNAIDS estimates that perhaps four times as many people are living with the virus.²⁴ That represents an adult prevalence of nearly 1.5%, the highest rate in Europe. Injecting drug use accounts for the largest share of infections, but sexual transmission is an increasingly common mode. Antiretroviral treatment has been available since 2003; by mid-2006, nearly 3600 people were receiving antiretroviral drugs. Meanwhile, according to conservative projections more than 50 000 people living with HIV will require antiretroviral treatment by 2010. The HIV situation in Ukraine is also characterized by a lack of prevention services for drug users; insufficient funding; lack of respect for confidentiality; persistent stigma and discrimination; and lack of integrated health care delivery.

Ukraine has the most severe HIV epidemic in Europe, with an estimated 377 600 people living with the virus at the end of 2005.²⁵ As of late 2006, approximately 100 000 people had been officially registered as having HIV, which means that three times that number of people are unaware that they are infected. The majority of new infections occur among injecting drug users, who accounted for 45% of newly reported cases in the first half of 2006.²⁶ The proportion of cases related to sexual transmission has rapidly increased, accounting for 37% of new cases in the same period.²⁷

The epidemic is also spreading rapidly beyond the regions in southern and eastern Ukraine where over two thirds of the all HIV cases have been reported to date. Sharp increases in reported infections are occurring in the central regions of the country in particular. The estimated adult HIV prevalence among adults in Ukraine was at nearly 1.5% at the end of 2005, and HIV prevalence among pregnant women was 0.45%.²⁸ That figure was the highest rate in Europe, but it is still not at the level at which Ukraine would be classified as having a generalized epidemic. However, HIV prevalence at the end of 2005 among pregnant women in five of the most affected regions of Ukraine—Chernigiv, Dnipropetrovsk, Donetsk, Mikolaiv and Odesa— already exceeded 0.8%, which indicates that Ukraine is rapidly approaching a generalized epidemic.

In the area of clinical progression and treatment, as of mid-2006, there were 6345 patients diagnosed with AIDS under clinical observation.²⁹ A total of 3594 patients were receiving antiretroviral treatment at that time, a major increase from fewer than 250 patients on antiretroviral treatment by mid-2003.³⁰ However, the expansion of antiretroviral treatment has yet to reduce Ukraine's continued high AIDS mortality rate. While 1635 new patients were given access to antiretroviral treatment in 2005, a total of 2188 people died from AIDS

²⁴ UNAIDS (2006). Report on the global AIDS epidemic. Geneva, UNAIDS. Estimated number of people living with HIV 410 000 (range 250 000 to 680 000)

²⁵ Data and information provided by reviewers from UNAIDS Ukraine, November 2006.

²⁶ Ibid.

²⁷ Ibid.

²⁸ Ibid.

²⁹ Ibid.

³⁰ Ibid.

during that same year—a number that represents over 25% of AIDS-related deaths to date.³¹ Based on conservative projections of clinical progression, it is estimated that over 50 000 patients will require antiretroviral treatment by 2010.³²

The following are among the other important issues related to the HIV situation in Ukraine:

- *Lack of services for injecting drug users.* Injecting drug users' ability to protect themselves and others from exposure to HIV is limited by a lack of appropriate, comprehensive and easily accessible harm reduction services, such as needle and syringe exchange facilities and substitution treatment. The situation regarding substitution therapy is indicative of the difficulties injecting drug users have in obtaining vital services. One medicine, buprenorphine, is currently being provided to a few hundred individuals in seven pilot projects across the country. However, that represents very little in terms of overall need; at one project in Odesa, for example, just 50 people have access to buprenorphine and nearly 150 people remain on a waiting list.³³ Only HIV-positive individuals are eligible for receiving buprenorphine through the pilot projects, which means the therapy's potentially crucial HIV prevention impact has not been drawn upon. Meanwhile, there is no access at all to methadone, a cheaper substitution drug that boasts a decades-long track record of effectiveness in dozens of countries around the world.³⁴
- *Insufficient funding in general.* Organizations and individuals involved in drafting the Round Six Global Fund proposal determined that the funds allocated to AIDS in Ukraine for 2006 totalled US\$ 48.5 million. That included US\$ 18.6 million from the state budget and US\$ 29.9 million from external sources, including the Global Fund, USAID, UN agencies and several other donors. The total amount fell US\$ 36.6 million short of the estimated overall need in Ukraine for that year. The gap, meanwhile, was expected to grow to US\$ 55.6 million in 2007 as the overall need increased while the government's planned expenditures on HIV/AIDS actually decreased by US\$ 1 million.^{35 36}
- *Lack of respect for confidentiality.* Health-care providers, including doctors and nurses in government-run AIDS centres, frequently fail to safeguard HIV-positive clients' confidentiality and privacy. According to a March 2006 Public Health Watch shadow report, "Approximately half of [people living with HIV] claim that their right to confidential testing has been violated. Two of the main reasons cited are: —lack of easily accessible free and confidential testing services; and

³¹ Ibid.

³² Ibid.

³³ Interview in Odesa on 9 October 2006 with Nataliya Kitsenko, the director of the HIV/AIDS and Drugs Issues Department of the Odesa Charity Fund 'The Way Home'. Her organization offers harm reduction services to drug users and has helped support a new self-help and advocacy group being formed by drug users themselves (see "Project 'Open Space' " box).

³⁴ The Ministry of Health has approved the use of methadone as a substitution therapy, but the Ministry of Justice continues to block its availability. The Network is one of many civil society organizations advocating to remove all obstacles to methadone access and to move buprenorphine out of its pilot phase.

³⁵ As per the final application submitted to the Global Fund in August 2006. A copy of the application was provided to the author by the Network. The estimated overall financial needs to adequately respond to the HIV epidemic were calculated at US\$ 85 million in 2006 and US\$ 100.6 million in 2007.

³⁶ It was announced in December 2006, that in 2007, the Government of Ukraine will substantially increase the amount and scope of funding for HIV services, with an increase of 260% to the national AIDS budget, from UAH37M (USD7.3) in 2006 to UAH 99M (USD19.6) in 2007.

—disclosure by medical staff to family, relatives or employer without patient consent.”³⁷

This failure stems from both inadequate training and weak mechanisms to enforce confidentiality laws and requirements.

- *Persistent stigma and discrimination.* Although Network staff and members stress that the situation is improving, HIV-related stigma continues to influence government and public attitudes to HIV-positive individuals and those most vulnerable to exposure to HIV (such as drug users, sex workers, and men who have sex with men). Police harassment of drug users remains a problem in some municipalities and oblasts, for example. Most observers, including Network staff and members, agree that awareness and information about HIV among the general public is insufficient—a situation that reinforces HIV-related stigma.³⁸
- *Lack of integrated health-care delivery.* The Ukrainian health-care system is structured on vertical lines. This means that treatment for HIV—including antiretroviral treatment disbursement and diagnostics (such as CD4 testing)—is provided only at special AIDS centres. People living with HIV seeking treatment for TB, however, have to go to a separate TB centre. Those seeking care for conditions not related directly to HIV or TB must go to yet another clinic or hospital. Often these facilities are far away from each other, if they even exist in a given municipality. Caregivers may only know about the specific conditions they are mandated to address. This system is time-consuming and confusing to many people living with HIV. The quality of care provided to people living with HIV could be greatly improved by integrating service delivery and training caregivers holistically.

Project ‘Open Space’: a group for injecting drug users organized by injecting drug users

In Odesa, two active drug users have been galvanized by the Network’s success in creating a strong, viable organization led by people living with HIV. The two young men, Aleksey Vlasov and Konstantin Shportun, are using the Network as a model for Project ‘Open Space’, a self-support and advocacy group for injecting drug users that they have recently launched. Their primary focus will be on advocating the rights of active drug users to be free from police harassment and abuse, arbitrary detention and mandatory ‘cold turkey’ detoxification. They want to show the general public and the authorities that they are “human beings like everyone else” and deserve equal access to health care. In particular, they say, it is vital for injecting drug users’ health that substitution therapies be available to all who need them and that nonjudgmental, compassionate rehab options become more common and accessible.³⁹

Still in its early development phase, Project ‘Open Space’ is being supported by the Odesa-based nongovernmental organization ‘The Way Home’, which provides harm reduction services. The project is believed to be the first attempt in Ukraine for active drug users to come together and take action designed to protect their health and advocate for their

³⁷ Available online: www.ungasshiv.org/index.php/en/ungass/shadow_reports_2006/public_health_watch/ukraine_preliminary_findings

³⁸ The extent of misinformation and lack of awareness were directly experienced by this report’s author. While attending the Network’s General Assembly meeting in September 2006, he was hugged by an HIV-positive Network member following an interview. The interpreter, who had been hired from a nearby city and was not affiliated with the Network, asked the author several minutes later, “Aren’t you worried you might get AIDS? That man looked very sick.” This occurred after she had been interpreting for three days at the meeting.

³⁹ A joint interview with Aleksey Vlasov and Konstantin Shportun was conducted in Odesa on 9 October 2006.

rights. Like the early founders of the Network in regards to people living with HIV, Vlasov and Shportun believe that drug users can and must take the lead in solving their own problems. They hope to create a members-based structure similar to the Network.

The project has the following initial objectives:

- to offer free legal advice and services to drug users in need;
- to film a high-quality documentary that highlights the problems injecting drug users regularly face, especially abuse and harassment from the police. As of October 2006, filming had already begun. The project's organizers hope to show it on television; and
- to advocate the rights of HIV-positive active drug users to obtain antiretroviral treatment.

Currently, many health-care providers put active users at the bottom of the list of those waiting for antiretroviral treatment. Among other claims, they say drug users cannot and will not be adherent to antiretroviral treatment regimens. Project 'Open Space' will train doctors in how to provide treatment to active users and will distribute research studies from abroad showing that drug users are no less adherent than anyone taking HIV medicines. Vlasov and Shportun (and, eventually, other drug users who become members) hope to work with both users and doctors to ensure that a full range of services, including for harm reduction, are available to drug users on antiretroviral treatment.

4. Network structure

Summary: Under the Network's bylaws, all activities, strategies and policies must be approved by its members—currently totalling some 320 across the country. That includes the seven members of the Coordination Council, which is the de facto board of directors and on which only HIV-positive individuals can serve. The head of the Coordination Council is the Network's chief executive, and that individual is also technically responsible to the membership. All important decisions are presented to the full membership for approval at its annual General Assembly meeting. Local branches and affiliated organizations are required to sign agreements with the central office regarding financial, reporting and policy requirements and expectations. However, they maintain a significant degree of autonomy based on the recognition that local staff and members are best placed to understand and respond to local needs.

