

Harm Reduction News

Newsletter Focus

ACCESS TO HIV TREATMENT

by Jay Dobkin

AIDS is reminding us that all contagious diseases are rooted in social and economic life. Poverty, war, and famine have been intertwined throughout history with typhus, dysentery, and syphilis. In the early 20th century, long before effective drug treatment became available, tuberculosis rates began falling in the United States as living standards for the poor started to improve. Similarly, the great advances in controlling infectious diseases have derived chiefly from improvements in sanitation, nutrition, and vaccination.

Now we face an epidemic that raises unprecedented challenges. Since the spread of HIV is rooted in the most basic and intimate behaviors, prevention forces us to deal with legal, cultural, and moral

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dilemmas of enormous complexity. On a bio-medical level the challenges are also unique. As the first widespread disease caused by a retrovirus, AIDS raises extraordinary obstacles to vaccine development and effective treatment.

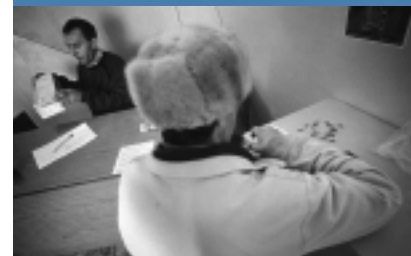
And yet AIDS also reminds us that there are basic and fundamental similarities in responding to such complex challenges: that respect for human dignity and human rights are paramount; that peers, families, and communities must be mobilized; and that the needs and wishes of patients and their communities must be reflected in developing effective responses. The AIDS epidemic in Central and Eastern Europe and the former Soviet Union (CEE/fSU) is especially challenging since it is overwhelmingly associated with a criminalized and severely stigmatized behavior: injection drug use. Effective control and treatment of HIV in this region

will require contributions from many sectors in society—perhaps most critically from the people and communities most directly affected.

In this issue of *Harm Reduction News* contributors from CEE/fSU and elsewhere elaborate on these challenges and begin to provide outlines for effective solutions. Comprehensive prevention efforts across the region—from the Balkans to the Baltic states—reflect local, regional, and international collaborations. In St. Petersburg we can see the painstaking efforts to develop access to medical care resources; in Moldova, an NGO coalition generates palliative care for AIDS patients; in Odessa, a self-help movement prepares its constituents for large-scale antiretroviral treatment. Physician experts from Poland and France describe mature programs delivering comprehensive services to injection drug users. They provide a powerful weapon to those just beginning to build such resources: a concrete response to the complaint that drug users cannot be engaged in care effectively. Support from international organizations for equitable and comprehensive treatment for HIV-infected or at-risk drug users is growing dramatically as we can see from perspectives as varied as the European AIDS Treatment Group, the U.K. Department for International Development, the Global Fund to Fight AIDS, Tuberculosis, and Malaria, and the World Health Organization. Finally, there is a reminder from South Africa that progress against AIDS is intricately bound up in the progress toward (or retreat from) open and democratic societies.

This newsletter reminds us that the struggle against AIDS among drug users within CEE/fSU presents enormous challenges. But it should also remind us that a formidable and growing array of committed individuals and groups has entered the battle.

Jay Dobkin, M.D., is the director of the AIDS Program at Columbia-Presbyterian Medical Center in New York City.



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OPEN SOCIETY INSTITUTE

Open Society Institute (New York)

Chairman
George Soros

President
Aryeh Neier

400 West 59th Street
New York, NY 10019 USA
Tel: 1.212.548.0600
Fax: 1.212.548.4679
www.soros.org

International Harm Reduction
Development Program

Director
Kasia Malinowska-Sempruch

Associate Director
Sue Simon

Program Officer
Anna Moshkova

Program Officer (Budapest)
Monica Ciupagea

Program Officer (Budapest)
Konstantin Lezhentsev

Program Coordinator
Matthew Curtis

Program Coordinator
Magdalena Sklarski

Program Coordinator
Erin Finnerty

IHRD New York:
Tel: 1.212.548.0679
Fax: 1.212.548.4617
e-mail: IHRD@sorosny.org
www.soros.org/harm-reduction

IHRD Budapest:
H-1051 Budapest,
Nador u. 11 Hungary
Tel: 361.235.6199
Fax: 361.327.3864

Editor
Rebecca Foster

Design
Michael Winikoff

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The International Harm Reduction Development program (IHRD) supports local, national, and regional initiatives in Central and Eastern Europe, the Russian Federation, and Central Asia that address drug problems through innovative measures based on the philosophy of harm reduction. Harm reduction is a pragmatic and humanistic approach to diminishing the individual and social harms associated with drug use—especially the risk of HIV infection. The approach places an emphasis on human rights, common sense, and public health. In practice, harm reduction encompasses a wide range of drug user services including needle and syringe exchange, methadone treatment, health education, medical referrals, and support services.

IHRD REDUCES DRUG RELATED HARM BY:

Providing grants and technical support to local direct service providers. IHRD supports over 180 harm reduction projects in more than 20 countries of Eastern Europe and the former Soviet Union. While all interventions are tailored to local conditions and client needs, most projects include a needle exchange component. Making clean needles available to injection drug users has proven effective as an HIV prevention strategy.

Supporting regional, population-based, and topic-specific initiatives. IHRD supports regional conferences, trainings, and projects on issues such as street kids, HIV prevention in prisons, ethnic minorities (such as Romani communities), methadone treatment, and commercial sex workers.

Promoting local and regional capacity-building. IHRD builds capacity by funding and organizing trainings, workshops, and conferences for a variety of

harm reduction stakeholders including NGO staff, government officials, policy officers, prison workers, and health care providers.

Advocating for progressive drug and HIV/AIDS policies. IHRD works to support the involvement of drug users and people living with HIV in program development and policy making; promotes human rights and public health oriented drug policies; and seeks guarantees of equal access to HIV treatment and other health care. IHRD funds community organizing efforts, legal advocacy, media and information programs, professional networks, development of best-practice guidelines, conferences, fellowship programs, and other initiatives.

IHRD is part of OSI's Network Public Health Programs and works in close cooperation with the Soros foundations network and the Drug Policy Alliance.

OSI MISSION

THE OPEN SOCIETY INSTITUTE aims to shape public policy to promote democratic governance, human rights and economic, legal and social reform. On a local level, OSI implements a range of initiatives to support the rule of law, education, public health, and independent media. At the same time, OSI works to build alliances across borders and continents on issues such as combating corruption and rights abuses. A private operating and grantmaking foundation based in New York City, OSI was created in 1993 by investor and philanthropist George Soros to support his foundations in Central and Eastern Europe and the former Soviet Union. Those foundations were established, starting in 1984, to help countries make the transition from communism. OSI has expanded the activities of the Soros foundations network to other areas of the world where the transition to democracy is of particular concern. The Soros foundations network encompasses more than 60 countries, including the United States.



DRUG USERS NEED ACCESS TO HIV DRUGS

Slava of the Moscow Harm Reduction program visits a hospital in the suburbs of Moscow. Photo © John Ranard 2004

It is unjust to judge people as likely to be noncompliant because they are drug users while overwhelming evidence proves that drug users can do as well as any other HIV-positive individual if the health care system is adapted to meet their needs.

by Mauro Guarinieri

In Central and Eastern Europe and the former Soviet Union, the vast majority of HIV-positive people are injection drug users (IDUs), but few of them have access to the antiretroviral (ARV) treatment that could save their lives. Active drug users, a widely disenfranchised and marginalized population, are often denied access to adequate health care, excluded from clinical trials for new drugs, and badly informed about the best way to manage HIV treatment—if they are lucky enough to get it.

The data is stark. In the Caucuses and Central Asia, 76.2 percent of the registered HIV cases are IDUs, and only 0.3 percent of them receive ARV. In the Baltic states of Estonia, Latvia, and Lithuania, 80.1 percent of the registered HIV cases are IDUs, of which 1 percent receives ARV. And in Belarus, Moldova, Russia, and Ukraine, 88 percent of the registered HIV cases are IDUs, but only 0.6 percent receives ARV.

The need for change is urgent. The negative attitude of many physicians about treating drug users is based on misconceptions and “common sense” rather than on medical evidence. Many are still hesitant to offer ARV treatment to active drug users for fear that drug use can lead to poor adherence and the consequent development and transmission of resistant

strains of the virus. Because of these same fears, clinical drug trials rarely include IDUs.

Studies have found, however, that drug users can adhere to a therapy regimen if it is appropriately designed. It has not been proven—only suspected—that IDUs fail to comply with treatment regimens. It is unjust to judge people as likely to be noncompliant because they are drug users while overwhelming evidence proves that drug users can do as well as any other HIV-positive individual if the health care system is adapted to meet their needs.

