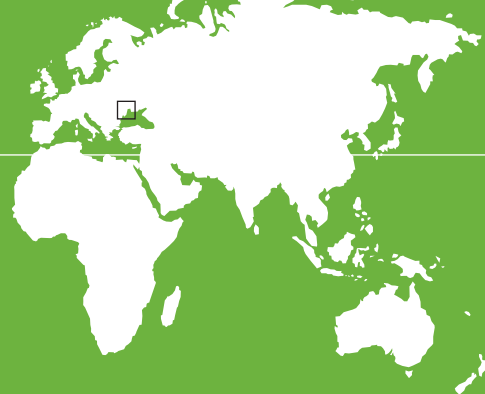




Valeria, HIV-positive mother and activist in Ukraine, with her daughter

Photo: UNAIDS/WHO.V. Suvorov



Working towards the decrease of stigma in Ukraine

Strategies of the All-Ukrainian Network of People living with HIV/AIDS

Natalia Ruda

The first HIV cases were registered in Ukraine in 1987 and ever since stigma became an inevitable part of people infected with and affected by HIV and AIDS. With the development of the HIV epidemic in the country, the focus of HIV-related stigmatization was changing. At the onset, main targets for stigmatization were foreigners (in particular, of African origin) who were associated with the main source of infection. By the mid 1990s HIV-related stigma had acquired a strong link with injecting drug users because the virus was spreading in their community at a tremendous speed. Several other groups including sex workers and men who have sex with men 'joined the club' of stigmatized people. Infected members of these groups underwent double stigmatization: first for their HIV status and second for the supposed behaviours that lead them to become infected.

The scale of the HIV epidemic continues to grow in Ukraine: by January 1, 2008 the number of officially reported HIV cases was 122,674, including 22,500 AIDS cases.¹ The HIV prevalence rate is about 1.4% of the adult population. According to UNAIDS, this is one of the highest rates in Europe. Fortunately, recent studies demonstrate a decrease in HIV-associated stigmatization. According to a survey by the Kiev International Institute of Sociology the level of intolerance to people living with HIV (PLWH) has decreased over the last 15 years. Whilst in 1991 the percentage of the Ukrainian population that believed that PLWH should be completely isolated constituted 42.5%, in 2006 it had decreased to 24.6%.² The most recent qualitative

survey conducted by the Kiev International Institute of Sociology covered three areas of life: education, employment and health care.³ The results revealed the following problems, which seriously affect the life of PLWH in Ukraine:

1. Health care

- Ignorance and fear toward HIV and AIDS among medical staff
- Discrimination against PLWH in medical institutions:
 - getting health care of lower quality or in a humiliating way
 - violation of confidentiality rules
- Personal barriers of getting professional health care, such as self-stigma or prejudices of PLWH with regards to ARV.

2. Education

- Problems with access of HIV-positive children to educational establishments
- Hostility and discrimination against HIV-positive children.

3. Work and employment

- Violation of the right of non-disclosure of HIV status
- Unfair attitudes towards HIV-positive employees
- Passiveness of PLWH in asserting their rights and lack of litigation.

According to the survey report, the cause for low tolerance and poor integration of PLWH in social life derives from their stigmatized perception, which is, in turn, the consequence of persistent interdependencies between low awareness of HIV and its transmission, fear, erroneous stereotypes and prejudice.³ A recent study by the Health Policy Initiative (USAID) revealed various levels of stigma and discrimination among providers of HIV/AIDS medical services in three regions of Ukraine. The research demonstrated that almost half of the surveyed providers believed that a patient's status should be made known to others and almost one-third

believed that HIV-positive people should be given medical treatment separately from other patients. Some health workers demonstrated stigmatizing attitudes regarding HIV-positive patients and co-workers. This was shown by the respondent's views on treating PLWH separately and barring HIV-positive medical staff from practicing medicine.⁴

Some experiences

The All-Ukrainian Network of People Living with HIV/AIDS (the Network) is the most powerful HIV service organization in the country. Our experiences in witnessing and documenting cases of stigmatization and discrimination correspond with the findings

Conducting nationwide public events allows drawing attention to the issue of HIV-related stigma and discrimination of a large part of the population

of the survey mentioned above. An example is a recent case, which took place in a village in the central part of Ukraine. An HIV-positive single mother of two (2.5 and 5 years of age, with the latter being HIV positive) tried to get a place for her younger son at a nursery school (as for her older son, she did not even try, fearing rejection and stigmatization). She still faced a serious resistance from the parents of other children. They organized and instructed the school to reject this child. Regardless of detailed explanations on how HIV is transmitted, parents remained persistent. That the mother of this child and his elder brother have HIV was sufficient for them to assume that there was a high risk of HIV transmission to their children. Despite all the efforts made by the members of our network, the administration of the nursery and even the village authorities, the child was not accepted.

A tragic case of discrimination of PLWH in the health-care system took place on November 13, 2007 in the city of Donetsk

(Eastern Ukraine). A 31-year-old HIV-positive woman needed urgent hospitalization due to post-surgery complications. A social worker called the ambulance and informed the doctors about the woman's HIV status (as required by the Ukrainian legislation). The ambulance doctors refused to come, saying that *"it wasn't their specialization and that such patients should have their own emergency services."* It took 7 hours to get a private ambulance, however it was already too late and the woman died. Nobody took responsibility for this death. Only one ambulance doctor, a shift boss on duty, was reprimanded *"for an ungrounded refusal in transporting an HIV-positive patient"*.