Core of the Network: members

The more than 320 members and 200 volunteers across the country represent the heart of the Network. Members need not be HIV-positive, but they must demonstrate a commitment to the Network's focus on improving the lives of people living with HIV and those vulnerable to HIV transmission. The main steps in becoming a member, as outlined in the Network's bylaws, are the following:

1. A person seeking to become a member prepares a written request addressed to the head of the Coordination Council (the Network's overall governing body) and gives it to his or her regional representative, who registers it.
2. After the candidate volunteers at a local group for at least six months, his or her request to be a member is put on the agenda of the next general meeting of regional representatives.
3. Prior to the meeting, the candidate is interviewed and asked about his or her reasons, motivation, and goals as a member.
4. All existing members in the region are eligible to participate in the voting. Two thirds of the members in the region must be present for the vote to be valid.
5. The candidate's name is proposed for membership at the annual general meeting of the Network. All eligible participants vote on slates presented by individual regions. If the candidate is approved, he or she is officially a member.

The steps to becoming a member are relatively time-consuming and rigorous for several reasons. According to Network bylaws, all decisions—including those involving staffing, policy, and finances—are subject to the approval of the members. All top-level staff, including the chief executive and the seven individuals on the board of directors (known as the 'Coordination Council'), technically report to the members and serve as they wish. In addition, members are expected to sustain and grow their local branches. Their commitment must therefore be matched with energy, useful skills and a clear understanding of the necessity of teamwork and compromise.

The Network at the national and local levels

The Network consists of a central office in Kyiv and local entities in cities and regions across the country. They work closely together but have different responsibilities under Network bylaws and policies. Many individuals based at the central office were first engaged with the Network at the local level; their subsequent moves to Kyiv have often been based on the need for certain types of expertise, notably organizational skills, at the central office.

On the surface it seems as though such ‘poaching’ of talent would be detrimental to local entities. However, efforts are made at both the national and local levels to ensure that qualified and properly trained replacements are ready to step in at the local level when a staff member moves to Kyiv. National staff members seek to work with local counterparts to establish similar contingency plans to address instances of illness, resignations and terminations of employment, especially vis-à-vis staff in high-profile or high-skill positions.

The central office: structure and responsibilities

As of October 2006, about 35 full-time employees⁴⁰ worked at the central office, which had a budget of US\$ 2.8 million in 2006.⁴¹ Under Ukrainian law, all employees technically report to the chairman of the Coordination Council (see Section 4.3.1), who is also the chief executive. The signature of that individual—who has been Volodymyr Zhovtyak since registration in 2001—is the only one allowed on most official documents.

Network bylaws stipulate that the chief executive and all members of the Coordination Council be HIV-positive. That criterion does not apply to other staff at the national level (or at most local entities, which have different bylaws). Currently, the central office is structured so that two individuals have clear and distinct responsibilities that complement but do not overlap each other; one of them is HIV-positive, but the other is not.

The chief executive, Zhovtyak serves as the ‘face’ of the organization. He plays a key role in setting broad advocacy policies and strategies; interacts regularly with government officials, donors and the media; and oversees the running of the Coordination Council, the Network’s de facto board of directors.

The nuts and bolts of the Network, meanwhile, are overseen by programme director Hanna Khodas, who has been with the organization for five years. Khodas is responsible for administrative functions such as staffing; determining job descriptions; settling internal disputes and conflicts; arranging and chairing meetings of managers and staff; and ensuring effective internal communications so that all Network staff and members are fully informed regarding priorities and strategies. Staff members responsible for interaction and relations with local entities also report to her. As Khodas put it, “I run the Network from behind him [Zhovtyak].” She said that when both are in the office they make a point of meeting at least once day in order to share as much information as possible about key issues, both internally and externally.⁴²

The central office is divided into separate departments, including:

- programmes, training and administration;
- information;

⁴⁰ Interview with Hanna Khodas in Kyiv on 11 October 2006. In October 2006, approximately 30% of full-time staff at the national office are HIV-positive.

⁴¹ Interview with Volodymyr Zhovtyak in Kyiv on 5 October 2006.

⁴² Interview with Hanna Khodas in Kyiv on 11 October 2006.

- law and legal services; and
- international partnership (which focuses on fundraising and building the organization).

The number of departments and their scope and responsibilities are intended to be flexible, a condition deemed necessary as the Network continues to grow rapidly and introduce new strategies and policies. At the time this report was being prepared, for example, Network leaders were considering the addition of two more distinct departments—one to focus solely on treatment, and the other on policy and advocacy.⁴³

Broadly speaking, the central office undertakes the following activities on behalf of the Network:

- organizing and leading advocacy campaigns at the national level, including lobbying the national government, working with international donors and coordinating advocacy strategies with other civil society groups;
- serving as the main 'public voice' of the Network in national-level media and communications;
- setting broad strategic and policy guidelines for the entire Network, including local entities and all members, and coordinating the establishment of structures to ensure consistent and open communications;
- helping build the capacity of local branches and affiliated organizations. This may take the form of direct financial and technical assistance,⁴⁴ provision of equipment (such as computers), training (for activities as wide-ranging as how to raise funds to how to work with local AIDS centres in improving antiretroviral treatment delivery),⁴⁵ providing resources and assistance for problem-solving,⁴⁶ and sharing of information and resources across the Network; and
- administering funds provided by the Global Fund and other donors. The central office in turn solicits proposals from regional and local entities, evaluates and makes decisions in response to the proposals, and then distributes funds accordingly.

The central office is also about to take on a new responsibility that will be its most challenging yet. In November 2006, the Global Fund announced that one of its Round Six AIDS grants would go to Ukraine. The Network and the International HIV/AIDS Alliance of Ukraine are co-Principal Recipients of the grant, and both will have significant administrative responsibilities over the grant's five-year lifespan. (See Section 7.2.1 for more information on the Round Six grant.)

⁴³ Interview with Volodymyr Zhovtyak in Kyiv on 5 October 2006.

⁴⁴ Direct financial support to local groups can and has been used for nearly any purpose required, including for salaries, rent, transportation and equipment. In comparison, the Global Fund generally imposes far more restrictions on how its funds can be used—for instance, they often cannot be used for overhead expenses. Local Network branches and affiliated organizations typically receive both kinds of funds, direct and flowed from the Global Fund, from the national office. In both instances, all expenditures must be itemized carefully and thoroughly.

⁴⁵ The Network either provides the training itself, with its own staff and members, or uses outside consultants. For example, it may solicit support from international donors and civil society groups to provide the sort of training beyond its existing capacity.

⁴⁶ For example, legal experts from the national office could be used to mediate disputes or improve relationships with law enforcement officers.

Grant making criteria

Grant making is one of the main administrative responsibilities of entities serving as Global Fund Principal Recipient. The Network will likely need to hire new staff with skills in this area as well as train existing staff with no current experience in grant making.

The Network is not new to the world of grant making, of course. It regularly provides grants to local branches and affiliated organizations in addition to unaffiliated nongovernmental organizations engaged in HIV service delivery in Ukraine. Some funds for grants are allocated from the Network's regular budget; others, meanwhile, flow from Global Fund monies the Network has received through the ongoing Round One grant and has been charged with distributing at the local level.⁴⁷ As is common in most grant making institutions, some of the grants are awarded as the result of competitions, while others are non-competitive.

The most recent Network policy document (June 2006) lists its grant making criteria. It is unclear whether and to what extent the Round Six Global Fund grant will alter the existing criteria. According to the policy document, the following factors are among the first to be taken into consideration at the beginning of the grant making process:

- the number and responsibilities of people living with HIV working at the organization;
- the image of the nongovernmental organization (which requires a positive answer to the question, 'Is it respected?');
- the nongovernmental organization's transparency;
- the nongovernmental organization's organizational structure and development;
- the nongovernmental organization's success in attracting funds for its activities from other sources, notably local governments, businesses, and domestic and international donors; and
- the extent and strength of partner relations with other nongovernmental organizations and local government institutions and structures.

Financial support and budget

The Network's budget has grown sharply every year since it was founded. This has enabled it to expand across the country and provide additional grants to local groups, especially local branches and affiliated organizations. According to Zhovtyak, the Network's budget for 2006 is about US\$ 2.8 million.⁴⁸ That compares with income of 11.16 million hryvnas (US\$ 2.2 million) and 6.79 million hryvnas in 2005 and 2004, respectively.⁴⁹ The bulk of the 2005 funding—75%—came from the International HIV/AIDS Alliance in Ukraine as part of its management of the Round One Global Fund grant. In addition, 8% of the 2005 income came from the Netherlands Organisation for International Development Cooperation; 6% from the European Commission; and smaller amounts from donors including Doctors of the World-USA, the Elton John AIDS Foundation (which has been providing core funding since inception), Norwegian Church Aid, UNAIDS and the United Nations Children's Fund (UNICEF).⁵⁰

⁴⁷ In 2005, for example, the Network awarded 32 grants through the Global Fund.

⁴⁸ Interview with Volodymyr Zhovtyak in Kyiv on 5 October 2006.

⁴⁹ As per the Network's 2005 annual report. Available online at www.network.org.ua/en/about/report/.

⁵⁰ *Ibid.*

The annual increases over the past few years are quite substantial, but they are nothing compared with what is likely to happen in the near future. As co-Principal Recipient of the Round Six Global Fund grant, the Network's annual budget could conceivably quadruple in 2007, according to Zhovtyak, and remain at that level during the course of the grant.⁵¹ That will require the hiring of more staff, especially those with financial management expertise, and training and promotion of qualified individuals already working with the Network.

Structure and responsibilities at the local level

Just five years ago, the Network was represented only in Kyiv, Odesa and a couple of other areas in the country. By October 2006, however, it had expanded or was in the process of expanding to all of Ukraine's 27 regions and administrative units except Lutsk.⁵²

Local representation is achieved in two ways, through official branches (a total of 13 as of October 2006) and affiliated organizations (a total of 20).⁵³ The former are formally part of the Network, while the latter organizations work closely with the Network but are registered separately. Most of them are independent nongovernmental organizations—with a large percentage of self-help groups (known as 'initiative groups') that had sprung up somewhat spontaneously in their municipalities and regions—that share the Network's vision, wanted to collaborate with it, and met specific Network criteria. (In addition to these 33 groups, the Network also has more informal arrangements with several other nongovernmental organizations, according to Nataliya Kovnir, the Network staff member who oversees relations between the central office and local regions. Those groups receive small amounts of financing from the Network for services such as supplying coffee and tea in community centres.)