Further, there is little evidence to suggest that ineffective therapy leads to widespread transmission of resistant strains. To confirm this, drug companies should start studying the actual interactions between their products and common recreational drugs. In vitro pharmacokinetic experiments, case reports, and animal model studies have limited application to clinical settings. It is important to design interaction studies that accurately reflect the situation found in clinical practice.

In private, representatives of drug companies have expressed many concerns about including drug users in their trials. Clinical trials using illegal drugs, for instance, would require permission from governments that are reluctant to allow such studies for fear

of being perceived as “soft on drugs.” It would also be difficult to find a supply of pure illegal drugs since there are no approved versions. And, frankly, the pharmaceutical companies have no financial incentive to run such trials.

Drug users are members of society with full rights, including the right to the best medical treatment that is available in their countries. An HIV-positive person should never be refused treatment simply because he or she is a drug user. HIV treatment for drug users should not be contingent on their agreement to enter drug treatment programs. It is unethical to insist on abstinence as a condition of medical treatment if this is beyond the capability of the drug user.

People disagree about what should be done with the little information that exists on the interactions between illegal and prescribed drugs. Some individuals and organizations express the view that the state does not have an obligation to protect those who break the law. Others believe this to be a dangerous argument both from a human rights and public health standpoint. All citizens should be granted a right to health regardless of their lifestyle.

Mauro Guarinieri is chair of the European AIDS Treatment Group in Bologna, Italy.

THE OBSTACLES TO HIV TREATMENT FOR DRUG USERS

by Konstantin Lezhentsev

In the era of HAART (highly active antiretroviral therapy), the length and quality of life for people living with HIV/AIDS has significantly improved. Access to the life-saving therapy is limited, however, in developing countries and countries with transitional economies. In the developed world, HIV is now officially described as a chronic infectious disease. But elsewhere HIV remains a death sentence for 90 percent of people living with HIV/AIDS (PLWHA).

HIV-positive injection drug users (IDUs) are a special category of patients whose access to treatment is not limited by economic barriers. Health care providers can be unwilling to meet the needs of IDUs, and use a moralistic and stigmatizing approach influenced more by law enforcement attitudes than health care principles. When care is provided, it is often far from adequate. Health care providers seem to be in denial of the simple public health policy fact that access to medical care for HIV-positive IDUs is crucial for overcoming the epidemic and saving the lives of thousands of patients, especially in Central and Eastern Europe and the former Soviet Union (CEE/fSU) where IDUs comprise up to 90 percent of the HIV-positive population.

Recent studies in developed countries show that even with the wide availability of antiretroviral (ARV) medications only 40 percent of IDUs receive HAART. A study from Vancouver, Canada, demonstrated an increase in uptake of ARV treatment by IDUs but still 30 percent of eligible IDUs were not receiving therapy. The situation in CEE/fSU is even more alarming with less than 1 percent of HIV-positive IDUs receiving ARV treatment.

Obstacles to adequate treatment abound in all CEE/fSU countries. These challenges influence the success of any HIV/AIDS initiative, including those of the Global Fund to Fight AIDS, Tuberculosis, and Malaria, the World Bank, or the World Health Organization's Three by Five Initiative that aims to provide ARV therapy to 3 million people by the end of 2005. The principal health care challenges are as follows:

The price of ARV medicines and diagnostic equipment. The average cost of a year's course of ARV treatment is \$7,000–\$9,000 per patient. The ARV market in the region is monopolized by large pharmaceutical companies that have locked out generic, less expensive brands in the majority of countries.

A lack of national protocols that meet international standards. The majority of the countries in the region do not update their guidelines on HIV treatment to include internationally proven criteria for treatment initiation, first- and second-line drug combinations, standards for changing regimens, and laboratory monitoring. The limited treatment programs, therefore, are guided mostly by HIV care recommendations that include sub-standard regimens such as monotherapy and bitherapy. Without any standards for

first- and second-line regimens, the rational procurement of ARVs from national and local health care budgets is difficult to impossible.

Help for IDUs and those living with HIV/AIDS is often provided through a vertical and centralized infrastructure. The system of care and treatment delivery in the region is organized around AIDS centers, which were created in the beginning of the epidemic with the purpose of monitoring the epidemiological situation. The system, therefore, is isolated from other vital services, such as drug and tuberculosis treatment. The separate location of AIDS centers, with their well-known stigma, limit their effectiveness and coverage of patients.

Lack of substitution therapy treatment programs in the region. The fact that most of the countries in the former Soviet Union still cannot make substitution treatment programs available reveals the tendency to favor a punitive approach to drug use over the higher priority of slowing the HIV/AIDS epidemic. Integrated programs on HAART delivery and substitution treatment (with methadone and/or buprenorphine) have been proven to be critically important in giving IDUs access to HAART. Limited access to substitution treatment is one of the main obstacles for effective HAART delivery for up to 80 percent of PLWHA in the region.

The region's HIV/AIDS challenges are compounded by limited nongovernmental organization (NGO) involvement in care and treatment. The expertise of NGOs working on HIV/AIDS prevention among vulnerable groups (especially harm reduction NGOs) is not used adequately. Some NGOs lack the commitment, knowledge, and expertise to effectively meet the treatment needs of their clients. The recent organization of PLWHA and vulnerable groups into NGOs of their own has prompted more effective integration of NGOs into the care and treatment area.

Stigma and discrimination continue to undermine adequate responses to the HIV/AIDS crisis. Despite the fact that the epidemic has been developing in the region for the last decade, there are still cases of open discrimination of PLWHA in medical facilities. The driving force for this is mostly fear and the lack of basic knowledge among health care personnel about HIV transmission; the separation of AIDS services from the rest of the health care structure ("Go to the AIDS center, it is their business to treat you..."); and discriminatory regulations in some countries that instruct health care personnel not to deliver treatment to IDUs.



Access to HIV treatment should be measured in the number of lives that are saved and not in the number of discussions about why treatment cannot be made available.

Nogi, Volgograd, Russia. Photo © John Ranard 2004

But even after taking into account all of these health care factors, the single biggest obstacle to the effective scaling up of treatment programs remains the lack of political will to overcome the HIV/AIDS epidemic. Without political will, little can improve. Governments should secure the basic right of their citizens to health care, a right that should take priority over any competing interests, such as drug policy and international trade agreements. International expertise should be delivered to the region adequately, sustainably, and on a region-specific basis. Technical support for treatment cannot be adequately provided through random and occasional regional meetings or by sending out information packets to the ministry of health.

Additionally, community development and capacity building of PLWHA groups is needed to effectively tackle stigma and discrimination, spread treatment information to other groups, and reach out to and support patients who are usually marginalized from the health care system. Finally,

advocacy messages should be backed up by model pilot projects for treatment and care, especially in countries where the infrastructure for starting HIV treatment is weakest.

Access to HIV treatment should be measured in the number of lives that are saved and not in the number of discussions about why treatment cannot be made available. The world has heard enough sad experiences from Africa where the endless discussions about “infrastructure development and patient education” were just an attempt to hide the real reasons for not making treatment available: the international trade agreements that put profit over people’s lives and the lack of government commitment to overcoming the HIV/AIDS epidemic.

Konstantin Lezhentsev is a program officer for IHRD in Budapest, Hungary.

PROTOCOLS ON HIV CARE AND TREATMENT

MAIN PRINCIPLES FOR THE EFFECTIVE DELIVERY OF HAART TO IDUS LIVING WITH HIV/AIDS—PROTOCOLS ON HIV CARE AND TREATMENT FOR THE CIS REGION, WHO, 2004

Care must be accessible. Services should be located in places that are accessible by the client and situated in general health care facilities.

Multimodality interventions and integrated care (one-stop service). The maximum number of the most-needed services should be available at one location. Methadone treatment and other drug treatment services are a vital component of the integrated care principle.

Appropriate care should be offered. Patients need services they can utilize no matter their condition, from ARV regimens to less complicated therapeutic procedures such as prevention and treatment of opportunistic infections.

Outreach strategies. The most effective programs have formed strong links with community-based organizations and have used peer educators and counselors drawn from client groups.

POLITICS HOLDS BACK HIV TREATMENT

How could the effort to address Ukraine's disastrous ARV situation with thousands of people in need have gone so wrong?

by *Hanna Khodas and Denis Poltavets*

Ukraine has one of the fastest rates of growth of the HIV/AIDS epidemic in the world, according to the United Nations Development Program. By now about 1 percent of Ukraine's population is HIV-positive. Sexual transmission of the virus is on the rise, but still 80 percent of the transmission is by injection drug use. Over 10,000 people are in need of antiretroviral (ARV) treatment, but only 137 people have been receiving it.



Coordinator of the Ukrainian Harm Reduction Association, Ksenia Shapoval, second from left, with members of the Virtus Foundation harm reduction NGO in Dnepropetrovsk. Photo by Denis Poltavets.

