

What is Easy and What is Right

Plenary Address

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**Kasia Malinowska-Sempruch, Director
International Harm Reduction Development Program
Open Society Institute**

Good morning. It's an honor to address you all, and I thank you for this opportunity. This is a gathering that is most welcome and well overdue. The first time I came to Russia for an AIDS-related event was in 1994, in St. Petersburg. Only a few hundred HIV infections were registered then. It is distressing, a decade later, that hundreds of thousands have become infected. I am pleased to be here, but sad that those who have made the choice to manage their addiction through substitution treatment are not able to be with us, excluded by the fact that there is no substitution treatment available in Russia.

Though I am from Poland, my introduction to AIDS came outside of my home country, in the US in 1990, where I was taking a class on AIDS and Society. The more I learned, the more I was astonished by the way in which AIDS was a magnifying glass for inequalities. Whether in Africa, Asia, or European and US cities, it was those discriminated against and marginalized who made up the bulk of HIV infections. I had heard often about AIDS as a problem of people who made bad personal choices, but it turned out that risk was shaped by lack of access: to health care, to lawyers, to stable employment or government attention. In that context, groups like ACT UP and Gay Men's Health Crisis were very inspiring. People vulnerable to infection, those watching their friends dying, those who themselves were fighting to live, came together to set an agenda and demand attention from the institutions that were ignoring them.

Sixteen years later, I can think of many inspiring examples: the Treatment Action Campaign in South Africa who have sued and marched for the right to affordable antiretrovirals; the Thai Drug Users Network who are speaking out in the midst of a brutal drug war; and of course many of you in this room who began needle exchange and substitution treatment when no one had thought it was possible. The lesson from them then is one that bears repeating today. Responding to AIDS is not about doing what is easy. Instead, it is about doing what is right. It is about putting people before prejudice, and continuing, no matter how often others say it's not necessary or it's too difficult or that it won't work.

I came to harm reduction about eight years ago from the broader field of HIV prevention. During my time at the UN, where I worked for six years, it was easier to engage with general sex education, condom promotion, trainings for physicians and nurses, or gay groups concerned about their health than it was to talk about harm reduction and the drug policies that stood in the way of harm reduction. But AIDS is not easy, is it? As the epidemic progressed, it was obvious that in our region injecting drug use was driving

infections, and driving them fast. First Poland and the former Yugoslavia, then Ukraine, Belarus, Moldova, Russia, Kazakhstan – all over we were learning of increasing numbers of drug users infected with HIV. And as we watched the numbers grow—as the UN year after year announced that the epidemic in our region was increasing more rapidly than anywhere else in the world, it became necessary to ask: How have we let this happen on our watch? Why haven't we learned the lessons of other countries? Have we been doing what was easy, or what was right?

Things now are much better than they were. There are some needle exchange programs operating in most countries represented here today. The Global Fund has started to make prevention and treatment more available. International donors are recognizing that HIV is not just a problem of African countries. National governments are recognizing that it is not acceptable to express concern in public while privately believing, as one official put it, that “AIDS and drug users will solve each other.”

It is encouraging that President Putin has increased funding for HIV, and that there have been sharp increases in World Bank and bilateral and Global Fund support for HIV programs in Central Asia, in Russia, and in Ukraine. There is now enough money in our region for many people to be fully employed in the area of HIV prevention and care – a big step from the past. The number of international staff dedicated to HIV in our region is not what it is in other parts of the world, but it has grown. The challenge is making sure that this growing workforce has a real impact. It is easy to say that we now have greater commitment to HIV. It is right to put mechanisms in place to make sure that the money follows the epidemic, that funding and attention go to help those who are actually infected, or most vulnerable to infection. Eighty-five percent of all HIV cases in Russia, for example, have been among injecting drug users. How is it that even as foreign aid and domestic spending increased, a survey by the Russian Harm Reduction Network found that funding for needle exchange services in thirty-eight Russian cities actually declined by nearly thirty percent between 2004 and 2005? Why is it, despite all the evidence and new funds, that there is not one country in our region where needle exchange has been taken to national scale? What does it mean when governments, like that of Kazakhstan or Ukraine, promise to implement methadone treatment in their Global Fund grant proposals but find it impossible to remove the legal and systemic obstacles to make it happen?

It is easy to talk about the need to reduce stigma. Who can disagree? It is harder, but right, to talk about the fact that stigma reduction will never be successful unless it comes with analysis of power and accountability, and a real discussion of the way that drug policies shape risk. When police arrive along with an ambulance to a drug overdose in Uzbekistan; when law enforcement in Ukraine takes away antiretroviral treatments from drug users saying that they are probably tablets of Ecstasy; when police wait by needle exchange sites to arrest or take money from drug users in Tajikistan; when laws require that people who are in possession of small amounts of drugs be put in prisons where risk behavior is common but condoms, needles and drug treatment are not available, then you see that stigma reduction and HIV prevention begin with humane, rational drug policy.

Looking at the link between policy and prevention means facing the tensions between the law enforcement approach that treats drug users as something to be contained and controlled, and the public health approach that focuses on reducing risk. It is easy to talk of the public and private sectors working together, what the UN has called the ‘three ones.’ What is right is to recognize that the coordinated response may do little for drug users or sex workers, who are regarded by many of those on the coordinating committee as not worth the trouble.

