

Helping HIV-positive People in Russia Access Care and Support

Case Managers Improve Quality of Care by Helping AIDS Patients in Saratov Oblast Navigate Complex Network of Medical and Social Services

It's not a far stretch of the imagination to liken the work of Olga Fyodorova and Vladimir Dementyev to that of shepherds tending their flock. They look out for the best interests of the people under their care, marshalling these individuals through fields and valleys made treacherous not by wolves and other predators, but by ignorance, fear, and discrimination. They offer knowledgeable advice and a compassionate shoulder to lean on. They serve as advocates, pushing for much-needed care and support. And—just as important—they offer kindness and respect to people who have long since become accustomed to being treated as societal outcasts.

Fyodorova and Dementyev are pioneers of a new system of healthcare service delivery for people living with HIV/AIDS (PLWHA) in Russia. As two of the country's first HIV/AIDS case managers, each day they help clients in the Saratov Oblast city of Engels access the care and support services they need to live better, more productive lives. The project was introduced by a twinning partnership that links city and oblast healthcare institutions with counterparts in Bemidji, Minnesota, and New York City. Supported by the American International Health Alliance (AIHA) with funding from the United States Agency for International Development, this partnership is working to improve the quality and scope of healthcare and related services available to PLWHA in Russia.

"People with HIV in our country have a wide range of problems that go far beyond healthcare issues. They can face legal problems, employment problems, financial and public assistance problems, passport and visa problems ... the list goes on and on," explains Fyodorova, who has worked as a nurse for more than 24 years, the last five in an outpatient drug abuse unit. With injection drug use accounting for the majority of HIV infections in the region, her long experience has made her all too familiar with the many challenges PLWHA come up against each day.



Russia's first HIV/AIDS case managers, Olga Fyodorova and Vladimir Dementyev. (Photo: courtesy of Linda Brandt)

She also knows first-hand that the stigma surrounding the virus compounds these problems exponentially.

"Even people who work in healthcare or social services lack basic knowledge about HIV/AIDS, so you can be sure PLWHA face discrimination," Fyodorova says, recounting a scene she witnessed to emphasize this assertion. "One doctor used to call such patients in for an office visit by shouting to the entire waiting room 'OK AIDS carrier, come on in now.' If that type of stigmatization and lack of compassion exists among medical professionals, just imagine what the bias is among the general population."

Dementyev, her fellow case manager, can attest to the difficulties PLWHA face in Russia. He himself is HIV-positive. "Without the case management system, HIV/AIDS patients are faceless strangers trying to navigate a difficult system on their own. They encounter roadblocks virtually every step of the way. If they need medical care, they aren't expressly refused. No one says 'I will not treat you because you have HIV,' but still no treatment is provided," he says, explaining that after this happens time and again, HIV-positive people learn to expect very little. "With me, there is no white coat separating us, no history of fear or animosity often associated with healthcare providers. We work together as partners and they have a real voice in the steps we take to solve their problems."

As a former injection drug user, Dementyev can relate to his clients because he has faced the demons of addiction. And, having been clean for nearly six years, he is living proof that drug dependence can be overcome. "After I found out I was HIV-positive in 1999, I became involved with a harm reduction project implemented by a local nongovernmental organization (NGO) called Socium and also directed a support group for PLWHA through another NGO called Anti-AIDS Saratov," he recounts, explaining that working with active drug users actually helped him stay focused on his own recovery. The work also led him to the case management program. He began attending training courses conducted jointly by AIHA and University Research Co. LLC (URC) in October 2004, learning from experienced case managers from Minnesota, including Linda Brandt, former executive director of the Rural AIDS Action Network in Minneapolis.

It was this peer-to-peer collaboration between the US and Russian partners that helped Engels lay the groundwork for positive change by introducing healthcare professionals and policymakers to a variety of methods for providing PLWHA with the comprehensive, integrated care and support they need.

As head of the Engels Healthcare Department, Mikhail Afanasyev proved instrumental in moving forward with implementation of the case management system. "In my position, I always have to approach new ways of doing things with a healthy dose of skepticism because things that work well in another setting may not be appropriate for our system in Russia. In fact, that is actually true of case management," he says, explaining that the concept falls outside the parameters of the country's administrative framework for healthcare.

Not to be deterred, the US partners—in close cooperation with AIHA and URC staff—focused on demonstrating that case management was indeed a viable option for Engels and, according to Afanasyev, their work quickly yielded positive and quantifiable results. "Detection rates improved immediately because we started screening high-risk groups as a result of better cooperation with various NGOs. That was the proof I needed to move forward—that and the fact that my colleagues and I really wanted to come up with a new approach to HIV/AIDS," he says, explaining that Russia had already taken the first step toward creating a system of HIV care by establishing a network of AIDS centers some years ago.

"As long as we are working to broaden that system by incorporating follow-up care, it seems logical to me that we introduce case managers," Afanasyev asserts. "The concept is very similar to what already exists for people with tuberculosis or mental health problems. For these ailments, we have a set framework with defined protocols for prevention and treatment. Now we need the same for HIV/AIDS. Some elements, such as testing and laboratory services, already exist. What we still need to work on is treatment and support, and it's my job to pull all the necessary services together into one cohesive system," he continues.



Mikhail Afanasyev, head of the Engels Healthcare Department. (Photo: Kathryn Utan)

In March 2006, Fyodorova and Afanasyev embarked on their first partnership exchange to the United States, each looking to learn about specific issues that will answer many of the questions they have encountered as they work to put what they've already learned into practice.

"The majority of my clients need the services I provide as case manager as much as they need the air they breathe," Fyodorova says. "The US partners who came to Russia to provide training and technical support have a tremendous amount of knowledge and experience. They gave us the basics, explaining that case managers must know how to link their clients to appropriate and sympathetic

specialists. Not just healthcare providers, but also lawyers, psychologists, addiction counselors, employment agents, and other people who can help fulfill their needs. During my time in the United States, I'll get the chance to see for myself how all these various service providers interact. I want to see how the system operates from the time a patient enters the system and throughout the continuum of care," she acknowledges.

For his part, Afanasyev is eager to learn about the US system of blood banking and how the civil sector works to fill the gaps left by government and private healthcare providers. "Regardless of what federal HIV/AIDS care and treatment model Russia implements in the future, I think we can resolve many of our oblast's problems by adopting the case management system," he maintains.

Agreeing with Afanasyev's assertion, US partner Linda Brandt notes, "It is obvious that the city of Engels is taking charge of its HIV/AIDS situation and that many important changes are being made. We can truly make the claim that Olga and Vladimir are the first HIV/AIDS case managers in Russia. They—along with the other professionals we are collaborating with—are hard-working, dedicated people who are making a real difference in the lives of citizens in their community. Many would doubt that so much could be accomplished in such a short time, but teamwork has helped create a network that is solid and moving forward," she says, concluding, "When a strong team of committed professionals has the courage to work together as agents of change, success is virtually assured."