Amid this crisis the Global Fund to Fight AIDS, Tuberculosis, and Malaria (GFATM) committed itself in 2003 to pouring \$92 million into a comprehensive HIV/AIDS program for Ukraine over five years. Ukraine's ministry of health was the recipient of the funds for the "Treatment, Care, and Support" component of the project. All-Ukrainian Network of People Living with HIV/AIDS and the HIV/AIDS Alliance in Ukraine were partners in preparing and realizing that component of the project.

The GFATM project was to include a substantial scale up in ARV treatment for 4,000 people living with HIV/AIDS (PLWHA) by the end of 2003. Later the number was reduced to 2,100 people. The ministry received funds from GFATM to proceed with ARV drugs for 2,100 patients. But the drugs never materialized and so PLWHA, USAID professionals, and others started to complain.

After negotiations between GFATM and the government in January 2004, GFATM suspended implementation of the project in Ukraine. The official story is that the government had not complied with the time line and proto-

col for procurement and could not prove that it had a working plan in place to fix the problems. The private and more honest explanation is that the ministry of health mismanaged the funds with questionable tender processes and under-the-table deal making with pharmaceutical companies. The ministry, essentially, was making money by holding the GFATM money.

Besides the 2,100 people who were supposed to receive ARV drugs for the first time, another casualty of this decision was the group of 137 patients who were on ARV treatment. Interrupting ARV treatment is potentially disastrous as it can cause the development of resistant strains of HIV. Luckily, a number of groups decided not to let a political scandal put dozens of ARV patients at risk. The HIV/AIDS Alliance in Ukraine, the All-Ukrainian Network, and representatives of the international community, including UNDP, World Health Organization, and Médecins Sans Frontières, launched a tough and successful campaign for non-stop treatment for the 137 patients.

Management of the Ukraine GFATM project has been handed over to the International HIV/AIDS Alliance in hopes that the project can move forward more smoothly. The introduction of new drugs in any country is complex, so even under the best of circumstances it will be several months before new patients see ARV drugs.

How could the effort to address Ukraine's disastrous ARV situation with thousands of people in need have gone so wrong? The ministry of health demonstrated a lack of political will, a lack of professionalism, and a lack of transparency and cooperation. Instead of seeking support from as many organizations as possible, it tried to do things almost secretly and according to its own procedures—which were already outdated 14 years ago when the Soviet Union collapsed.

While GFATM stood on principle by withdrawing the funding, it made a mistake in channeling it through the government in the first place. A little research into the HIV/AIDS care situation in Ukraine might have led the GFATM to the International HIV/AIDS Alliance at the outset.

Perhaps Ukraine's experience will stand as a cautionary tale for other countries receiving GFATM funds: before you start a project, you should reject outmoded forms of management and consider cooperating with all possible partners.

Hanna Khodas works for the All-Ukrainian Network of PLWHAs in Kiev, Ukraine. Denis Poltavets is the IHRD coordinator for Ukraine. Anna Moshkova and Konstantin Lezhentsev also contributed to this article.

SELF-HELP FOR PEOPLE WITH HIV

by Artur Ovsepyan

The Odessa region of Ukraine now has more than 9,000 people living with HIV/AIDS (PLWHA), making it the worst instance of the epidemic in the country. Most of the PLWHA—highly stigmatized and often referred to as “the plague of the 21st century”—are injection drug users who have difficulty receiving treatment in any medical institution other than an HIV/AIDS clinic.

The nongovernmental organization Life+, which has been working to improve the quality of life for PLWHA in Ukraine since 1999, set up a PLWHA self-help group in 2001. I was one of the first members. At first, the group visited patients only at the AIDS center, and then we noticed that some people could not come to our meetings. We wanted to reach out to more people but we weren't sure what to do or how to do it. We realized, however, that if we wanted change we were going to have to do it ourselves.

That same year, Life+, with the support of International HIV/AIDS Alliance in Ukraine, assessed the care and support situation for PLWHA. We found that PLWHA had almost no information about HIV treatment, reproductive health, or living with HIV. We taught ourselves about various systems of home-based care for people living in terminal stages of AIDS, and then created our own model.

Memories of our first activities fill me with emotion. It was the first pilot project ever in Ukraine started and run by us—HIV-positive people. The project, Non-Medical Home-Based Care for People Living with HIV/AIDS, aims to provide psychological, legal, and non-medical care and support to PLWHA in Odessa. More than 1,000 people in Odessa need home-based care.

As Ukraine's response to the HIV epidemic has changed over the years, so have our activities. When antiretroviral treatment became more widely available, we developed trainings for adherence with our partner Médecins Sans Frontières. In the home setting our group informs clients about the importance of adhering to their physician's recommendations; helps establish habits for drug ingestion; and

provides information about alternative approaches to health care, such as juice therapy and the influence one's psychological state can have on the disease. By far the majority of the services we provide are counseling and psychological and informational consultation.

between social workers and clients; psychological burn-out of social workers; lack of cooperation from the government; and fundraising. Yet we are taking steps to address these issues and increase the number of our clients as well as our partner organizations.



Social worker making a home visit to a client in Odessa. Photo courtesy of Life+.

The first pilot project ever in Ukraine started and run by us—
HIV-positive people.

The project's one staff member and 11 volunteers use a variety of means to spread information to clients, such as posters, information sheets, and personal contacts. Over 80 percent of our clients are injection drug users who need harm reduction services. Some of our clients have recovered from drug use, as have some of the social workers. I have been in remission for three years. All of the people in our project understand the needs of our clients from personal experience. We have 52 people officially registered as clients and each month we see about 50–70 new clients.

Of course, we have run into difficulties, such as establishing a trusting relationship between clients and social

Despite the challenges, our steady progress gives us optimism about the future for treatment, care, and support for PLWHA in Odessa. Ukraine's increased funding for HIV/AIDS projects through the Global Fund to Fight AIDS, Tuberculosis, and Malaria means that the services provided by our project will increase in value and need every month. We must now look toward increasing the volume of the project, our outreach, and the spectrum of services we provide to our clients.

Artur Ovsepyan is the project manager of Non-Medical Home Based Care for People Living with HIV/AIDS in Odessa, Ukraine.

AIDS AND HARM REDUCTION ACTIVISTS JOIN FORCES

With the need to spend so much energy on survival, it is hard to put advocacy issues high on the agenda, but groups are trying, especially with the help of growing harm reduction networks and coalitions.



Protesters at the interministerial conference on HIV/AIDS in Dublin in February 2004. Photo courtesy of CEEHRN.

by Raminta Stuikyte

In Central and Eastern Europe and the former Soviet Union (CEE/fSU), drug users are often denied HIV treatment because “to get treatment you should prove that you are useful to society,” as one client at an AIDS clinic in St. Petersburg was told. In CEE/fSU, 8 out of every 10 HIV-positive people contract infection through dirty needles yet only one-fifth of those receive any antiretroviral (ARV) treatment.

Lessons from Brazil, France, Poland, Spain, the United States, and other countries have shown clearly that HIV care for injection drug users (IDUs) is realistic and effective. The world’s four million HIV-positive IDUs need coordinated drug and HIV treatment, including substitution treatment.

In February, more than 200 individuals and organizations representing IDUs and people with HIV/AIDS around the globe, including the Central and Eastern European Harm Reduction Network, European AIDS Treatment Group, Gay Men’s Health Crisis, IHRD, and the Thai Drug Users Network, took coordinated action to press the World Health Organization (WHO) for full, equal, and universal access to ARV treatment for IDUs.

In a letter, the activists called on Jong-Wook Lee, M.D., director general of WHO, to ensure the inclusion of IDUs in the scale-up of ARV therapy in its plan to treat three million people by 2005—the so-called Three by Five Initiative. They also called on WHO to address the social, cultural, and medical barriers that deprive IDUs of access to HIV treatment; recommend that governments remove repressive laws and policies against IDUs and make health care principles a

priority over law enforcement; include methadone hydrochloride on the List of Essential Drugs as part of the AIDS kit; distribute information on potential interactions between ARV and street drugs; and ensure the equal involvement of active drug users in clinical trials of new ARV therapies. In rapid response to the letter, WHO has started the process of proposing methadone for the List of Essential Drugs.

Harm reduction and HIV treatment activists have been building their capacity for the last year to arrive at this successful point. At March 2003’s International AIDS Treatment Preparedness meeting in Cape Town, several AIDS treatment advocates pointed out the need for better and stronger links between HIV/AIDS advocacy, harm reduction, and drug users’ groups. A few months later in Minsk, CEE/fSU’s community activists were strengthened into a loose network, and a core group of 20 advocacy projects in 11 countries received funding for their work. There have also been other occasions for activists to express their point of view, such as Europe and Central Asia’s first interministerial conference on HIV/AIDS in Dublin.