We often hear that harm reduction is a superficial solution to a comprehensive problem of drug use and addiction. I hear that to have a true impact on HIV prevention, drug users need to stop using drugs. Talking about a need for drug treatment is easy. It’s harder, but it’s right, to talk about how many of those who go for drug treatment in our region are offered nothing but detox, often at significant expense to them or their families. A recent survey of clients of harm reduction projects in Penza found that half of respondents had tried to stop using drugs five or more times, and another 17.5 percent had tried to stop more times than they could remember. The dedication with which drug users seek treatment is truly impressive. Much less impressive is how little good treatment is actually available. Chaining people to beds is not drug treatment. Humiliating them and their families is not drug treatment. And with so many returning to drug use even after periods of abstinence, we need to make sure that there are harm reduction services so that drug users, wherever they are in their drug using, don’t wind up with HIV as a penalty for relapse.

It is easy, and increasingly common in many of the countries of our region, to talk about the generalizing of the epidemic, and the rising numbers of women infected through sexual transmission. Officials now will say: “Why do drug users need special attention, when nearly half of new infections are among people who didn’t use drugs?” Even representatives of friendly and committed international agencies, who list needle exchange and substitution treatment as central interventions in their own policy papers, will tell you that it is strategic to talk about epidemics of youth, that if we talk about risk to women, and to the general population, it will be easier to get people to care. That may be easy, but is it right? I find this discourse somewhat surprising. For years now, we have been talking of mostly young, male injecting drug use and the HIV that follows. Did anyone imagine that those young men are not sexually active? The fact is that many of the women who have gotten infected are the sexual partners of drug users, and many of the children being infected are the children of drug users. It is the lack of sexual health services to drug users that can be credited for those infections. The answer to generalizing epidemics in our region is not to turn away from services for drug users. Rather, it is to give more attention to what prevention for female sexual partners of drug users should look like, decide what new programs are needed, and recognize that ignoring the realities of drug users’ lives also punishes families of drug users and whole communities.

It’s been common with HIV to blame the people we are serving rather than looking at the problems with the system itself. We have seen this pattern in many countries and contexts with AIDS—the claim that Africans can’t tell time, and so cannot adhere to

treatment, that gay men are irresponsible and so don't deserve prevention, that drug users are too chaotic and disorganized to benefit from help. It is so easy to use Difference, to excuse Indifference. It is easy, and justified, to talk proudly of increases in the numbers on HIV treatment. But it is right to also talk about how we set up systems that exclude the majority of people who need them, the ways in which we fail to make the clinics friendly to drug users or train the staff and then blame the defects on the patients themselves. It is hard, but right, to acknowledge that people are grappling with multiple health challenges, with HIV and TB, and that many drug users who need comprehensive care are instead dismissed and kicked like footballs from one clinic to another. The stories show how much work we have to do. The children in Kyrgyzstan driven from their school after a doctor at the AIDS centre reveals the HIV status of a father on television. The Ukrainian patients dismissed from the TB clinic after their HIV diagnosis is discovered. The drug users offered monotherapy in Russia years after triple combination therapy had become the recognized standard, or given two drugs and then told that if they want the third, they will have to pay.

Harm reduction, whether you are talking about syringe exchange, substitution treatment, or overdose prevention, emerges from three basic principles: that those who use illicit drugs can make positive changes to protect their health and that of their families and communities; that drug users have a critical role in shaping the services they need; and that the HIV programs should meet people where they are rather than expecting them to conform to where we want them to be. The act of using an illicit drug does not mean that you are no longer human and so no longer deserving of human rights. Drug users are registered, warned not to infect others, forcibly tested, told to abort their pregnancies, and put last on the list of those waiting for HIV treatment, but are rarely told by programs that they are human under the law or worthy of protection. This is a message that many specialists and professionals have failed to deliver.

There is, of course, another story, one many of you in the room have helped to create. There are those here who have created programs to carry clean needles and information into the streets. There are those who work in drop in centers that offer drug users not only HIV prevention options but also a cup of coffee and a place to do their laundry or receive medical care. Police who remind their colleagues that drug users are our children and neighbors and offer assistance rather than arrest, and researchers who have shown that drug users and people living with HIV are themselves experts worthy of consultation. You have done amazing work. It has been hard, but it has been effective, and you have done it right.

The good news is, the science is with you. The evidence is with you. As you heard at the opening plenary from representatives of UNAIDS, CDC, The Global Fund, The World Bank, international expertise is on your side. Six steps—none of them easy, but all of them right, can change the course of this epidemic.

First, make substitution treatment available to all who need it. Follow the lead of the World Health Organization, which has added methadone and buprenorphine to its list of essential medicines.

Second, sharply scale up needle exchange. UNAIDS estimates that coverage of sixty percent of IDUs is needed for effective HIV prevention.

Third, end the mass imprisonment of drug users that accelerates HIV. The HIV Task Force of the UN Millennium Project has urged that drug policies be changed to reduce incarceration of drug users.

Fourth, make ARVs available for drug users. WHO protocols emphasize that all who need HIV care should be treated, and that with proper support, adherence to HIV medication among drug users is the same as that of other patients.

Fifth, make effective drug-free treatment available on demand, and link it to harm reduction.

Sixth, the sexual health needs of drug users must be addressed at a large scale.

I leave you with mixed feelings of optimism and despair. I feel heartbroken about the hundreds of thousands of infections and illness and death that will follow unless we act. I am devastated by the fact that so many are suffering when we knew what needed to be done to prevent it. At the same time, it is this knowledge based in science, reason and good will, that gives me hope and confidence that we can turn this awful tide.

To all of you who are a part of producing this knowledge, thank you for reminding the world that drug users are part of the public described by the term “public health.” Thank you for what I hope will be your continued strength in showing that HIV services should serve the needs of the people at risk rather than the interests of professionals, administrators and bureaucracies. I look forward to the next regional conference where we gather again to celebrate the advances we have made together, the courage that it took to move beyond our own comforts and old prejudices, to inspire hope, to begin new programs, and to save lives.