NGOs and HIV in Russia: Lessons from a Unique Case Study

Julie Stachowiak and Alena Peryshkina

The goal of the government is to develop rules and work to transform them into laws, while the goal of business is to make money. The objective of organizations in the social sector is to promote the health and well-being of people... These organizations serve another, no less important, goal. They awaken the feeling of civil responsibility. All that one can do in the role of individual citizen is to vote once every couple of years and to pay taxes regularly. By participating in the work of organizations of the social sector, one can correct or amend certain problems that they see in society.

—Alena Peryshkina, director of AIDS infoshare

Understanding AIDS in Russia has much more to do with one’s feelings about and grasp of the essence of Russia than about biological aspects of HIV transmission or paradigms of social epidemiology that have been imported from other settings. In the twelve years since the founding of AIDS infoshare, an NGO founded by myself and two Russians, my colleagues and I have existed in a unique world where we were able to observe, simultaneously, the reactions and actions of international “experts” and “players,” as well as Russians in roles ranging from ministry officials to people newly diagnosed with HIV infection. All the while, the Russian epidemic was following its own path, a curve virtually untouched by all of the “urgent attention” that it received—the high-level meetings, the international funding, the press conferences and reports, and the scandals and accusations.
That is not to say, however, that progress has not been made. NGOs working in AIDS have been pioneers in helping to determine the direction of post-Soviet civil society since its rocky beginnings and have brought attention to controversial and politically embarrassing aspects of Russian society as well as approaches to disease control that were hindering prevention and care efforts. And, while perhaps not in a way that will affect statistics and graphs, countless individuals have had their lives touched and changed by the work of NGOs, including people vulnerable to HIV infection, those already diagnosed with the virus, and those people involved with NGOs in their struggle against AIDS.

A Glimpse at the Evolution of Civil Society in the USSR and Russia

Soviet policy toward civil society was based on the beliefs of Karl Marx, who viewed civil society as a means for the bourgeoisie to oppress the proletariat and further their own interests (Knox, 2005). As the main thrust of most organizations and movements that constitute modern civil society is to give assistance and a voice to vulnerable people, Soviet ideology ran counter to such ideas. The state was mandated to ensure that there simply were none who were vulnerable, under the “from each according to his abilities, to each according to his needs” vision of Soviet communism. People were, of course, called into service as volunteers to help their neighbors, from citizens’ brigades charged to maintain public places to groups of children dispatched to work on collective farms or paint schools. These activities, however, were not self-motivated or organized; rather, they were approved, mandated, and managed by the state.

As time passed and international communication increased, the citizens of the USSR entered their own uneasy period of enlightenment, when they began to receive and spread reports of things outside of their borders being different—better—than they had been told. As Western images in the form of movies, magazines, and other media gained wider underground circulation, Soviet citizens began to wonder if their government’s definition of “good enough” was as good as it could get. By the 1980s, the black market was a huge economic force that brought in goods to desperate consumers no longer satisfied with long lines and dwindling selection at stores named simply “Fruits and Vegetables” and “Clothes.” In addition, as it turned out, there were vulnerable people in society whose needs were not being met by