Meanwhile, international agencies, such as WHO, are increasingly seeking the involvement of community-based organizations (CBOs). The Global Fund to Fight AIDS, Tuberculosis, and Malaria, for instance, requires that CBOs be included in the country coordinating mechanisms that are responsible for planning and overseeing grants from the Global Fund.

But while there are many positive intentions declared and good meetings taking place, it is up to the CBOs to speak out, advocate, and make themselves heard. Community activism in CEE/fSU is young (as young, in fact, as the HIV epidemic), services are limited, and the political-social climate is often antagonistic. With the need to spend so much energy on survival, it is hard to put advocacy issues high on the agenda, but groups are trying, especially with the help of growing harm reduction networks and coalitions.

An international coalition of activists, such as the signatories to the WHO letter, can serve an important supplementary role to CBOs. Some of the next issues the group plans to attack are the prevention of restrictive rescheduling of buprenorphine; improved work with regional and international media; and building a Harm Reduction Knowledge Hub in CEE/fSU.

Raminta Stuikyte is the director of the secretariat of the Central and Eastern European Harm Reduction Network in Vilnius, Lithuania.



ONE MAN TRYING TO GET MEDICAL CARE

Astrakhan Syringe Exchange. Photo © John Ranard 2004

by Vladimir Musatov

I met Vadim in the spring of 2000 in the mobile harm reduction bus for drug users in St. Petersburg that the non-governmental organization (NGO) Humanitarian Action has been running for the last six years. At the time I was working as a medical coordinator for the bus, which conducts HIV prevention activities for injection drug users (IDUs). On the bus, people can see a doctor, get tested for HIV, hepatitis C, and syphilis; talk about their problems with the project's psychologist and social workers; and receive condoms, distilled water, and clean needles.

Vadim received the results of his HIV test. He was positive. The surgery was called off and Vadim was released from the hospital without any clear guidelines or recommendations for the future.

Vadim stood out among the other clients. He always emphasized the importance of the bus project to other drug users. That was the year of “shock” when HIV infection came to our city. Now we think we know what people living with HIV/AIDS want or need, but four years ago we had no idea.

In the summer of 2000, Vadim fell and broke both of his shins. At the trauma department of the local city hospital the doctors set a date for Vadim's surgery. But then Vadim received the results of his HIV test. He was positive. The surgery was called off and Vadim was released from the

hospital without any clear guidelines or recommendations for the future. It was shocking for all of us at Humanitarian Action. We found an orthopedist who suggested treatment without surgery in the form of a “boot” made out of light plastic that encased his leg up to the hip. After much painful work, Vadim celebrated a huge and important victory when he learned to walk on his own again.

After he recovered from his injuries, Vadim had a relapse and we checked him into an infectious disease hospital for detoxification in autumn 2001. After the treatment, we arranged for him to go to a rehabilitation center in the Pskov region. But Vadim did not like the country life, his legs hurt, and he returned to St. Petersburg. In early 2002, Vadim and his wife Yulia started to visit the bus regularly again, always bringing homemade cookies with them.

By the end of 2002, Vadim was in remission, able to help his relatives, and even going on business trips to Moscow. But then he developed problems with his eyes and Vadim now had to negotiate eye surgery. By this time the city had decreed that people living with HIV/AIDS (PLWHA) must have access to medical care. Unfortunately, gaining access to health care was still difficult for Vadim. After a couple of doctors refused to treat Vadim, we finally checked him into an infectious disease hospital to assess the possibility of such a surgery from the infectious diseases point of view—he was fine for the surgery. We then found an understanding eye doctor. The surgery went well. As Vadim said, there were “no beds behind the drapes, no cups and plates marked with red, and none of the other things an HIV-positive person experiences when in a regular hospital.”

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DEMOCRACY HELPS HIV/AIDS ADVOCACY



A Treatment Action Campaign march in South Africa. Photo by Faizel Slamang, courtesy of TAC.

by Nathan Geffen

The HIV/AIDS epidemic raises a whole range of political concerns, from women's rights and educational standards to international trade laws and the gap between rich and poor. HIV/AIDS and governance is a crucial issue in its own right. The roles of democracy, openness, and respect for human rights in alleviating the epidemic are important for emerging democracies to understand, and South Africa's experience provides some useful lessons.

South Africa has a catastrophic HIV/AIDS epidemic. Over 5 million people have HIV and a recent Medical Research Council report found that the country's death rate increased by a massive 68 percent from 1998 to 2003, much of it only explicable by the wors-

ening epidemic. At least 600 South Africans die of AIDS every day. In wealthy countries, most people who develop AIDS have access to life-saving antiretroviral (ARV) treatment, which, for the vast majority of people, restores health and hope. Like most developing countries—with some notable exceptions such as Brazil—only a small minority of people who need ARV and other AIDS medicines have access to them in South Africa. It was against this background that the Treatment Action Campaign (TAC) was formed in 1998 to advocate for treatment, better prevention efforts, and the removal of stigma.

TAC has worked to get the South African government to implement a treatment plan. It has also campaigned

against overpricing by pharmaceutical companies and unfair trade pressure on the South African government by the United States and European Union. After five years of effort, TAC and other HIV/AIDS advocates are now witnessing real successes. HIV/AIDS medicine prices have fallen dramatically and in the first few months of 2004 the government began implementing a comprehensive treatment program. Nearly 3,000 people now receive treatment in the public health sector that serves predominantly poor people. Although a few hundred thousand need treatment immediately, the program is expanding.

TAC's struggle to get the South African government to implement a

treatment plan has received much international media coverage, partly due to the unscientific views on HIV/AIDS held by President Mbeki and his minister of health Manto Tshabalala-Msimang. Both politicians have said that they doubt that HIV causes AIDS or that there is a large epidemic in South Africa. They say ARV medicines are not effective (or safe) and that HIV tests mean nothing. Lately, the minister of health has promoted nutritional home remedies such as garlic and olive oil as substitutes for ARVs. If the president had responded rationally to the HIV/AIDS epidemic, implementation of the treatment plan might have begun three years ago. Furthermore, the immense public confusion about the disease, caused primarily by these leaders' frequently bizarre statements, would not exist.

The South African AIDS struggle has exposed both the strengths and weaknesses of South Africa's democracy. The strengths have ensured that treatment has finally come, but the more fragile aspects have allowed the president and minister of health to stifle internal dissent on HIV/AIDS within the ruling African National Congress (ANC).

Highlighting the strength of South Africa's democracy is the simple fact that an organization such as TAC could not have operated under apartheid, much less made headway on its goals. South Africa's 10-year-old constitutional democracy has given us the right to free speech and protest. The free media has taken a moral stand on HIV/AIDS and, in general, been critical of the president and minister of health on this issue. All this was unimaginable before the end of apartheid.

In March and April 2003, TAC launched a peaceful civil disobedience campaign to compel the government to adopt a treatment plan. The campaign involved willfully breaking the law (primarily through sit-ins). Before the transition to democracy, the police would have been unrelentingly brutal. But for the most part they acted with restraint and professionalism. The change to democracy has been accompanied by a welcome change in police culture.

South Africa's Constitution, renowned for being one of the world's most progressive, guarantees the right to life and dignity, and compels the government to make health care accessible within its available resources. TAC used these provisions in a high-profile court case that compelled the government to implement a program to reduce the transmission of HIV from pregnant women to their newborns. TAC has used the threat of Constitutional Court action to extract concessions on a treatment plan from the minister of health. The constitution also contains provisions on administrative justice, which

Highlighting the strength of South Africa's democracy is the simple fact that the Treatment Action Campaign could not have operated under apartheid, much less made headway on its goals.

allow the public to gain access to information. TAC has used the Access to Information Act to obtain information in the public interest that is essential to our work and which the minister of health has attempted to block from publication.

The long history of struggle in South Africa under apartheid left in its wake a large segment of society that is well versed in political struggle and that embraced TAC's objectives and methods. Since most of TAC's members are also ANC supporters, we have tried to find ways to ally ourselves with the government on HIV-related issues rather than remain in perpetual conflict. For example, TAC supported the government in a court battle against the pharmaceutical industry to reduce medicine prices. Our intervention is credited with causing the capitulation of the industry.

South Africa, however, has many autocratic legacies to overcome. Journalists frequently ask us why the president holds the views he does on HIV/AIDS. More important: How is the president able to impose his

irrational views on the country? In part it is the immaturity of South Africa's political institutions and its watchdogs, such as the Human Rights Commission. Another problem is South Africa's list-based voting system, which makes it difficult for members of parliament from the ruling party to dissent from the president. There is little moral pressure from opposition parties, which are tainted by their past connections with apartheid or align themselves with big business, to change HIV/AIDS policy. Finally, during its military campaign against apartheid, the ANC required a unified front and highly centralized policy making. In spite of the democratic structures it has established, the ANC still does not easily tolerate internal dissent.