Any organization interested in becoming affiliated with the Network can apply. The Network's Coordination Council votes on whether to accept an application, with decisions based on factors such as perceived organization viability, understanding and acceptance of Network focus and mission, and local need. If approval is obtained, the Network will help guide a local organization through the registration process if necessary.

As stated in the Network's policy document (June 2006) both local branches and affiliated organizations must meet certain criteria, which are broadly similar for both types of entities. Among the criteria, the local groups must:

- provide a wide range of services;
- conduct general meetings with obligatory documentation, including documentation on membership;
- have demonstrated organizational capacity (premises, responsibilities, strategic and operative planning, and a system of monitoring and evaluating all activities);
- initiate and conduct mass events;
- establish and sustain agreements on collaboration with governmental, nongovernmental and other organizations in the region; and

⁵¹ Interview with Volodymyr Zhovtyak in Kyiv on 5 October 2006.

⁵² Interview with Terry White in Kyiv on 3 October 2006. According to a subsequent e-mail correspondence with White, recent steps had been made to establish Network presence in Lugansk and Rivne. An initiative group had begun functioning in the former in 2006, and a local group in Rivne had initiated contact with the Network. A team from the national headquarters was scheduled to travel to Rivne in November 2006 to assess the situation.

⁵³ Interview with Nataliya Kovnir in Kyiv on 2 October 2006. Kovnir is the Network staff member who oversees relations between the national office and local regions.

- have successful results regarding fundraising activities.

Relationship between national and local levels

In accordance with the Network's grassroots background and desire to empower communities to the fullest extent possible, each local organization has significant autonomy in its home area. For instance, Kovnir said, "We cannot tell regional networks what to do, even if [their] policies are not exactly the same as those of the national level." If there is a discrepancy or dispute, she said, "We can only refer them to the statutes." The statutes she is referring to are the agreements that all local groups are required to sign with the national Network upon affiliation. The agreements outline various requirements and expectations, including the submission of quarterly reports about all activities, services and clients; financial updates; and monitoring and evaluation outcomes. Specific information that the national Network expects to obtain may include, for example, the number of clients on antiretroviral treatment, how many people drop by a community centre on an average day, and cases of discrimination reported and how they were addressed.

In the early days, the Network did not require contractual arrangements with local organizations. This lack of formal structure reportedly constrained the central office's ability to identify and address a couple of cases of financial administrative mismanagement.⁵⁴ Now, however, the agreements stipulate that the central office has the ability and authority to take action if, for example, a local organization fails to send in reports on a timely basis.

The agreements also state that local organizations cannot act independently in the name of the Network. An example of how this works in practice is how the local group is expected to act when a local newspaper wants to interview staff and clients for a story. The local group can respond under its own name—i.e. as Life Plus in Odesa—but cannot give the impression or indication that it is speaking for the All-Ukrainian Network of People Living with HIV/AIDS (unless specific clearance is obtained in advance from Kyiv). "Brand management" is the main reason for this policy: The Network believes that it must be seen as consistent and unified for it to be taken seriously at all levels on an ongoing basis. Over the years its leaders have come to the conclusion that it can best achieve useful policy change on behalf of all people living with HIV if it is perceived as professional, organized and prepared. These attributes are particularly useful when dealing with the government, according to some Network staff and members.⁵⁵

The Network's insistence that local entities cannot act independently in the name of the Network may at first glance seem to contradict staff members' assertion that local groups are largely autonomous. Yet significant autonomy does appear to exist. It is concentrated around decisions regarding staffing, cooperation with local government authorities, and what kind of services to offer. National-level staff members prudently recognize that such kinds of decisions can and should be determined at a local basis based on keen understanding of local need.

At the same time, however, there is far less autonomy than many national-level staff may claim in regards to finances and monitoring. Most local entities have sought and continue to seek funding on their own from a variety of sources, including government agencies, private-sector businesses, bilateral donors and nongovernmental organizations.

⁵⁴ Interview with Terry White in Kyiv on 3 October 2006.

⁵⁵ Interview with Iryna Borushek in Kyiv on 5 October 2006.

The central office encourages such efforts and assists local entities in developing fundraising capacity. These efforts are important, but most local groups continue to receive the majority of their funding from the central office, often through its capacity as sub-recipient of Global Fund money from the Round One grant.

Local groups' dependence on the central office extends beyond funding as well. According to Kovnir, "Local branches frequently ask for help in filling out forms" and for assistance in other areas such as those related to medical issues, including "how to solve problems and understand complications regarding treatment."⁵⁶ Kovnir serves as a combination point person/gatekeeper for such questions and concerns—indeed, for the full range of issues that local groups wish to raise. Staff, members and volunteers at the local level know to contact her directly. She is then responsible for referring all concerns and questions to the appropriate person or people at the central office. Responses and feedback from the central office are expected to flow through her as well. This system

- enables Kovnir to be aware of all national-local interaction, for which she is responsible;
- ensures that issues are in fact addressed by the relevant person or department; and
- limits the amount of direct contact with top-level staff regarding issues that they have no time or ability to respond to directly.

This structure works, Kovnir said, because it is "not amorphous."⁵⁷ In her opinion, it is an example of why the Network has been successful as well. "Our Network works because there are clear job responsibilities and clear organization responsibilities," she said, echoing similar comments from Khodas. "It is clear who is subordinate to whom, who should be contacted about what questions, and why that person is qualified and expected to respond," she added. It should be noted that as outlined in agreements between the central office and local groups, programme director Hanna Khodas is the 'court of appeal' should differences persist between what a local group wants and what the responsible person at the central office is able or prepared to provide.⁵⁸

Network leaders are regularly apprised of local groups' activities through the quarterly reports they are required to submit. Kovnir collects the reports, distributes them to members of the Coordination Council, and summarizes regional activities and key issues that the Council may need to address directly.

Kovnir acknowledged that her ability to act as the sole gatekeeper has become increasingly difficult as the Network continues to grow. A solution in the process of being implemented is to "teach coordinators at the regional level to do the same kind of work that I do, and then to report directly to me," she said.⁵⁹ A significant portion of the questions and concerns could then be addressed by the regional coordinators, with only the more difficult or complicated ones being referred higher up the chain. The regional coordinators would be required to submit their own quarterly reports to Kovnir prior to her distribution of reports to the Coordination Council.

⁵⁶ Interview with Nataliya Kovnir in Kyiv on 2 October 2006.

⁵⁷ Ibid.

⁵⁸ Interview in Kyiv with Hanna Khodas on 11 October 2006. Khodas noted that it is "extremely rare" for her to become involved in this capacity.

⁵⁹ Ibid.

In general, regional representatives and other locally based members expressed satisfaction with the quality of their links with the national level.⁶⁰ They felt that their questions and concerns were for the most part addressed promptly and thoroughly. Moreover, nearly all interviewed said they benefited from the central office's emphasis on sharing information and resources among groups at all levels. The one wish consistently mentioned was that more funds would be available from the central office to help expand services and to put aside some money in 'rainy day' accounts. That appears to reflect less on their level of contentment with the central office than on the ever-growing need for HIV-related services and the chronic shortage of funds in the country for such purposes.

Resolving conflicts within the Network

The Network's stated priority of ensuring local groups' autonomy is important for underpinning its grassroots, locally driven citizens' advocacy focus. Yet it also raises questions about how to resolve conflicts or disputes. The agreement all local groups are required to sign with the central office does not indicate specific conflict resolution steps, but its very existence provides both sides with a strong incentive for action should violations occur. The Network's ethos is not to respond aggressively in such cases, however, but to seek a resolution of conflict. In a few isolated incidents, for example, some local groups were failing to send in reports in a timely fashion. Staff from the central office subsequently visited the local group and worked with them to identify the reasons for the delay and rectify them.

The appropriate response is less clear in regards to policy differences. For example, how might the central office respond if a local branch excluded men who have sex with men from services or sought to limit active drug users' access to antiretroviral treatment or substitution treatment—all of which are counter to the Network's policies and advocacy efforts at the national level? The short answer given by central office staff is that nothing of this sort has ever happened.⁶¹ If it did, Kovnir said, the principles of autonomy would forbid the Network from unilaterally severing its ties or "kicking out" the local group. Instead, she said, the central office would "send experts in to try to mediate, to sort things out."

If an impasse were reached that proved impervious to mediation or discussion over a period of time, then the Network could conceivably reduce or eliminate funding to the local group.⁶² Given local groups' reliance on funds from the Network, that drastic step would likely be effective in either prompting the local group to alter its policies or causing it to sever ties completely. One reason that such policy disputes have been uncommon is that the Network is in regular contact with members at all levels and seeks to ensure that key strategy and policy decisions are determined only after members' opinions are solicited. Every effort is then made to achieve consensus.

Zhovtyak acknowledged that the potential for disagreement and dispute will only increase as the Network grows larger—as more members, staff and clients are added.⁶³ "It will be a crisis if we don't watch everything closely," he said, especially if local groups do not offer

⁶⁰ A total of 13 regional representatives and members of local groups were interviewed during the Network's annual General Assembly meeting in Foros from 26-29 September 2006. Additional interviews with locally based staff were conducted over the next two weeks in Cherkassy, Chernigiv, Odesa and Simferopol.

⁶¹ Interview with Nataliya Kovnir in Kyiv on 2 October 2006.

⁶² This possibility was mentioned both by Nataliya Kovnir (interviewed in Kyiv on 2 October 2006) and Hanna Khodas (interviewed in Kyiv on 11 October 2006).

⁶³ Interview in Kyiv with Volodymyr Zhovtyak on 5 October 2006.

appropriate services or are not expanding in ways that they have agreed to. He added, “We’d like to meet this challenge by creating mobile experts’ group to go to individual regions, say for two weeks at a time, to deal with existing problems and identify those that might arise. We’re always thinking of new ways to stay in touch with local groups.”