First steps against HIV-related stigma

The Network started in the late 1990s, when a group of HIV-positive people initiated the process of HIV and AIDS normalizing in the Ukrainian society. They started talking openly about their HIV status, therefore HIV in Ukraine acquired a face – the face of a young person, striving to live, work and love. They also started networking with other people living with HIV in various regions of Ukraine, encouraging them to create self-help groups in order to support each other and get united. This form of social gathering was the first step to empowering HIV-positive people in the country. Afterwards many of these self-help groups became regional offices of the Network – a major moving force of changes in the HIV and AIDS arena.

Initially HIV-positive activists responded to stigma and discrimination intuitively. Their actions acquired a more systematic and programme-based character after gaining proper experience. In 2006, the Network received the Red Ribbon Award for its interventions against stigma and discrimination at the XVI International HIV/AIDS Conference in Toronto (Canada). The main strategies we have used over the years are: 1) raising public awareness and promoting tolerant attitudes towards PLWH through public events, media

campaigns and educational campaigns; 2) mobilizing PLWH as story tellers and famous persons as 'Ambassadors'; 3) involving PLWH in decision-making processes at the government level; and 4) addressing cases of discrimination by starting court cases.

1. *Promoting tolerant attitudes towards PLWH* – In our experience, conducting nationwide public events allows drawing attention to the issue of HIV-related stigma and discrimination of a large part of the population. Annually, we organize two national events, namely AIDS Memorial Day and World AIDS Day. Every third Sunday in May, on AIDS Memorial Day, we organize an action-requiem together with partner organizations nationwide. The aims of the event are to remember people who died of AIDS on the one hand and draw attention of Ukrainians to HIV and AIDS-related problems on the other. Various events like church ceremonies, candle light memorial ceremonies, theatre performances, quilt exhibitions, information fairs and visits to AIDS centres are conducted. Every year more cities and towns in the Ukraine

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join this event. In 2007 it was conducted in 46 places. Over 7 million Ukrainians were informed about AIDS Memorial Day through mass media.

World AIDS Day (December 1st) is now commemorated nationwide as a result of the Network's efforts. In 2003 we proposed to change the title of this event to 'Day of Solidarity with People Living with HIV'. At that time, HIV-associated stigma and discrimination was flourishing. A simple change of the day's name allowed shifting the focus from 'combating

AIDS' to development of tolerant attitudes towards people infected and affected by the epidemic. On December 1st the Network's activists together with other stakeholders participate in multiple public

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events. The Ukrainian government reports to the nation about achievements and problems on the way to combating the HIV and AIDS epidemics. In turn, HIV activists draw attention of people to the issues of stigmatization and discrimination of PLWH.

2. *Involvement of PLWH as story tellers and famous people as Ambassadors* –

Experience taught us that it is important to mobilize PLWH as story tellers, who share personal experiences of stigma and discrimination. Our activists take part in talk shows on national and regional TV and radio, present their stories during public events, and publish life stories in books and newspapers. Our organization published several collections of personal stories of PLWH with their photos, and several photo albums and sets of greeting cards with photographs of PLWH. These publications are extremely popular among school children and students.

Several years ago we started involving famous people as Ambassadors. This strategy proved successful. Pop stars and famous sportsmen are believed to be powerful sources of reliable information for young people. We managed to utilize them to draw attention to issues of HIV-related stigma and discrimination. A famous Ukrainian singer starred in a video ad with a male HIV activist in solidarity with HIV-positive people. On December 1, Lilia Podkopaeva, the Olympic champion in gymnastics, together with the Network organizes charity concert-marathons aimed at

formation of tolerant attitudes towards PLWH. A world-famous boxer, Vitaly Klitchko, openly stands for tolerant attitudes towards PLWH. He participates in charity events, such as auctions and sport competitions. When we conducted a charity auction called 'Simply Children' aimed at raising funds for HIV-positive children, famous singers including Sir Elton John, sportsmen and business people made considerable contributions.

3. *Involvement of PLWH in the decision making* – Involvement of PLWH in decision-making processes at local and national levels is critical to tackle the issue of stigma and discrimination. The latest achievement of the Network in this regard is appointment of its Executive Director, Volodymyr Zhovtyak, in the position of Deputy Chairman of the National Council on TB and HIV/AIDS. This creates opportunities for us to coordinate activities of corresponding ministries, other government authorities and public organizations for effective implementation of a joint policy, consolidate use of funds and improvement of the monitoring system with regards to HIV prevention.

4. *Addressing cases of discrimination by filing lawsuits* – Due to involvement of the legal department of the Network five lawsuits were filed on the protection of rights and interests of PLWH in the regions. In one of the cases a teacher who discriminated against a pupil because of his HIV status was convicted.

Future actions

The qualitative survey report by the Kiev International Institute of Sociology drafted over 30 recommendations that urge governmental and non-governmental organizations to take appropriate action to diminish stigmatization and discrimination of PLWH.³ We carefully reviewed these recommendations and found most of them extremely useful. Recommendations that we will consider first are:

1. to conduct a systematic information campaign targeting the society as a

whole – this will help overcome fear, false stereotypes and prejudice against PLWH;

2. to form and implement a primary prevention strategy at state level that will contribute to public awareness of the HIV problem and disseminate information on how HIV is transmitted, paying special attention to vulnerable groups and regions with highest HIV prevalence;
3. to develop a mechanism for observation of legislation concerning HIV and AIDS.

We believe that our work contributes to the gradual decrease of stigmatization of PLWH by Ukrainian society. In the words of Dmitry Sherembey, a member of the Coordination Council of the Network: *"I believe that the process of destigmatization has started and we are facing positive changes in Ukraine. However there is still a lot to be done. The only way to 'cure' society from stigma and discrimination is to provide people with true and reliable information."* ■

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