One of the worst long-term legacies of apartheid is the appalling education system. The failure to teach science appropriately, especially to black students, means that most citizens are unequipped to deal with the confusion created by the president's unscientific views on HIV/AIDS. TAC runs an extensive education program on HIV/AIDS aimed at youth and adults that has helped some communities improve their knowledge of the disease. But unless this mammoth educational task is embraced by the government, many South Africans will remain confused about HIV/AIDS.

Despite these shortcomings, South Africa's democracy has proven sufficiently robust for TAC to make progress toward achieving its objectives. South Africa's neighbor Zimbabwe, by contrast, has a health system in ruins and a population that endures hunger and AIDS with no respite in sight. Its tyrannical president, Robert Mugabe, holds relatively rational views on HIV/AIDS but has no respect for democracy. A functioning constitutional democracy has been important for addressing the health problems of the poor, especially when leaders, such as president Mbeki, embrace nonsense over science.

Nathan Geffen is the national manager of Treatment Action Campaign in Cape Town, South Africa.

METHADONE AND HIV TREATMENT

Providing HAART to active injection drug users who are not on methadone is rare, but not impossible.



Methadone patients in Silesia, Poland. Photo by Marek Beniowski.

by Marek Beniowski

Injection drug users are difficult to serve because of the nature of their unstable, underground lives. Nonetheless, it is important to try to reach and treat them because drug injection is closely associated with social deprivation and multiple health problems, such as hepatitis B and C, tuberculosis, and endocarditis. For many drug users the most serious problems arise when they get HIV.

Both antiretroviral drugs and methadone give hope for stabilizing and normalizing drug users' lives. Methadone is a substitution therapy that allows drug users to quit using without going through painful withdrawal. The so-called era of highly active antiretroviral treatment (HAART), which extends the lives of HIV-infected people, began in the mid-1990s.

Attitudes toward HIV-infected drug using people are improving in many countries in Central and Eastern Europe and the former Soviet Union (CEE/fSU). A couple of years ago it was difficult to even talk about caring for such patients. The harm reduction approach has created a better understanding that the health and well-being of drug users is important.

Yet the services provided—including harm reduction, methadone, and HAART—are still often inadequate.

This is true not only in CEE/fSU, but also in places like Germany where an HIV-infected person who wants to get methadone must first be infected with hepatitis C or another chronic virus.

Everywhere the problem seems to be one of scale. At the Center for AIDS Diagnostics and Therapy, in the district of Silesia, Poland, for example, there are 130 patients in methadone treatment, 80 percent of whom are HIV-infected. Almost 40 percent of the patients have some kind of job, and 30 percent are treated with HAART, which is free in Poland if a person is insured. This is all wonderful news for the 130 patients at the center and the roughly 570 others on methadone in Poland, but there are about 40,000 others in need of treatment. Poland has 12 program sites and the expectation of getting four new methadone programs over the last four years has not yet worked out. The programs that are working have waiting lists. In the Silesia center the wait ranges from six months to a year and a half.

Generally, we do not see many conflicts between HAART and methadone treatment, although sometimes, when we have to increase the methadone dose by 20-30 milligrams, we see a problem with the HAART drug efavirenz, but certainly not enough to justify withholding one or the other treatment. Providing HAART to active injection drug users who are not on methadone is rare, but not impossible. At the center we only have four patients on heroin out of the 200 being treated with HAART (the others are on methadone or not drug users.) To be a drug user in Poland is difficult—even with methadone or HAART—and the country's system of care makes it unlikely that this will change. So there are still obstacles when we try to reduce the vulnerability of patients, especially when it comes to providing HAART to drug users.

Why and how people decide to engage in dangerous behaviors is difficult for most of us to comprehend. But we must understand it and respond with effective education and prevention measures. Strategies to contain and reduce infectious diseases related to drug injection must embrace ethical, clinical, legal, and human rights issues, as well as political and public concerns. If we do not work to reduce harm, we will only end up maximizing it.

Marek Beniowski is the director of the Center for AIDS Diagnostics and and Therapy, in the district of Silesia, Poland.

A FRENCH MODEL OF HIV CARE FOR IDUS

Harm Reduction News (HRN) interviewed Michel Kazatchkine who runs a large clinical immunology department at the Hôpital Européen Georges Pompidou in Paris, which treats about 1,600 HIV-infected patients, 30 percent of whom are injection drug users (IDUs). Kazatchkine is also the director of the French National Agency for AIDS Research (ANRS), chair of the Technical Review Panel for the Global Fund to Fight AIDS, Tuberculosis, and Malaria, and, as a medical doctor, professor, and author, holds numerous other positions in the HIV/AIDS field.

HRN What should be the role of harm reduction projects in delivering HIV care to IDUs living with HIV/AIDS?

MK In our experience in France, harm reduction projects do not have the infrastructure, human resources, or continuity to deliver and monitor antiretroviral (ARV) treatment to IDUs living with HIV/AIDS. Harm reduction centers are key, however, in providing care in a broader sense, including helping to orient patients to the appropriate health care structures when needed and providing access to HIV testing and counseling. That is why it is essential that physicians be a part of harm reduction teams.

HRN What are the main obstacles to access to ARV treatment for IDUs in France?

MK There are several obstacles. First, IDUs have insufficient information about the treatment of HIV and co-morbidities such as viral hepatitis. Second, the discriminatory attitude of some health professionals has contributed to unequal access to ARV treatment for IDUs. The situation has improved, however, with the expansion of the public care system for IDUs, including syringe exchange programs and substitution treatment centers. Studies show that the level of adherence to treatment among IDUs undergoing substitution therapy is no different or even higher than that observed in other patients.

HRN Can you describe the role of the “integrated care with substitution therapy” approach at Hôpital Européen Georges Pompidou and in other programs targeted to HIV care for IDUs?

MK This means integrating care of IDUs within an HIV program rather than integrating HIV care into an IDU program. The main elements of the program are to have a physician who is trained in the care of IDUs permanently on call to solve crises that may occur in any department of the hospital; accommodating the needs of IDUs within HIV/AIDS health care structures by, for instance, leaving outpatient clinics open in the late evening; having physicians who are capable of prescribing substitution therapy work with HIV/AIDS specialists that work in the outpatient clinic; trying, as much as possible, to have every needed specialist available in the same place, i.e., a dermatologist, psychologist, nurse specializing in adherence support, etc.;



Michel Kazatchkine.

having one physician on the team that is specialized in co-infections with viral hepatitis; and holding regular meetings between harm reduction teams, the physicians, and the nurses to discuss the obstacles encountered in the care of IDUs.

Even if this degree of integration is not possible, from our experience it is essential that professionals from harm reduction programs and from the HIV/AIDS-specialized hospitals at least take the time to listen to and understand the needs of IDUs.

HRN Please tell us your experience organizing the evening clinic at the hospital.

MK We opened the evening clinic in 1988, at a time of high discrimination against people with HIV/AIDS. The aim was to provide asymptomatic patients the opportunity to see their physician without disrupting their normal schedule (and thus without having to justify their absence from work for daytime appointments.) The price the patients had to pay for the convenience was that everyone in the waiting room would know that everyone else there was HIV-infected. And also, somehow, in the frenetic activity of the hospital during the day, the drama and trauma of being seropositive is more “diluted” than in the silence and isolation of the evening clinic. Even so, the evening clinic has grown. From 6 p.m. to about 11 p.m., four or five physicians work with one ophthalmologist, one psychologist, and one dermatologist. There is also

continued on the next page

a nurse, a secretary, and two to three volunteers. These volunteers from the nongovernmental organization AIDES have been present since the very beginning of the evening clinic and are most helpful in supporting the patients. The professionals do not receive extra pay for their work in the evening clinic. It is understood and accepted as a normal commitment of working in an HIV department.

HRN Based on your experience, what is your position on adherence to ARV therapy in IDUs?

MK The evidence is that adherence is no more a problem in IDUs than in other categories of patients, at least in IDUs who are undergoing substitution therapy. Thus, there is no reason to use adherence as an *a priori* alibi to reject IDUs from care for HIV/AIDS, as it is in a number of countries in Eastern Europe and South East Asia. The issues of adherence and support are merely issues of personalizing health care and adapting it to the needs of individuals rather than to groups of individuals.

HRN What can people concerned with HIV treatment for IDUs in Central and Eastern Europe and the former Soviet Union (CEE/fSU) learn from the French experience?