Key governance bodies

Coordination Council

The Coordination Council is a seven-member group that functions like a board of directors at the top of the Network. All of its members must be HIV-positive and members of the Network. Elections are held every two years, and existing members are eligible for re-election—although at least two individuals must rotate off during each election cycle. The rotation policy was devised so that the leadership is rejuvenated on a regular basis.⁶⁴

Interested individuals can propose themselves for membership on the Council or be proposed by another Network member. Each candidate is then required to write a short outline of his or her ideas for the future of the Network and submit them to the General Assembly, which comprises the entire Network and meets once a year. At the General Assembly, members vote to determine who sits on the Coordination Council. This process helps ensure that the Network’s leadership is directly accountable to the full membership.

Members of the Coordination Council select one of their own to be the chairman. The individual filling that role, which since 2001 has been Volodymyr Zhovtyak, also serves as the Network’s chief executive. The chairman runs all Coordination Council meetings and devises the agenda of quarterly meetings. Most Network strategy and policy decisions must be approved by the Council.

As outlined in the Network’s most recent policy document (June 2006), the functions of the Coordination Council include the following:

- representing the interests of the Network at regional, national and international levels;
- developing Network policy and overseeing its implementation. Each member of the Council is responsible for overseeing a specific policy area, such as financial, external relations, and internal organization;
- developing strategic directions of activity, in tandem with representatives from the regions, and planning how to implement such activities;
- reviewing and making decisions regarding regional representation and affiliations with local groups;
- helping regional representatives establish partnership with appropriate structures and stakeholders in their regions;
- assisting in the strengthening of regional entities’ organizational capacity; and
- participating in decision-making processes on financing of initiative groups, regional representations, regional branches and charity programs.

⁶⁴ Because there are no set term limits for individual Council members, some individuals have been re-elected to and subsequently have remained on the body since it was first established in 2001. They include Volodymyr Zhovtyak, Iryna Borushek and Sergei Fedorov. In an interview in Kyiv on 5 October 2006, Borushek said that to date the process of deciding who would rotate off had been fairly uncomplicated because at least two individuals were ready and willing to leave the body. The bylaws do not specify steps to be taken should more than five members seek to be re-elected. In such an instance, the individuals with the lowest number of votes from the full membership would conceivably be required to rotate.

Regional representatives

Ukraine is divided into 27 separate administrative units regions—24 ‘regular’ regions (oblasts), the Crimean Autonomous Region, and the cities of Kyiv and Sevastopol. As of October 2006, the Network was represented in or in the process of establishing representation in 26 of them. Within each region there may be more than one local branch or organization affiliated with the Network, but there is only one regional representative. That individual, who must be a Network member, coordinates the activities of all members in his or her region and works closely with the central office and other regional representatives to facilitate information-sharing and resource disbursement.

Regional representatives are proposed and selected at regional general meetings, which must be held every three months in each region. The individuals selected are subject to approval by the Coordination Council. Regional representatives are responsible for convening and chairing the quarterly regional meetings, and they are answerable to Network members in their region. They cannot be directors of other organizations, including those affiliated with the Network, but they can be board members of them.

Among the other responsibilities of regional representatives are the following:

- collecting and analysing information in the region concerning the number of people who receive treatment, the number of HIV-positive children, and the type and scope of services provided for people living with HIV at AIDS centres and other relevant health-care facilities;
- conducting needs assessments of HIV-positive people;
- documenting cases of violation of the rights of people living with HIV;
- working with the mass media to create and sustain a positive image of the Network;
- initiating, organizing and conducting mass events;
- actively participating in city and regional coordination councils created to oversee the response to AIDS;
- establishing partnerships with governmental and nongovernmental, local and international AIDS-service organizations;
- participating in meetings of the Council of Regional Representatives, and helping determine the Network’s strategic plans;
- representing the Network and the interests of HIV-positive people in the region at local, regional and national levels according to the goals and objectives of the Network; and
- submitting quarterly reports about all relevant activity in the region.

5. Clients, services and recent achievements

Summary: Through its local branches and affiliated organizations, the Network provides services to thousands of HIV-positive clients across Ukraine (the term 'client' is used to refer to any person who uses services provided by a local branch or affiliated organization). It also works with "indirect clients", such as injecting drug users, health-care workers, journalists and law enforcement officials, as part of a broader effort to increase social tolerance, raise awareness about HIV prevention, and reduce stigma and discrimination. More than 20 distinct types of services are offered around the country. They range from hosting self-help groups to providing psychological support to prisoners to adherence support for those on antiretroviral treatment. The Network's advocacy efforts have resulted in numerous high-profile achievements in recent years, notably a series of meetings with the Ukrainian president in November 2005. At that meeting, the president cancelled a corruption-ridden and poorly structured antiretroviral drug tender decision and vowed to take personal control over the government's response to the epidemic.

Client criteria

In September 2006 the Network held its annual General Assembly meeting in Foros, a resort town in the Crimean Autonomous Republic. The very first agenda item was painfully personal to many participants—the slow scrolling on the video-projector screen of the names who had died over the past year. More than 100 names were included, from Sophie (age four) to Valentina (age 51). The room was silent for several moments, with many people in the room shedding tears as they watched the grim litany pass by.

This anecdote illustrates the best of what the Network strives to be: a citizens' advocacy group that has not strayed from its core goal of caring for and trying to improve the lives of people living with HIV around the country. The term 'client' is used to refer to any individual who receives services from a local branch or affiliated organization. Most clients are referred to the Network's local group by staff at AIDS centres, often after learning the results of their HIV test; by other people living with HIV; and by other nongovernmental organizations, including those that provide information and support for injecting drug users.

Most local groups have slightly different criteria, but in general they seek to register each person who seeks out and receives any service—whether merely visiting a community centre for a cup of coffee or utilizing a full suite of services from treatment adherence support to transportation assistance to regular participation in self-help groups held onsite. Individuals have the option of being as open as they choose when registering. Some give their full names, for example, while others provide only a pseudonym or ask to be listed by a number. All identifying information is kept confidential and will not be divulged under any circumstances—to law enforcement authorities, say—in the absence of a specific request (often required to be written and signed) by the individual himself or herself. At most local groups, there are no minimum requirements for an individual to remain an official client. Some may drop by every day, while others seek assistance sporadically and far less frequently.⁶⁵

⁶⁵ As found in interviews with more than 15 regional representatives and members of local groups, conducted between 26 September and 13 October 2006, most local groups do not have official criteria regarding requirements to remain a client. They do cancel registrations of those who die, of course, and will do the same if they are told an individual has moved to another region and joined a different group. Otherwise, they feel it is important to maintain an individual's registration for as long as possible to ensure having a full record of his or her requests and needs.

Cherkassy oblast branch

The Network's Cherkassy oblast branch was registered in August 2004. Two years later, it had 18 staff members and five volunteers. A total of 82 clients were registered as of October 2006.

The organization's director, Lena Stryzhak, was diagnosed with HIV in 2000 when she was pregnant.⁶⁶ At the time, she said, she knew nothing about HIV and for several months did not discuss her status with anyone except a psychologist. In 2002, her psychologist put her in touch with another HIV-positive person and they decided to create a self-help group in Cherkassy, a city of 300 000 people in central Ukraine. The group's first meeting was in April 2002.

The office occupies a large one-story building in a tree-shaded park off a main road, about three kilometres from the city centre. Prior to obtaining a lease on the abandoned building two years ago, the group had no office and thus found it difficult to build up a client base. The group subsequently obtained funds to renovate the structure and as of October 2006 was about halfway through its efforts. Already in place were a toy-filled playroom for children; office space for staff; consultation rooms; a brightly painted kitchen; a rest and relaxation room; and a laundry room with a washing machine that clients can use.

The local branch's main focus has been on seeking to improve access to ART and diagnostics. As of October 2006, a total of 23 adults and 14 children in Cherkassy were on antiretroviral treatment. However, the local AIDS centre does not offer CD4 tests or other diagnostic services and only provides antiretroviral drugs to children. All treatment provision for adults in the city can only be obtained at the AIDS centre in Kyiv, a three-hour trip (one way) in a crowded minibus for most people. Setting aside an entire day for the journey can be difficult for many people living with HIV, especially those who are ill and cannot afford transportation costs.

Stryzhak said she and her staff are working with the local AIDS centre in an effort to have all treatment services available in the city. The organization has also sought to improve the quality of medical care at the centre by, for example, proposing that local doctors go to Kyiv for basic training on how to better care for and treat people living with HIV.

Among its other recent activities have been the following:

- conducting a toy drive to fill the children's playroom;
- successfully soliciting assistance from local businesses, including a McDonald's restaurant;
- organizing campaigns involving staff, volunteers and people from the area to clean parks and public spaces in the neighbourhood. This was conducted as part of an effort to attract more clients;
- offering palliative care services to terminally ill people, including food and psychological support; and
- contacting members of the local media and discussing HIV treatment and prevention. Staff and volunteers also seek to publicize the centre by bringing journalists to visit the new facility. A series of articles about it have appeared in the local press.

⁶⁶ The information in this box was provided during two interviews with Stryzhak, on 27 September (in Foros) and 13 October 2006 (in Cherkassy).

Local groups generally prefer that people register because it helps them to offer more comprehensive care and support, and also improves the accuracy of record-keeping for funders. However, any person who wishes to use services is allowed and encouraged to do so even if he or she does not wish to register.

Broadly speaking, clients include all HIV-positive people, adults or children, and children born to HIV-positive mothers. The Network also has identified groups of individuals it considers 'indirect clients'. Although not HIV-positive themselves, they are often included in Network outreach and advocacy efforts as part of an effort to increase social tolerance, raise awareness about HIV transmission prevention, and reduce stigma and discrimination. These groups include the following:

- injecting drug users;
- young people from 18 to 35 years old;
- men who have sex with men;
- children and teenagers;
- journalists;
- health care personnel; and
- law enforcement officials at all levels.

The total number of clients across the Network at any given time is difficult to determine. It fluctuates regularly even as it continues to increase overall. The Network tends to focus on cumulative numbers instead. As of October 2006, it had supported more than 18 000 people (including nearly 2000 children) in a wide range of activities and services across Ukraine⁶⁷.

The number of clients at local groups also varies extensively. In Odesa, for example, Life Plus has more than 1000 clients, while the Network branch in Cherkassy reported having 82 clients.⁶⁸ Such differences are based on factors such as

- how long the organization has been in place (Life Plus, for example, predates the founding of the Network while Cherkassy's branch is just two years old);
- capacity and resources (Life Plus has sought and received grants over the years from a much wider variety of international and local funders outside the Network);
- local need (HIV prevalence in Odesa is higher than the national average, yet it is lower in Cherkassy); and
- experience and advocacy tradition (many Life Plus members have been with the organization for more than five years).

