

## **Overcoming HIV related stigma in the healthcare system: protection of human rights: Ukraine**

### **Case study**

#### **What was the issue?**

Stigma and discrimination against people living with HIV / AIDS (hereinafter - PLWH) are highly prevalence occurrences in Ukraine. Thus, much of PLWH face difficulties in accessing health care for reasons related to their HIV status. According to the survey among people living with HIV, conducted in 2013 ([www.stigmaindex.org/Ukraine](http://www.stigmaindex.org/Ukraine)) 11% of interviewed PLWH at least once within the last 12 months were faced with the restriction of access to medical services for reasons related to their HIV status. Despite the fact this indicator reduced by almost at a half compared to the survey conducted in 2010, people living with HIV, who identified themselves as a member of a most at risk (or 'key' population) are still experiencing stigma and discrimination in health care facilities (14%).

#### **Why was change needed?**

From the People Living with HIV Stigma Index and a Stigma Level Assessment conducted by the Network among healthcare providers showed high level of stigma and discrimination in healthcare facilities. A number of cases were related to potentially 'actionable' human rights violation performed in direct or indirect refusals in medical treatment provision. Having lack of knowledge and information on their rights patients often make the wrong or even fatal decisions to avoid applying for medical assistance. It leads to significant health deterioration or even death. At the same time due to the lack of finance regional HIV- service NGOs cannot afford hiring lawyers who can protect the rights of PLWH or provide legal counselling on regular bases.

#### **How could the situation be improved?**

There was a need of an intervention that would focus on documenting of stigma-related cases of human rights violation in healthcare facilities and would develop an algorithm for patients and NGOs based on the legislative framework to counteract stigma and discrimination.

#### **What were the barriers to change?**

In general it could be stated lack of public interest to the problem of stigma and discrimination associated with HIV to KP representatives, particularly from the side of personnel in health care institutions. As a consequence of this there is a lack of understanding of the negative impact of stigma on the overall situation with HIV / AIDS. And the other factor having impact on the spread and display of discrimination and stigma was that significant part of HIV-positive people in Ukraine were not aware of their rights and/or could not protect them in their everyday life.

#### **How long did change take and who was involved in making the change?**

Since 2013 The Network has been implementing **USAID | RESPECT project** that allowed provision of on-going legal assistance and rights protection to the clients faced stigma and discrimination in healthcare settings in the four regions of Ukraine. In 2015 All-Ukrainian Network of PLWH and its implementing partners selected HCF in focal regions for developing and introducing KPs- and PLWH-friendly policies and practices which resulted in clients' referral algorithms of enrollment to HIV treatment program. As a result of project efforts stigma and discrimination level for PLHIV and key populations was assessed among staff of 38 pilot medical facilities, all this HCF developed and implemented PLHIV/key population-friendly policies, 4,658 health workers took part in 202 training events in stigma and discrimination reduction and 483 clients were enrolled to HIV treatment program as a result of the decreased stigmatized attitude from health care providers.

The **“Overcoming HIV related stigma in the healthcare system: protection of human rights” project** funded by **GNP+ within the framework of OptTest** program provided an opportunity for collecting of S&D and violation of patients' rights cases and development of a guidelines for those working in the field of human rights protection. Besides, a patient information material was developed that includes all the necessary information on how to determine that one's rights have been violated and how to act to restore the rights based on legislation.

### **How was change made?**

An integrated approach is the key to success: during the preparation for the project it became clear that it is necessary to work simultaneously in two directions: to increase the knowledge and skills of both medical workers and patients themselves.

First of all, it was necessary to change the attitude of medical personnel to HIV-infected patients. The majority of stigma and discrimination cases were due to the lack of knowledge among health professionals on the topic of HIV. Many of them were not sufficiently acquainted with the legislation in the field of HIV, which entailed making wrong decisions. Lack of general knowledge about the epidemiological situation with HIV led to the fact that health professionals did not understand their importance in the prevention and treatment chain.

Another factor that led to the violation of the rights of PLHIV/key population was that there were no policies in the medical institutions for dealing with such patients. Ignorance of the algorithm of their actions by medical personnel led to conflicts with patients.

To solve these problems, training modules for medical personnel have been developed for all necessary issues. After that, trainings were conducted for the staff of all the pilot medical institutions that participated in the project. And as a result, it became possible to develop PLHIV/key population-friendly policies in each HCF.

On the other hand, work was done with the clients themselves. This work included gathering information about violations of the rights in order to work with a client in a multidisciplinary team consisting of a social worker, a psychologist and lawyer. Each of the team's specialists was directed to the solution of their task. As a result, social support was provided to the project clients, as well protection of their legal rights, informing and training how to protect the rights, as well as work with self-stigma and improvement of the psychological state.

### **Are there any ongoing issues?**

During the implementation of the project it became evident that the chosen approach is effective both in working with patients and in working with medical personnel. Moreover, this line of work is claimed and brings positive results both in terms of improving access to treatment, and in reducing the level of stigma and discrimination towards PLHIV/key population.

**What lessons have been learnt?**

Non-governmental organizations can and should build effective interaction with medical structures to achieve effective work with different categories of patients. It is also necessary to conduct consistent work with the clients themselves in order to teach them to defend their rights, believes in themselves and their strength. And at the same time, medical structures, educational institutions and the state as a whole should not stand aside from all described processes, but go through institutionalization of the processes of training medical personnel with the knowledge and skills they need. It is necessary to expand training programs at the national level to train qualified specialists in accordance with the requirements of the time.