MK The most important short-term challenges in CEE/fSU are:

- ▶ Establishing outreach infrastructures to which IDUs could come with full confidence, where they would receive medical attention, substitution therapy, and appropriate orientation as well as attention to their social problems.
- ▶ Identifying among the healthcare structures that will deliver ARV treatment those physicians and nurses who are willing to be trained in the care of IDUs.
- ▶ Promoting tolerance and fighting stigma in the general population.
- ▶ Setting up one or two pilot programs that include every stage, from the street to the specialized HIV/AIDS structure in a hospital, and publicizing the successes.



Photo © John Ranard 2004

Vadim was hospitalized in the spring of 2003 with skin candidosis and erysipilatus inflammation of the lower legs—all conditions of worsening HIV. Then he was diagnosed with tuberculosis. His CD4 count, which indicates the status of one's immune system, was 350 cells—for a healthy adult the count is usually between 500 and 1,500. He spent three months in the Botkin Hospital and over six months in the tuberculosis ward of a local hospital. His CD4 cell count decreased to 250. By the end of 2003, Vadim was suffering from a generalized bacterial vessel infection, coupled with severe weight loss and anemia.

According to his clinical and laboratory tests in January 2004, Vadim was supposed to have combined antiretroviral (ARV) treatment. Thanks to the PLWHA community in

Moscow and our colleagues from a clinic in Berlin, we treated Vadim with comibivir and efavirenz. We are currently trying to get the full ARV treatment course for Vadim. Médecins du Monde and Jay Dobkin, a medical doctor from New York, helped secure enough therapy for several months. After that we plan to ask for funding from the city health budget.

Three months into the treatment, I witnessed the therapy's positive results. My feelings about Vadim's progress were probably similar to those of the doctors who observed the effects from the first penicillin trials in patients with pneumonia. He soon recovered from the anemia and candida in his mouth and we were eventually able to transfer him to outpatient treatment. Today, Vadim is stronger, has gained back some weight, and he and Yulia are expecting their first child.

What has changed in our understanding of HIV over the last four years since Vadim was refused surgery for his broken legs? Medical professionals now realize the importance of uniting their efforts with NGOs, such as Humanitarian Action, and using their experience and potential to establish links between doctors and patients, as well as ensuring that NGOs assist the patients with medical and social support. What has not changed is that the point where medical institutions and people who use drugs meet is harm reduction programs. Vadim could not have been helped at all without the participation of Humanitarian Action. Whether run by the government or NGOs, harm reduction programs continue to play a crucial role in the health of drug users.

Vladimir Musatov is vice director of Botkin Hospital and medical coordinator of Humanitarian Action Foundation's treatment initiative in St. Petersburg, Russia.

LAUNCHING A COMPREHENSIVE HIV PREVENTION INITIATIVE

by Sue Simon

According to official statistics, between 1984 and 2002 there were 1,767 cases of HIV infection reported in Serbia and 53 in Montenegro. Due to the deficiency of routine data on the prevalence of HIV, especially among vulnerable populations, the true numbers are thought to be at least 10 times higher.

While these seroprevalence rates may seem low in comparison to other countries in the region, many factors put Serbia and Montenegro at risk of a significantly expanded HIV epidemic. These include a severely depressed economy (widespread unemployment and expanding poverty), a highly mobile population due to years of conflict (more than 600,000 refugees and internally displaced persons), and government instability (leading to reduced social welfare and health care services).

Research has shown that windows of opportunity to stop, slow, or even stabilize the HIV epidemic in countries with low prevalence rates are small. Fortunately, the U.K. Department for International Development has provided \$2.3 million for an evidence-based HIV prevention program targeting vulnerable populations in Serbia and Montenegro. Launched in February 2003 by Imperial College and IHRD in collaboration with the Republican AIDS Commissions (RACs) of Serbia and Montenegro and the United Nations Development Program (UNDP), it is hoped that the HIV Prevention among Vulnerable Populations Initiative (HPVPI) will serve as a model for effective HIV prevention strategies in South Eastern Europe.

“There has been a marked absence of HIV prevention services for vulnerable populations in the region,” said Tim Rhodes, PhD, a director of the Centre for Research on Drugs and Health Behaviour at Imperial College. “With HPVPI we hope to redress this imbalance by developing pragmatic and proven-to-be-effective HIV preventions, such as syringe exchange and outreach, for injection drug users, sex workers, men who have sex with men, and other at-risk groups. We urgently need to develop such interventions to maintain low levels of HIV prevalence.”

During the first phase of HPVPI, a broad assessment was done of HIV needs

and priorities in Serbia and Montenegro. More than 100 consultations were held with government officials, members of the RACs, people living with HIV/AIDS, and representatives of groups with potential involvement in HIV prevention efforts targeting vulnerable populations. Out of these myriad discussions the implementation phase of HPVPI was designed with activities slated to begin in May 2004.

HPVPI will encourage sustainability by combining support for 12 HIV prevention projects with capacity building, establishment of a network, advocacy, and evaluation. The HPVPI Secretariat, housed within UNDP, will collaborate closely with Global Fund mechanisms, government ministries, the RACs, the NGO sector, and international partners to address the needs of vulnerable populations in urban and rural areas. Moreover, the initiative will encourage an evidence-based approach by integrating strong research and monitoring efforts from the outset.

“We are enthusiastic about HPVPI and look forward to close collaboration,” said Radomir Buric, a senior program officer at UNDP. “HIV infection is a big threat among vulnerable populations in Serbia and Montenegro. There have not been enough resources dedicated to prevention, treatment, or care, and the level of stigma associated with vulnerable groups has been a barrier to good public health practices. U.N. agencies are dedicated to fighting HIV and I am confident that working together we will have great success.”

Punitive drug laws and policing as well as a dearth of health and social welfare services for vulnerable populations contribute to public health problems and depriving individuals of their basic human rights. Countries that do not have a strong foundation of HIV/AIDS prevention, treatment, and care services have to work harder to develop public policies to address these problems. HPVPI should help in this process and provide replicable models for South Eastern Europe and beyond.

Sue Simon is the associate director of IHRD in New York City.

The HIV Prevention Among Vulnerable Populations Initiative (HPVPI) in Serbia and Montenegro was designed with the aid of a broad range of stakeholders, ensuring that its methodology and interventions will be responsive to the needs of different populations and local environments. Unique among HIV prevention efforts for its comprehensiveness, HPVPI's components encompass:

Supporting HIV strategies for prevention, treatment, and care for vulnerable populations. HPVPI will collaborate with civil society, international agencies, the Republican AIDS Commissions and relevant government ministries of Serbia and Montenegro to develop coordinated state HIV interventions and policies.

Developing evidence-based HIV prevention demonstration projects for vulnerable populations. Vulnerable groups have been identified as priorities by virtue of patterns of risk behavior; marginalization and/or stigmatization; and historic or current lack of access to medical and social care. HPVPI will support projects prioritizing direct service provision, community organizing, and policy/advocacy work.

Strengthening the capacity of HIV prevention projects and advocating for a more supportive policy environment. Capacity building seeks to foster skills and experience through hands-on technical assistance, training, and study tours with local, regional, and international experts.

Transferring HIV prevention expertise and capacity within Serbia and Montenegro and South Eastern Europe. HPVPI will support the creation of the HIV Prevention in Serbia and Montenegro Network (HPSMN), which will be comprised of HPVPI projects, projects receiving Global Fund support, and all other interested stakeholders.

Developing an evidence-base of HIV risk behavior and intervention among vulnerable populations. HPVPI will create close partnerships with public health and research institutions to provide training and support for monitoring, evaluation, and research; epidemiological and qualitative research; estimates of intervention coverage; and dissemination of empirical evidence.



Sex workers in parking lot, Tolyati, Russia. Photo © John Ranard 2004

ARE SEX WORKERS EQUAL?

by Laura Selakova

When she was 18, Agne had to leave the orphanage in Latvia where she was raised. The state provided her with an apartment, and a social worker helped her to find the only job she was qualified for as a poorly-paid cleaner. Someone she met took advantage of her naiveté and told her she would get a lot of money for selling her apartment. After she sold it she had no apartment and little money, so she started to spend nights with friends or on the street. When her friends suggested she try sex work, she did. Three years later, at 21, Agne still hopes to find a “real” job and start a “normal” life. She also hopes that she will have enough strength to refrain from the drug use that is common among two-thirds of Latvia’s sex workers.

According to the laws in Latvia, where sex work is legal, all human beings, regardless of their race, sex, religion, or any other distinction, are equal before the law and the courts. The state guarantees that it will protect the human rights of sex workers. But sex workers who are not legally discriminated against are subjected to other, subtler but equally fierce forms of discrimination.

The women who choose sex work tend to come from disadvantaged families or orphanages, like Agne. They do not have the necessary life

skills to get a job that will pay them enough to get an education or raise their children. Latvia has had one of the fastest economic growth rates in Europe over the last few years, but women still make up 58 percent of the unemployed.