(See "Life Plus" box, and the "Cherkassy Branch" box)

The number of clients per day can also fluctuate widely. All local groups allow and encourage people to visit whenever they like; on some days just five people will visit, and on others as many as 50. Flexibility is therefore an important part of each group's efforts.

⁶⁷ UNAIDS Ukraine, personal communication, November 2006.

⁶⁸ Interviews with Lena Stryzhak from Cherkassy were conducted on 27 September and 13 October 2006. Interviews with Peter Polyantsev from Odesa were conducted on 28 September and 9 October 2006.

Services at the local level

Local branches and affiliated organizations offer a wide range of services for clients. However, there are great differences in terms of the number and type of services that each local group is able to provide. The reasons are generally the same as those explaining the differences in number of clients (see Section 5.1), notably experience, capacity and local need. Certain core services, including peer-to-peer counselling, self-help groups, and referrals to doctors, are provided in all regions. More than 20 other services are provided in at least one or more regions, depending on specific needs, resources and available expertise at the local level.

All services can be grouped under the Network's mission to improve the lives of people living with HIV in Ukraine. The forms of assistance provided early on, such as transportation and nutrition support, remain important to many people. They have been joined in some regions by more complicated services that require specially skilled staff and volunteers, such as legal consultations, providing services to people living with HIV in prisons, and interventions and outreach among HIV-positive men who have sex with men. One common special area of interest is children, both those living with HIV and the HIV-negative children of parents living with HIV. Several local groups have day care facilities for children and may even provide a teacher in instances when real or perceived discrimination keeps HIV-positive children out of public schools.

The advent of antiretroviral treatment in many regions has also created the need for new and sometimes unanticipated types of outreach and support. In some cities, for example, Network staff have held training sessions with local police to explain what antiretroviral drugs look like and their purpose. The goal is to teach police and other law enforcement authorities that antiretroviral drugs are legal drugs and therefore to dissuade them from confiscating the medicines from drug users. Some staff have gone as far as preparing documents that specifically state the purpose of antiretroviral drugs and why adherence is vital. They urge drug users to have these documents on them at all times in case they are stopped by the police. It is likely that these kinds of specialized services will grow in scale throughout the Network as more funds become available and local groups share information about implementation.

In terms of staffing, social workers—some full-time staff, some part-time and some volunteers, depending on resources available—are the most common non-administrative personnel at local groups. They tend to operate on a case management approach, which means they are assigned individual clients and work closely with them to coordinate access to the most extensive range of services that might be necessary. They also seek to integrate clients into public-sector health and social welfare systems in order to maximize treatment, care and support efforts.

Life Plus in Odesa

Life Plus is an independent nongovernmental organization that is affiliated with the Network and performs the functions of its regional representation in Odesa. The port city of more than one million people in southern Ukraine is in one of the most heavily affected regions in terms of HIV and drug use prevalence. Life Plus was founded by local activists (all people living with HIV) in the late 1990s and was registered in 2001, at which time its formal partnership with the Network was established.

In October 2006, the organization had 47 Network members and more than 1200 clients—the second highest number in the Network. It has long been regarded as an experimental organization that initiates new and innovative projects that are considered for adaptation in other regions. For example, one of its staff members, Peter Polyantsev, is organizing an initiative to reach out to men who have sex with men, an underserved and vulnerable community not only in Odesa but across the country as a whole.⁶⁹

Life Plus offers a wide range of services for clients and has undertaken several advocacy and community-building activities. Among them are the following:

- the organization has established a day care centre for HIV-positive mothers and children within the local AIDS centre;
- specifically trained counsellors provide treatment adherence support both at the Life Plus office and at the AIDS centre; and
- the organization provides drug users with cards they can carry with them that explain the purpose of antiretroviral drugs and that they are legal medicines. The goal is to prevent the police from confiscating them if they stop drug users for questioning, searches or harassment.

Although the situation is slowly improving, Life Plus and people living with HIV in Odesa face numerous challenges in obtaining quality and consistent access to care. Among them are these.

Lack of diagnostics. At the beginning of October 2006, no CD4 tests had been available anywhere in the city for more than three months. The AIDS centre had announced that no kits were available, but it never gave any indication as to when the problem would be fixed. Such shortfalls had occurred previously as well. Life Plus has been lobbying the AIDS centre to rectify the problem as soon as possible and to take measures in the future to ensure that it does not happen again—such as increasing its projections at the beginning of each year to match reality, and then ordering a more appropriate number of kits from the national government. At several points during various diagnostics shortfalls, Life Plus staff have taken blood to Kyiv in coolers, on overnight trains, to get urgent CD4 and viral load testing done.

Lack of antiretroviral drugs. More than 600 people in Odesa (two thirds of them Network clients) were on antiretroviral treatment, as of October 2006. However, there is a waiting list numbering more than 1000 people living with HIV.

Substandard TB treatment and care. Of the three TB clinics in the region, only one offers decent care, according to Life Plus staff. Meanwhile, there is a shortage of masks in the city and region (none were available in pharmacies in October 2006, for example), which makes it difficult for service providers to protect themselves. As a result, Life Plus staff often find it difficult to arrange visits to critically ill TB patients who are isolated and in dire need of basic assistance, including food and nutrition support. (To protect other clients, Life Plus asks all clients seeking to visit its facilities to bring papers from a doctor stating whether or not they have or have had active TB. If still infectious or in the course of TB treatment, they will ask potential clients to not visit until they are cured.)⁷⁰

⁶⁹ Interviews were conducted with Peter Polyantsev on 28 September (Foros) and 9 October (Odesa).

⁷⁰ Interview with Aleksey Linkov, coordinator of the Life Plus community centre, in Odesa on 9 October 2006.

Poor integration of services for people living with HIV. Life Plus staff members accuse many health-care providers of failing to take responsibility for providing quality care for people living with HIV. As one staff member noted, doctors “play football” with children by referring them to other facilities if they are unable or unwilling to treat them.⁷¹ As a result, it can be difficult for people living with HIV and parents of HIV-positive children to manage their care because they must travel back and forth to various facilities and see different specialists. Only rarely are medical records and information shared.

In addition to publicizing such problems and advocating change, Life Plus also seeks to work directly with individual doctors and caregivers. As explained by Life Plus Projects Coordinator Yuliya Anufriyeva, “At first, our relationship with doctors wasn’t good. They couldn’t understand what Network wanted to do; they thought we were trying to take over their jobs. We had to explain that we’re here to help them. We stressed that we assist them in economizing their time by providing non-medical help that they’re unable to offer”⁷².

Recent achievements and activities

The Network undertakes advocacy campaigns at both the national and local levels. The campaigns are often agreed upon by the Coordination Council and included as part of the broad policy goals outlined annually. These goals are intended to guide the organization’s work over the upcoming year. Although local groups regularly seek assistance from the central office for advocacy campaigns at the local level, they are generally free to determine their own strategic goals based on local needs.

National level achievements

The Network’s most successful recent achievement—particularly in terms of increasing its visibility and cementing its status as an influential voice on behalf of people living with HIV—occurred in November 2005. That month, two members of the Coordination Council, Volodymyr Zhovtyak and Iryna Borushek, attended a series of meetings with Ukrainian President Yushchenko. The first meeting was perhaps the most important for the Network. Zhovtyak, Borushek and Yushchenko were joined by Health Minister Yuri Polyachenko and other top-level public officials to discuss a wide range of issues regarding the HIV epidemic in Ukraine, including prevention, treatment, care and support of HIV-positive individuals.⁷³

Participants at the meeting agreed to intensify cooperation and coordination among government agencies and civil society, including the Network, in the country’s HIV response. In addition, Yushchenko pledged to personally take control of the government’s efforts to combat HIV and tuberculosis. He vowed, for example, that within the next year every district AIDS centre would have the resources and capacity to conduct anonymous HIV testing, and that every regional centre would have at least 20 beds for patients in need.

During the meeting, Zhovtyak also raised another important issue of particular concern to the Network: the government’s mismanagement of tenders for procurement of antiretroviral drugs. The lack of transparency and controls in the initial process led to a

⁷¹ Interview with Olga Alexandrova in Odesa on 10 October 2006.

⁷² Interview with Yuliya Anufriyeva in Odesa on 10 October 2006.

⁷³ The Network’s website contains additional information about these meetings: www.network.org.ua/en/about/three_meetings_with_the_ukrainian_president.

situation in which the government was paying up to 30 times more for many antiretroviral drugs than nongovernmental organizations already providing the medicines in the country, including MSF.⁷⁴ The President reportedly was unaware of the situation. He immediately ordered the Ministry of Health to cancel antiretroviral drug purchases based on the current tender and to initiate the process again in a more open, transparent manner that would lower costs for the government.

The President's decision, prompted by the Network's direct advocacy, was followed later that month by another crucial development in the effort to reduce antiretroviral drug prices. At a ceremony attended by Zhovtyak, the prime minister and the head of the President's secretariat, former US President Bill Clinton and Ukrainian Health Minister Polyachenko signed a Memorandum of Understanding between the Clinton Foundation HIV/AIDS Initiative and the Ukrainian government. The agreement specified that the Clinton Foundation would provide the government with the following:

- assistance in purchasing antiretroviral drugs at lower prices;
- training for physicians working with people living with HIV; and
- support for harm reduction efforts, including projects to expand access to substitution treatment.

Yushchenko's ability to meet all of his promises was undercut by the ensuing political crises over the following year and various other complications.⁷⁵ Yet the prices the government pays for antiretroviral drugs has indeed been reduced, due in large part to the Network's continuing advocacy with the government and with pharmaceutical companies directly. According to a presentation at the Network's annual General Assembly in Foros, in September 2006, a month's supply of tenofovir and Truvada (a brand-name combination of tenofovir and emtricitabine) cost US\$ 17 and US\$ 26 a month, respectively, down from more than US\$ 500. A month's supply of Kaletra (a brand-name combination of lopinavir and ritonavir) cost US\$ 180, down from US\$ 270.⁷⁶

Zhovtyak and Borushek also participated in another key meeting in November 2005 at which Yushchenko was present. Also at the gathering, which was organized to discuss Ukraine's progress in addressing the epidemic, were United Nations Secretary-General for HIV/AIDS Special Envoy Lars O Kallings and UNAIDS Country Coordinator in Ukraine Anna Shakarishvili. Zhovtyak took the opportunity to press for improvement in the National Coordination Council on HIV/AIDS, a high-level group of stakeholders that had been established earlier in the year to help guide the national response.⁷⁷ He also reiterated the need for people living with HIV to participate in the decision-making process, realization and monitoring of AIDS programmes.