The state in some cases guarantees social assistance, but the amount is less than the minimum living wage. Even if it were sufficient to live on, in

Sex work should not be a reason for withholding HIV treatment.

order to obtain assistance, sex workers must participate in rehabilitation and job training programs that very often lead to low-paying jobs that can’t match the income of sex work. The state should have a special social assistance program for sex workers, but such a program is at least five years away, since they are a low political priority.

Sex workers also experience barriers and frustration when they try to get health care. More than 13 percent of Latvia’s sex workers are HIV-positive. By law, the state is supposed to provide free antiretroviral (ARV) treatment to everyone who is HIV-positive. But the

state’s financial resources are so limited that only about 100 HIV-positive or AIDS patients actually receive treatment. As of May 2004, Latvia had 2,836 registered cases of HIV, but the real number is thought to be three times as high. Sex workers must carry a “health card” and keep it updated by having monthly medical examinations. The police regularly monitor sex workers in the places where they work and give them fines when they violate such regulations.

A sex worker is unlikely to be accepted for ARV therapy because medical professionals worry about clients who have a chaotic lifestyle and the chance that their irregular use of ARV drugs could develop resistance in the virus. Sex work should not be a reason for withholding HIV treatment. Sex workers are able to access harm reduction and HIV/AIDS services at 10 new HIV counselling centers throughout Latvia. (See article on next page.)

While Latvian women engaged in sex work appear to be equal with other citizens before the law, economics, public policies, and social attitudes continue to make it difficult for them to get the help they need.

Laura Selakova is a chief specialist-epidemiologist at the AIDS Prevention Center in Riga, Latvia.

COLLABORATING TO PREVENT HIV INFECTION

After only two years the centers have done much to monitor and prevent the spread of HIV.



Zaza Tsereteli, left, and Inga Upmace, deputy director of Latvian National AIDS Center, right, at the LTSC in Riga. Photo by Sue Simon.

by Zaza Tsereteli

The HIV epidemic is spreading in the Baltic Sea area at one of the fastest rates in the world. In Russia, Latvia, Estonia, and most recently Lithuania, the increase has been particularly dramatic. In Latvia, for instance, the cumulative number of HIV diagnoses increased from 88 in 1997 to 2,717 in 2003. The driving force behind the epidemic has been infections among injection drug users (IDUs), who make up as much as 1 percent of the adult population in some of the countries. Sexually transmitted infections are also at a high level in the region, increasing the risk of the sexual spread of HIV.

Medical treatment for HIV/AIDS improved decisively in the mid-1990s when it was discovered that long-term treatment results could be achieved by using at least three HIV drugs simultaneously. This method became known as HAART (highly active antiretroviral therapy). Improving access to HAART in Baltic countries presents difficult

challenges, including access to and funding for HIV/AIDS-related drugs; strengthening the roles of nongovernmental organizations and communities in service delivery; improving the system of early diagnosis and treatment services; and strengthening social support services.

Officially, there is universal access to antiretroviral (ARV) treatment in the Baltic countries, which have registered and made available most of the ARV drugs. In early 2004, 167 patients were receiving treatment at the Infectious Diseases Center in Latvia, for instance, 40 percent of whom were IDUs. In Estonia, 68 patients were on ARV treatment, and in Lithuania, only 28 patients. However, the high cost of the drugs is problematic, especially for IDUs who rarely have health insurance.

More than anyone else, IDUs need access to a range of services, from ARV treatment to counseling and social support, but the stigma they experience is so severe that it prevents them from even attempting to access these services. In 2002, the Council of Baltic Sea States set up the Task Force on Communicable Disease Control in the Baltic Sea Region, with the aim of reducing the risk and burden of communicable diseases, including prevention of infections related to drug injection.

The Task Force helped to establish low threshold support centers (LTSCs) in the Baltic countries, to address prevention and care for vulnerable groups such as IDUs and sex workers. The Task Force worked to cultivate a real sense of ownership at the centers through the transfer of knowledge and

technology, and the development of a common understanding of problems and solutions.

The LTSCs, 10 of which have been set up in Latvia, for instance, serve anyone in need—no exclusions, no conditions. Clients can find needle and syringe exchange, health advice, and HIV testing and counseling, although ARV treatment is unavailable. Some centers provide HIV-positive drug users with meals and washing facilities. The hope is that the physical environment of the center, along with the tools for change, will empower individuals to take charge of their lives and understand treatment options. Clients have started peer-to-peer counseling in self-help groups.

The Task Force is planning to increase the number of centers across Latvia and the other Baltic countries where the same models have been introduced. After only two years the centers have done much to monitor and prevent the spread of HIV.

In March 2004, the Task Force issued a document on the impact of ARV drugs on HIV/AIDS policy in the Baltic region that underlined again that treatment should be made available to all of those who are infected with HIV, and preferably that treatment for drug users and their infections should be provided as integrated medical care.

Zaza Tsereteli is the international technical adviser on HIV/AIDS/STD of the Task Force on Communicable Disease Control in the Baltic Sea Region in Tallinn, Estonia.

NEW PUBLICATIONS

Illicit Drug Policies and the Global HIV Epidemic: Effects of U.N. and National Government Approaches, published in March by IHRD/OSI, is an in-depth analysis of how U.N. drug policies fuel the spread of HIV. The report can be downloaded at www.soros.org/initiatives/ihrd/news/drug-policy_20040316. For free copies in English, please write to IHRD@sorosny.org

Lessons Not Learned: Human Rights Abuses and HIV/AIDS in the Russian Federation, published in April by Human

Rights Watch, is available in Russian and English at www.hrw.org/english/docs/2004/04/27/russia8497.htm. Copies may be purchased from Human Rights Watch at <http://store.yahoo.com/hrwpubs/2004reports.html>.

Skills Training and Capacity Building in Harm Reduction, published recently by IHRD, is available online at www.soros.org/initiatives/ihrd/focus_areas/capacity. For free copies in English, please write to IHRD@sorosny.org

DRUG POLICY WAS DEBATED on a popular TV show in Russia on April 8 by Lev Levinson, human rights activist and director of New Drug Policy Alliance in Moscow, and Alexander Mikhailov, deputy chair of the Federal Drug Control Service. They debated on NTV's talk-show "K Barrieru" whether all people involved in illicit drug trafficking should be persecuted as criminals or if there should be a distinction between drug users and drug dealers. Levinson, who presented the second opinion, won the audience vote, which indicates that the Russian public is open to a pragmatic drug policy.



Anya Sarang at the International Conference on the Reduction of Drug Related Harm.

Photo by Matt Curtis.

collaborate on initiatives for drug user services. Speakers and workshops encouraged participants to network, make use of the broadening evidence base, and adopt pertinent programs.

"TRENDS IN EUROPEAN DRUG POLICIES," a conference co-sponsored by IHRD and the Max Planck Institute for Foreign and International Criminal Law, was held May 25–27 in Berlin, Germany. Decision-makers from CEE/fSU exchanged ideas on drug policies and the latest evidence in Europe about demand and harm reduction in hopes that countries that are updating their drug laws will learn from the experiences of other countries. The meeting should promote closer ties between officials and experts dealing with drug policy and encourage links between E.U. member states, newly accepted E.U. member states, and candidate countries.

DONOR CONTRIBUTIONS to Moldova's AIDS Control Program have increased through grants from the World Bank (\$5.5 million) and from the Global Fund to Fight AIDS, Tuberculosis, and Malaria (\$3.2 million). Tuberculosis efforts have been awarded \$2 million from the Global Fund, as well as \$4 million from USAID. The government, international organizations, civil society organizations, and other stakeholders are working to make the national HIV/AIDS programs participatory.

LEADING AUTHORITY on palliative care, Kathleen Foley, M.D., was chosen by the Joy McCann Foundation to be a 2004 McCann Scholar for her outstanding mentorship in medicine and science. Foley is the director of OSI's Project on Death in America.

A BABY GIRL was born to IHRD's director Kasia Malinowska-Sempruch on May 10. Welcome Kaya Sempruch!

NEWS BRIEFS

THE CENTER FOR PUBLIC HEALTH and Human Rights was opened by the Johns Hopkins University Bloomberg School of Public Health in the United States in April. Supported by OSI and directed by Chris Beyrer, an infectious disease epidemiologist active in HIV/AIDS prevention, the Center will do research, education, and advocacy around human rights violations that increase vulnerability to health risks, such as the denial of prevention and treatment services to drug users, and rights violations against women, sexual minorities, and marginalized groups. The Center's initial programs will be in the former Soviet Union countries, China, Burma, Thailand, and Tajikistan.