⁷⁴ Detailed in a Public Health Watch shadow report published in March 2006. Available online: www.ungasshiv.org/index.php/en/ungass/shadow_reports_2006/public_health_watch/ukraine_preliminary_findings.

⁷⁵ For instance, the president signed a decree mandating that a national clinic for HIV-positive children would be created and operating by 15 March 2006. The clinic had not yet opened more than six months after that date; however, due to unresolved issues regarding the allocation of premises and obtaining necessary equipment.

⁷⁶ These numbers were included in a presentation about Network advocacy efforts that was made to participants at the meeting on 26 September 2006.

⁷⁷ The council has 17 members from across the governmental and nongovernmental spectrum, including international donors and civil society organizations. Two slots are reserved for HIV-positive individuals; those slots are filled by Zhovtyak and Borushek.

Among the Network's other recent advocacy and awareness-raising efforts at the national level have been the following:

- continued efforts to push the government to increase antiretroviral treatment and HIV testing availability through the public sector; and
- working with the media to publicize issues such as poor service delivery and delays within the Ministry of Health, the high price of antiretroviral drugs, and corruption within the procurement and tendering processes.

Among the specific achievements from 2005 and 2006 have been the following:

Establishment of a legal department (2005). This new division increased the Network's ability to help people living with HIV in Ukraine obtain legal assistance free of charge in cases of discrimination and denial of rights. The department was created through Networking Against AIDS, a joint project of the Network and the European Coalition of Positive People. It received financial support from European Union's Technical Aid to the Commonwealth of Independent States (TACIS) programme through the Institution Building Partnership Programme, which supports civil society groups and local initiatives.

Establishment of community centres for HIV-positive people and those close to them. Four centres were created in 2005, in Chernigiv, Donetsk, Kyiv and Simferopol. They provide non-medical care to people in terminal stages of illness, offer informational seminars about HIV, and provide direct consultations from specialists including paediatricians, psychologists, infectious disease doctors and lawyers.

Drafting and submitting an application to the Global Fund's Round Six (2006). The application was approved in November 2006, and funds will probably be disbursed in 2007. The Network will serve as co-Principal Recipient, with primary responsibility for administering grants for treatment, care and support.

Mobilization to reach men who have sex with men, a critically underserved community (2005 and 2006). With targeted funding from the Elton John AIDS Foundation, the Network has supported the initiation of specific projects to provide treatment, care and support to men who have sex with men in four cities: Kryvyi Rig, Lviv, Odesa and Simferopol. At the time this report was being prepared, the Network was considering whether to expand this initiative to cover eight regions⁷⁸.

Recent activities at the local level

Activities at the national level often trickle down to affect local branches, of course. However, many of them also initiate smaller-scale advocacy efforts on their own that have a direct and important impact on their clients' lives. As a result, certain decisions and achievements are unique to a certain organization or are relatively unusual. Because information about these activities is shared across the Network, local groups elsewhere often seek to adapt an idea or project they think would be useful (and which they have the financial and human resources capacity to initiate) in their region or municipality. A sampling of some of the more unusual recent activities and achievements of local groups include the following (see the "Cherkassy" and "Life Plus" boxes for more information).

⁷⁸ Starting January 4th 2007, the Elton John AIDS Foundation will fund a three year, eight-region project to help improve the quality of life of HIV-positive men who have sex with men in Ukraine, through the Network.

- **Kharkiv**⁷⁹
 - successful prosecution of a court case defending the rights of HIV-positive parents to maintain custody of their children; and
 - holding a candlelight vigil on and soliciting extensive publicity regarding AIDS memorial day, in May, when those who have died from AIDS are commemorated.
- **Zaporozhiye**⁸⁰
 - organizing and publishing a newsletter for clients;
 - conducting training for local journalists on HIV-related issues and problems; and
 - providing psychological assistance to inmates in seven prisons, as per an agreement with local prison authorities. The local group hopes to obtain additional funds to expand services it provides to prisoners, including assistance in combating violations of their rights.
- **Kryvyi Rig**⁸¹
 - arrangements were made with city cinemas so that 15 HIV-positive children could attend movies for free;
 - a survey was conducted of city residents, asking their thoughts and attitudes regarding AIDS; and
 - palliative care services have been provided for 25 people. Staff and volunteers visit people who are dying, most of whom are all alone. Many have tuberculosis. The visitors bring food and medicine when possible, sit and talk with the clients, and help take care of legal and other issues if desired. The group hopes to obtain additional funding to expand the service because at least 50 people are on the waiting list.
- **Kirovograd**⁸²
 - the local group successfully lobbied a local prison to release an HIV-positive woman who was very ill. It has subsequently helped her get appropriate care.
- **Donetsk**⁸³
 - Local staff and volunteers provide services in six prisons (four with male inmates, and two with female inmates). They conduct self-support groups, offer psychological support, provide information materials about HIV, train individuals to provide peer consultation, bring in doctors to help treat sexually transmitted infections and provide training to prison staff to help reduce stigma and discrimination towards people living with HIV.
 - As a result of the local group's advocacy, as of August 2006 it was possible to receive antiretroviral treatment in local prisons. Within two months, five inmates were on treatment. Two prisons now also have the capacity to provide CD4 testing. The local group has signed an agreement with prison authorities to help them expand antiretroviral treatment and other treatment services to other prisons.
- **Yalta**
 - the city has a particularly large sex trade, including among young people. Therefore, a new local group in the city has plans to start a project for homeless children, many of whom are thought to be living with HIV. The group is designing a special outreach initiative to reach them.

⁷⁹ Interview with Marina Britvenko in Foros on 28 September 2006.

⁸⁰ Interview with Ruslan Parshakov in Foros on 27 September 2006.

⁸¹ Interview with Inna Turkova in Foros on 27 September 2006.

⁸² This account was presented during a group meeting in Foros on 26 September 2006.

⁸³ Interview with Svetlana Moroz in Foros on 27 September 2006.

6. Cooperation and Engagement

Summary: The Network seeks to form partnerships and work closely with as many stakeholders as possible to ensure realization of its advocacy goals and strategies. It currently works with government agencies at all levels of administration, international organizations, donor agencies, and domestic nongovernmental organizations. The Network's philosophy is that it must continue to advocate strongly with the government on behalf of people living with HIV—but do so as a partner, not as a rival. It thus seeks to create cordial relationships and collaborate with whatever government is in place. The Network also works with numerous international organizations, bilateral donors, and civil society groups. Cooperation has consisted of financial support, technical assistance, advocacy collaboration and policy development at the local, regional and international levels. By helping build the Network's capacity and lay the groundwork for its sustainability, the Network's partners comprise a vital web of support that is needed to strengthen service delivery to people living with HIV throughout Ukraine.

The Network does not consider a 'going it alone' approach to be in the best interests of people living with HIV in the country. Therefore, it has consistently sought to enhance its goals through cooperation and engagement with as many stakeholders as possible. Often there are strategic and procedural differences with some of these partners—notably government agencies—but the Network has refused to break all ties even as it lobbies, privately and publicly, for policy change. Currently, the Network claims to cooperate with at least 60 Ukrainian organizations, some 20 international organizations, four governmental ministries, 23 regional administrations and 44 municipal administrations. It is also a strategic partner of the Ministry of Health, UNAIDS and USAID.⁸⁴

Cooperation can take many forms. Some partners provide the Network with financial and resource support, while the Network works with others on projects and strategies to improve the HIV response in Ukraine. The Network has chosen to participate in Ukraine's National Coordination Council on HIV/AIDS, which was established in 2005 to help oversee the country's HIV response and prepare the Round Six Global Fund application. The council comprises government officials and representatives from international donors and civil society organizations. Two of its 17 members must be HIV-positive, and one must be the deputy head. Network members—Zhovtyak and Borushek—currently fill those roles, with Zhovtyak serving as the deputy head.

Engagement with the government

The Network's relationship with the government is complex, but necessarily so. The Network regularly criticizes the government for not living up to its financial and moral commitment to respond adequately to HIV. It is particularly scathing in its criticisms of the government's lack of political will and leadership to scale up provision of antiretroviral treatment and support services for HIV-positive individuals and those most likely to be exposed to HIV, such as injecting drug users. Yet at the same time, Network staff realize that its goals cannot be accomplished without government involvement. The public sector is the only stakeholder that has the potential capacity to provide services needed to the fullest extent. Its role will only become more important and dominant as the government's share

⁸⁴ As cited in the Network's 2005 annual report. Available online: www.network.org.ua/en/about/report/.

of antiretroviral treatment provision increases and it eventually folds in patients currently receiving treatment and other medical services from civil society groups.

Therefore, the Network philosophy is that it must continue to advocate strongly with the government on behalf of people living with HIV—but do so as a partner, not as a rival. As programme director Hanna Khodas noted, “Volodymyr [Zhovtyak] always says, ‘We must work with whatever government we have. We have to live here, in this country. We must show them respect. We have to keep lines of communication open...and thus relations should be as cordial as possible.’”⁸⁵ This philosophy also means that the Network is not openly political in any way. According to Khodas, “We won’t endorse specific parties, even though several have asked us for an endorsement and have even offered funds. We always say no, the same response we give to pharmaceutical companies that want to fund us.”⁸⁶

Network staff emphasized that regardless of what party is in power, the government generally feels compelled to listen closely to the Network. Staff members place a high priority on always being prepared and having a detailed grasp of all relevant issues regarding HIV in Ukraine. Combined with a professional demeanour, this expertise has earned them respect from most government officials, even those who disagree with the Network’s objectives and strategies.

As Borushek observed, “We must be one step ahead of the government so they see us as equal partners. It’s important that they see us as professional, organized and prepared. Therefore we train ourselves regarding all medical and financial issues. A good example was when we met with the President [in November 2005] and explained to him the problems regarding procurement in a detailed manner. We knew what we were talking about and could explain why it was so important.”⁸⁷

The procurement issue has indeed become one of the main points of engagement between the government and the Network. The Ministry of Health has signed a Memorandum of Understanding with the Network stating that once Global Fund Round Six funds are received, they will create a joint sub-committee to manage the procurement process. From the Network’s perspective, this will help avoid the delays, corruption and mismanagement associated with previous procurement processes.