A MEETING ON THE RIGHTS OF DRUG USERS was organized by IHRD, Human Rights Watch, and the Brazilian government at the Commission for Human Rights in Geneva on April 1. About 60 participants and speakers attended, including Aryeh Neier of OSI and Paisan Suwannawong of the Thai Drug Users Network. The Special Rapporteur on the Right to Health

made a strong statement about dealing with abuses against drug users—a major victory for advocates for the protection of drug users' human rights.

OVER 1,000 ACTIVISTS attended the 15th International Conference on the Reduction of Drug Related Harm from April 20–24 in Melbourne, Australia. Participants from IHRD's focus region, CEE/fSU, played a prominent role. In her keynote address, Anya Sarang, coordinator of the Central and Eastern European Harm Reduction Network, outlined the growing harm reduction movement in the region; Vitaly Djuma from Russia confronted officials from his country who dismiss the need for harm reduction; Balazs Denes described needed drug law reforms in Hungary; and so on. In acknowledgement of the region's growing efforts, this year's award for an outstanding contribution to harm reduction went to Anya Sarang, who has become a prominent advocate for harm reduction in the region and around the world.

PIONEERS IN RISK REDUCTION, drug use prevention, and disease control in South Eastern Europe met May 20–22 in Belgrade for the Vanguard 2004 conference. The conference provided a forum for user groups, youth organizations, and social and humanitarian groups from the region to

PALLIATIVE CARE FOR PLWHA

by Silvia Stratulat, Angelina Ursu, Stefan Gheorghita

The Republic of Moldova's 2001 National HIV/AIDS Program was one of the first programs in Central and Eastern Europe and the former Soviet Union (CEE/fSU) to include the essential component of palliative care for people living with HIV/AIDS (PLWHA). The World Health Organization defines palliative care as "an approach which improves the quality of life of patients and their families facing life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment, and treatment of pain and other problems, physical, psychosocial, and spiritual."

In 2001 the National HIV/AIDS Program succeeded in developing national standards for palliative care for PLWHA, which were published and distributed to all medical facilities and nongovernmental organizations (NGOs) in the country. The Nursing Association of Moldova and the National Center of Preventive Medicine have run palliative care training programs for physicians, health care managers, nurses, and medical students across the country. To increase public awareness the booklet, *Palliative Care for People Living with HIV/AIDS*, was published and broadly distributed.

Moldova ranks fourth in HIV/AIDS prevalence in CEE/fSU after Russia, Ukraine, and Belarus. Between 1987 and 2003 there were 1,982 HIV-positive people officially registered in Moldova. The infection is still predominantly spread by injection drug users (IDUs), although in the last three years the rate of sexual transmission has increased.

Palliative care is an integral part of the comprehensive clinical management of HIV. Countries like Moldova that are starting to develop their treatment programs and tackle the issue of access to comprehensive HIV care for their patients should ensure that all components of care are in place. A 2000-2001 study supported by the Soros Foundation-Moldova demonstrated that the needs of PLWHA extend far beyond disease treatment. PLWHA and their families need medical, psychological, social, and spiritual support to deal with the problems of HIV/AIDS, such as opportunistic infections, discrimination, and financial hardship.

The palliative care approach for IDUs is fundamentally the same as for other patients. The primary physician must create a care plan for pain management with the understanding that more than 80 percent of HIV/AIDS patients suffer from moderate to severe pain that requires opiate analgesic medication. Clinicians are often frustrated by drug using patients, and those negative attitudes can interfere with appropriate pain management—as can the self-destructive behavior of clients themselves. Providers must attend to the specific needs of the individual patient, acknowledging their drug use as part of the patient's medical history and developing an appropriate palliative care plan.

The government AIDS centers provide a range of services including testing, management of opportunistic infections, nutritional, social, legal, and financial counseling, and grief and bereavement support. Independently, several NGOs provide home-based palliative care services. Integrating palliative care fully into the national health care system remains a challenge.

Many steps need to be taken in Moldova to improve care for PLWHA. AIDS treatment centers, for instance, should have an interdisciplinary palliative care team, counseling and voluntary testing, and home-based palliative care programs that can work out of the centers. To address the stigmatization of PLWHA and IDUs, a public awareness campaign on HIV/AIDS should be launched and PLWHA and drug users should be partners in all efforts to shape health care programs designed to serve them.



Silvia Stratulat counseling HIV-positive drug users.
Photo courtesy of Soros Foundation-Moldova.

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The government needs to identify the legal, social, economic, cultural, administrative, and/or physical barriers to providing palliative care services, and amend laws and regulations to make opiate analgesics available in AIDS centers and for home-based care teams. All other essential HIV/AIDS drugs should be accessible in a range of formulations and dosages for medical use.

Combined, these efforts would do much to make the public and officials recognize the role of palliative care as essential to appropriate HIV/AIDS care and treatment.

Silvia Stratulat is an infectious disease specialist at the National AIDS Center. Angelina Ursu is a palliative care program assistant at the Soros Foundation-Moldova. Stefan Gheorghita is the director of the National AIDS Center. They all live in Chisinau, Moldova.

IHRD COORDINATORS

Albania

Valdete Sala and Ledia Curri
Open Society Fund–Albania
soros-al@osfa.soros.al

Armenia

Anahit Papikyan
Open Society Institute–Armenia
panaida@osi.am

Azerbaijan

Layla Imanova
Open Society
Institute–Azerbaijan
limanova@osi-az.org

Belarus

Anna Chernyshova
United Nations
Development Program
anna.chernyshova@undp.org

Nastia Kamlik

Positive Movement
kamnast@tut.by

Bulgaria

Elena Zlatanova
Open Society Institute–Bulgaria
ezlatanova@osf.bg

Croatia

Danica Eterovic
Open Society Institute–Croatia
deterovic@soros.hr

Czech Republic

Vlasta Hirtova
Open Society Fund–Prague
vlasta.hirtova@osf.cz

Estonia

Mall Hellam
Open Estonia Foundation
mall@oef.org.ee

Georgia

Lasha Zaalishvili
Open Society
Georgia Foundation
lasha@osgf.ge

Hungary

Katalin Szoke
Soros Foundation–Hungary
szoke@soros.hu

Kazakhstan

To be determined

Kyrgyzstan

Elvira Muratalieva
Soros Foundation–Kyrgyzstan
elvira@soros.kg

Latvia

Egita Prama
Soros Foundation–Latvia
egita@mail.sfl.lv

Lithuania

Virginija Ambraseviciene
Open Society Fund–Lithuania
virginij@osf.lt

Macedonia

Vera Dimitrievska
Open Society
Institute–Macedonia
vdimit@soros.org.mk

Moldova

Viorel Soltan
Soros Foundation–Moldova
vsoltan@soros.md

Poland

Aleksandra Duda
United Nations
Development Program
aleksandra.duda@undp.org

Romania

Alina Bocai
UNAIDS Romania
alina.bocai@undp.ro

Russia

Vitaly Djuma
Russian Harm
Reduction Network
vitaly@harmreduction.ru

Valeria Letyagina

Open Health Institute
vletyagina@ohi.ru

Serbia

Jadranka Stojanovic
Fund for an Open Society–Serbia
jstojanovic@fosyu.org

Slovak Republic

Tanja Rajniakova Hicarova
Open Society Fund–Bratislava
tana@osf.sk

Tajikistan

Zarina Abdullaeva
Open Society Institute–Tajikistan
azarina@tajik.net

Turkmenistan

United Nations
Development Program

Ukraine

Olena Kucheruk
International Renaissance
Foundation–Kyiv
kucheruk@irf.kiev.ua

Denis Poltavets
International Renaissance
Foundation–Kyiv
poltavets@irf.kiev.ua

Uzbekistan

To be determined

IHRD ADVISORY GROUP

Desmond Cohen is the former director of the HIV and Development Programme at the United Nations Development Programme.

Judit Fridli is the founder and chair of the Hungarian Civil Liberties Union.

Zuhra Halimova is the executive director of Open Society Institute Assistance Foundation–Tajikistan.

Krzysztof Krajewski is a professor of criminology at Jagiellonian University in Poland.

Ethan Nadelmann is the executive director of the Drug Policy Alliance.

Aryeh Neier is the president of the Open Society Institute.

Robert Newman is the director of the Baron Edmond de Rothschild Chemical Dependency Institute of Beth Israel Medical Center.

UPCOMING EVENTS 2004

September 8–10	September 29–October 2	October 7–9	October 21–24	October 31–November 1
Conference on Ethnicity and Addiction	The 3rd Intl. Conference on Substitutive Treatment and Rehabilitation of Drug Abuse	Schweitzer Seminar: Moving Harm Reduction Policy Forward	United States Conference on AIDS	International Drug Users Day
Vienna, Austria	Katowice, Poland	Kiev, Ukraine	Philadelphia, PA, USA	Zaandam, Holland
www.ethnicity-addiction.com	www.ceehrn.lt		www.nmac.org/conferences	www.drugusers.info