Cooperation with international organizations and civil society

Over the years, the Network has worked with numerous international organizations, bilateral donors, and civil society groups. Cooperation has consisted of financial support, technical assistance, advocacy collaboration and policy development at the local, regional and international levels. Initially the engagement was mostly one way, with the Network the recipient of most assistance. As it has grown larger, however, it has played a growing role in identifying ways to share its expertise and experience. For example, in September 2005 the Network was directly involved in conceptualizing and creating the Eastern European and Central Asian Union of PLWH organizations (ECUO), a regional network of organizations in 14 countries. It helped coordinate funding for ECUO, part of which it uses to provide technical assistance from its own human resources. (See ECUO box for additional information.)

⁸⁵ Interview with Hanna Khodas in Kyiv on 11 October 2006.

⁸⁶ *Ibid.*

⁸⁷ Interview with Iryna Borushek in Kyiv on 5 October 2006.

The Network's ability to build and sustain momentum as the pre-eminent voice of people living with HIV in Ukraine has been bolstered by, among others, the Ukrainian offices of the following international organizations:⁸⁸

- UNAIDS (coordination and counselling, information and technical assistance, grant provision);
- UNDP (financial support and technical assistance); and
- WHO and the World Bank (technical assistance and information support).

The International HIV/AIDS Alliance in Ukraine was one of the first funders of the Network, and it continues to support it financially. Moreover, the Network has served as a sub-recipient for the Round One Global Fund grant, which is administered by the Alliance. Their collaboration will expand now that they expect to serve as co-Principal Recipients of the Round Six grant. Other civil society groups with which the Network cooperates include the following:⁸⁹

- Elton John AIDS Foundation (long-term core financial and technical support, advocating of the Network at the international level);
- AIDS Foundation "East-West" (planning and conducting information campaigns, technical support, and joint projects for men who have sex with men); and
- Transatlantic Partners Against AIDS (joint advocacy measures)

The wide range and scope of these partnerships are important for several reasons from the Network's perspective. In Ukraine as in everywhere else, effective responses to HIV stem from informed, confident, experienced and innovative individuals and organizations working on the ground. By helping build the Network's capacity and lay the groundwork for its sustainability, the Network's partners comprise a vital web of support that is needed to strengthen service delivery to people living with HIV throughout Ukraine. At the same time, HIV-positive individuals are gaining—and increasingly imparting—valuable skills and expertise to the Network that will help reduce dependence on external assistance in the long run.

⁸⁸ As per the Network's 2005 annual report. Available online at www.network.org.ua/en/about/report/.

⁸⁹ Ibid.

Affinity in the region: the Eastern European and Central Asian Union of PLWH Organizations (ECUO)

One recent Network priority has been to work with organizations of people living with HIV in other countries to create regional forums for sharing information and resources. Network staff believe they can help boost the capacity of new groups and in turn have access to new ideas and strategies that might be useful in Ukraine.

In September 2005, the Network joined with organizations of people living with HIV in nine other countries to create the Eastern European and Central Asian Union of PLWH Organizations (ECUO). One year later, its membership had increased to 12 groups.⁹⁰ The organization's Secretariat is based in the Network's offices in Kyiv.

ECUO's mission is to "to promote the mobilization and capacity building of PLWH organizations of Eastern Europe and Central Asia; and to raise the quality and dignity of the lives of PLWH." It aims to widen access to treatment, care and support; increase the involvement of those living with HIV in all relevant decision-making processes; and improve and protect their human and civil rights across the region.

A small sampling of the activities the ECUO has undertaken, or plans to undertake, to reach these goals includes the following:

- providing technical assistance to member organizations of the ECUO (trainings, seminars, in country visits, etc);
- creating a common database concerning the availability of antiretroviral drug preparations inside the countries of the region;
- collecting and analysing information concerning accessibility of prevention, treatment and care in 10 countries of Eastern Europe and Central Asia. The results of the analysis were presented during a regional conference in Moscow in May 2006; jointly with UNAIDS, developing practical recommendations for the effective involvement of people living with HIV and other vulnerable communities with the "Three Ones" principles; and
- conducting a multiregional action dedicated to AIDS Memorial Day, in May 2006. The action, 'Stop AIDS. Keep the Promise!' involved more than 30 000 people in nine countries. It attracted the attention of mass media outlets throughout the region, thereby highlighting the HIV issue.

The Network played a significant leadership role in creating the ECUO. It has also pledged to provide technical support to other organizations in the group. However, as with its decision to become co-Principal Recipient of the Global Fund grant, the Network risks over-reaching and spreading its resources too thin. The Network continues to grow rapidly within Ukraine, a development that has its own potential complications in terms of resource and financial capacity. Redirecting scarce resources outside the country could limit its ability to support local groups in Ukraine, which is the cornerstone of its mandate to improve the lives of people living with HIV at home. This will be a major challenge for the Network to anticipate as it works through the ECUO to assist organizations of people living with HIV in neighbouring countries, many of which have significantly different types of epidemics, social structures, political and government systems and economic prospects.

⁹⁰ Organizations of people living with HIV from the following countries are involved: Azerbaijan, Belarus, Estonia, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, Mongolia, Republic of Moldova, Tajikistan, Ukraine and Uzbekistan.

7. Lessons learnt and current and future challenges

Summary: The Network is committed to the idea that its citizens' advocacy model will sustain its momentum and help lead a greater and more adequate HIV response in the future. Its efforts to date and the structure it has developed offer important lessons for similar organizations in many other countries. Recommendations and lessons learnt based on the Network's experience to date include:

- an efficient internal structure requires clear job descriptions and responsibilities;
- hire the best, regardless of HIV status or advocacy experience;
- do not be afraid to seek outside help and support from allies;
- a 'one size fits all' approach to local groups is impractical, unworkable and unwise; always be prepared; and
- accept local groups' autonomy and work as a team to resolve problems.

Also important to recognize are the challenges the Network is currently facing, as well as those likely to appear in the future. They include:

- lack of expertise among people living with HIV themselves;
- limited resources lead to rationing of services, fewer full-time staff than required to deliver services comprehensively, and restrictions on expansion;
- retaining close relations with (and ensuring quality control among) individual local groups as their number increases; and
- lack of consistency in the government.

Just seven years ago, being HIV-positive in Ukraine was a prediction of a very uncertain future. In the absence of any services or support, most people living with HIV hid from society and tried to cope on their own. This dire situation has improved remarkably in large measure due to the ability and inclination of people living with HIV, through the Network, to join together, support themselves, and advocate their rights to health and acceptance throughout Ukraine.

However, the HIV-related needs remain great and will continue to grow. HIV awareness is poor among the national population, an important contributory factor to the relentless rise in new HIV infections. The number⁹¹ of people living with HIV who currently have access to antiretroviral treatment and other vital services represents a small percentage of those in need—and certainly the need will only continue to surge as well.

The Network is committed to the idea that its citizens' advocacy model will sustain its momentum and help lead a greater and more adequate HIV response in the future. Its efforts to date and the structure it has developed offer important lessons for similar organizations in many other countries, especially those in which people living with HIV have recognized that they cannot rely on effective or comprehensive support from any source other than themselves. Yet the Network's work is far from done, and it and other stakeholders will

⁹¹ Of November 2006, of the estimated 11 990 who are in need of antiretroviral treatment, 4322 are receiving it.

face numerous challenges as they move forward. The lessons learnt over the past several years will help the Network face these challenges.

Several of the key lessons learnt are listed below; they may also be viewed as recommendations for organizations and individuals seeking to replicate the Network's model, structure and achievements. The recommendations are followed by notable current and future challenges specific to the Network, but which also have many useful elements common to efforts led by people living with HIV everywhere.

Lessons learnt and recommendations

- *An efficient internal structure requires clear job descriptions and responsibilities.* Often, grassroots-oriented advocacy groups fail to implement a solid internal structure because they want to encourage a culture in which all employees feel equally vital to the effort. The Network believes that vitality flows instead from a well-developed and coherent hierarchy similar to those used by businesses. Therefore, the central office has created an organization chart in which all staff members are placed. It is regularly updated so it is obvious to all who each staff member reports to and what department he or she is in. This lack of ambiguity helps ensure that issues and concerns raised both internally and externally are addressed by the appropriate person or department—and presumably in a timely manner.
- *Hire the best, regardless of HIV status or advocacy experience.* The Network bylaws stipulate that the organization must be driven by people living with HIV. However, this requirement has been interpreted as meaning three things only: that it be responsible to its members across the country, that the Coordination Council (the de facto board of directors) comprise only HIV-positive individuals, and that the face of the organization always be a person living with HIV. Otherwise, staffing decisions are based on recruiting and hiring the best people, regardless of their HIV status or background in advocacy.

This policy is based on the recognition that most advocates and activists may not have the requisite skills to build a viable structure. In many cases, the Network has needed to hire individuals with certain types of expertise, such as in non-profit administration and management, to create a professional, smoothly run organization. Two of the earliest individuals brought on, for example, were Iryna Borushek (who had been the executive director of another nongovernmental organization) and Hanna Khodas, who had worked at Counterpart Alliance Project. Borushek is HIV-positive, but Khodas is not.

It should be noted that this merit-based hiring policy operates simultaneously with the Network's efforts to provide training for people living with HIV in areas such as financial management, business administration, public health and public relations. The goal of this effort to build a cadre of qualified individuals across the country who are most directly invested in the Network's goals and success.

- *Do not be afraid to seek outside help and support from allies.* Within a year of its founding, the Network had contacted several individuals and organizations with expertise in building, managing and supporting nongovernmental organizations, including those led by people living with HIV. A British consultant, Terry White, helped prepare the Network for registration and gave advice on how to build a relevant structure and bylaws, professionalize the organization and identify and reach out to funders. Five years later, White continues to serve as

a consultant to the Network as it continues to grow and takes on new responsibilities. New organizations should realize that significant good will usually exists among outside individuals and groups, and that help subsequently will be forthcoming. In return, the organization must be prepared to utilize support and assistance effectively.

- *A “one size fits all” approach to local groups is impractical, unworkable and unwise.* In any network, there will be persistent differences among local groups in areas ranging from capacity, service delivery, initiative, experience and needs. In the All-Ukrainian Network, Life Plus in Odesa has more than 1000 regular clients, while some other local groups have fewer than 100. Life Plus also offers a far more extensive suite of services to clients than are available in other regions.

As evidenced by the Network’s growth to date, it is not in the best interests of organization leaders to attempt to create homogeneity within regions, however. The reasons for accommodating widespread differences include the following:

- the needs of clients differ in each region;
- local people living with HIV are best positioned to organize themselves and determine what kind of services they want to provide, and how; and
- more dynamic or entrenched local groups serve as examples and models to others, thereby creating incentives for service and capacity changes elsewhere.

The Network helps facilitate exchanges of ideas through regular meetings and information dissemination throughout all regions.

- *Always be prepared.* The Network’s ability to influence policy change and interact with government policy-makers has been enhanced by its mastery of relevant issues. It is a respected player as a result. This level of expertise should be encouraged at all levels. For example, according to Yuri Kayuda, the regional representative from Khmelnytsky, “The city knows we’re the experts. We thus have opportunity and need to exercise influence. We have the full opportunity to criticize the government and at the same time to share skills and information with them”⁹².
- *Accept local groups’ autonomy and work as a team to resolve problems.* A national network is nothing without its local branches and affiliated organizations. The people it claims to represent and serve—other people living with HIV—interact with members and staff at the local level. The grassroots model is built from the bottom-up, not from the top-down. These principles are important to recognize when building and sustaining a national network. As Hanna Khodas put it, “Never judge; instead, accept and try to help. Always try to be open. For example, in cases of mismanagement at the local level, try to understand why it happened and work with them to improve the situation. Don’t scold or be antagonistic.” Khodas also noted that it is important to allow local groups to seek out and identify their own solutions. “Don’t be intrusive,” she said. “Let them come up with own priorities. They know the particulars of the epidemic in their cities/regions.”⁹³

⁹² Interview with Yuri Kayuda in Foros on 27 September 2006.

⁹³ Interview with Hanna Khodas in Kyiv on 11 October 2006.

Challenges facing the Network

This report concludes with a summary of key challenges currently faced by the epidemic or likely to be faced in the future, given recent trends and developments.

Serving as co-Principal Recipient of a massive Global Fund grant

Undoubtedly the biggest challenge and the one that deserves special attention concerns the Network's impending role as co-Principal Recipient of a recently awarded Global Fund grant. Up to US\$ 151 million will be disbursed over five years, with the Network in charge of distributing funds for treatment, care and support (including TB/HIV-related activities). The other co-Principal Recipient, the International Alliance for HIV/AIDS in Ukraine, has responsibility for prevention-related funds.

The size and scope of the grant are almost unprecedented. "The Ukraine's Round Six application is the second largest in the world," said Andreas Tamberg, Fund Portfolio Manager of the Global Fund in Ukraine. He added, "We are concerned about the spread of HIV-infection in Ukraine and hope that with additional financing Ukraine will be able to scale up prevention and treatment programmes".⁹⁴

The Network's decision to apply as Principal Recipient was not taken lightly. Network leaders acknowledge that administering the funds will require a massive increase in the organization's administrative capacity in a very short time. This development alone will undeniably transform the Network in other ways. For example, it will have to balance dual (and some would say conflicting) roles as a process-oriented administrative body that works closely with the government and a community-based advocacy and rights organization with a history of acting as a watchdog over the government.

Programme Director Hanna Khodas said she is not worried about the capacity issue. "We grew from four to 35 staff members in just six years, so we understand how to grow. It's not new to us, and we continue to grow. We have identified a growth strategy with our consultants, and believe although difficult, the process will be well managed."⁹⁵

At the same time, however, Andriy Klepikov, the executive director of the Alliance (the Network's co-PR), cautioned against downplaying the difficulties in building the capacity to administer such a complex funding mechanism. He said, "We were ready back in 2004 [when the Alliance replaced the original Principal Recipients of the Round One grant] because we had an organization behind us"—its international headquarters in the United Kingdom. "The Network doesn't have this," he added.⁹⁶

Klepikov also said he was not convinced that the Network had thought carefully about the fact that its Global Fund Principal Recipient role will change its nature. To some extent, he said, the new role will transform the organization into a "network of institutions instead of a network of people." When that happens, he said, "it may be difficult for the Network to retain its core representation element," which places priority on relations with local groups and individuals.⁹⁷

⁹⁴ See www.aidsalliance.kiev.ua/ru/news/pdf/info/release_GlobalFund_eng_final.pdf.

⁹⁵ Interview with Hanna Khodas in Kyiv on 11 October 2006.

⁹⁶ Interview with Andriy Klepikov in Kyiv on 12 October 2006.

⁹⁷ Ibid.

Klepikov added that the Network's success in growing quickly and efficiently would likely render moot many of his concerns. Moreover, both he and Network staff say their relationship is generally good and that they are pleased to be working together more closely in the future. Nevertheless, Klepikov was not alone in highlighting Global Fund-related challenges. Terry White, the longtime consultant currently based at the Network headquarters in Kyiv, also stressed the inherent difficulties in properly and efficiently managing the programme. He observed as well that he was unaware of any previous situation elsewhere in the world when such a large and influential community-based advocacy group had become so heavily involved in working directly with a government to fund and ramp up services while also seeking to retain an independent regional and national watchdog/advocacy role.⁹⁸

Other challenges

Some other notable challenges are listed below. Many of them are not unique to the Network or the Ukrainian situation. Indeed, they often exist or will exist in other environments and among other organizations, including those organized and led by people living with HIV.

- *Lack of expertise among people living with HIV themselves.* Many people living with HIV involved in the Network have little or no professional training or experience. Their lack of expertise could make it difficult to ensure that the Network remains led by people living with HIV as it grows into a larger and more complicated entity. The Network has provided training for some people living with HIV in areas such as financial management, business administration, public health and public relations. However, it may need to allocate greater attention and resources to this effort in order to maintain professional and efficient management and service delivery across the country. A continual process of training will be necessary also as the epidemic changes in Ukraine and different kinds of services and assistance are required.
- *Limited resources lead to rationing of services, fewer full-time staff than required to deliver services comprehensively, and restrictions on expansion.* An important unresolved question at the local level concerns how to prioritize limited financial and human resources. For example, Bogdan Zaika, the director of a Network community centre in Kyiv, said he faced a choice between
 - adding more clients yet being able to provide a smaller number of services; or
 - providing more comprehensive care to a smaller number of clients.

He said he had chosen the second approach and focusing on those most in need. Individuals deemed to be less in crisis were referred elsewhere for services.⁹⁹ In Odesa, meanwhile, the coordinator of the Life Plus community centre said the number of social workers on staff had declined from five to three. He said there was not enough funding to hire new ones to replace those who left.¹⁰⁰

- *Retaining close relations with (and ensuring quality control among) individual local groups as their number increases.* As the Network continues to grow, it will be more difficult for the central office to directly observe local activities as closely as it may like. This

⁹⁸ Interview with Terry White in Kyiv on 3 October 2006.

⁹⁹ Interview with Bogdan Zaika in Kyiv on 2 October 2006.

¹⁰⁰ Interview with Aleksey Linkov in Odesa on 9 October 2006.

could be a problem because the Network's reputation could suffer if local groups are poorly prepared to assist clients. It may also be difficult to ascertain whether local and regional groups are meeting the advocacy and service requirements and expectations outlined in their contacts with the central office. The Network appears to recognize such potential concerns, as per Nataliya Kovnir's observation that the central office was training regional representatives to take over many of the direct oversight functions.¹⁰¹ In this case, adding an extra layer of management would seem to be a good idea so as to spread out responsibilities.

- *Lack of consistency in the government.* The political upheavals over the past two years in Ukraine have limited the government's ability to concentrate closely on the HIV epidemic. In some cases, for example, multiple government changes have made it difficult for advocacy and service organizations to ensure that commitments made by officials in one government are upheld by officials in others. This lack of continuity has already had significant negative repercussions on the intensity and scope of the public-sector response to HIV, including the roll out of antiretroviral treatment and substitution treatment. There are still not enough funds available for these services across the country, with the result that tens of thousands of people remain in need. The Network believes its only option is to work with whatever government is in charge and seek to maximize the provision of funds and other resources for AIDS.

Already there are indications that this effort will continue to be a frustrating and time-consuming one. As estimated by Network staff and others involved in drafting the Global Fund Round Six application, the level of spending for HIV/AIDS in the proposed national budget for 2007 is lower than that allocated in 2006.¹⁰² If that holds true, it will be a devastating blow to all people living with HIV and organizations involved in HIV/AIDS activities.

¹⁰¹ Interview with Nataliya Kovnir in Kyiv on 3 October 2006.

¹⁰² As per the final Round Six application submitted to the Global Fund in August 2006; a copy of the application was provided to the author by the Network. The government allocated US\$ 18.6 million in 2006, but planned to allocate US\$ 17.7 million in 2007.

The Joint United Nations Programme on HIV/AIDS (UNAIDS) brings together ten UN agencies in a common effort to fight the epidemic: the Office of the United Nations High Commissioner for Refugees (UNHCR), the United Nations Children's Fund (UNICEF), the World Food Programme (WFP), the United Nations Development Programme (UNDP), the United Nations Population Fund (UNFPA), the United Nations Office on Drugs and Crime (UNODC), the International Labour Organization (ILO), the United Nations Educational, Scientific and Cultural Organization (UNESCO), the World Health Organization (WHO), and the World Bank.

UNAIDS, as a cosponsored programme, unites the responses to the epidemic of its ten cosponsoring organizations and supplements these efforts with special initiatives. Its purpose is to lead and assist an expansion of the international response to AIDS on all fronts. UNAIDS works with a broad range of partners – governmental and nongovernmental, business, scientific and lay – to share knowledge, skills and best practices across boundaries.

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A Nongovernmental Organization's National Response to HIV: the Work of the All-Ukrainian Network of People Living with HIV

The All-Ukrainian Network of People Living with HIV was founded in the late 1990s by people alarmed by the rapidly growing epidemic in their country, and the lack of resources and support for themselves and others affected by HIV. Since then the Network has grown to provide services throughout the country. Key strategy components are: increasing access to care and support; lobbying and advocating to protect the rights of people living with HIV; seeking to increase social acceptance of people living with HIV; and enhancing the organizational capacity of the Network. This document outlines the development of the Network and highlights lessons learnt.

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