

This publication is to be released by civil society organizations working in the field of combating the HIV epidemic in Latvia, Lithuania, Tajikistan and Kazakhstan with the support of the International Treatment Preparedness Coalition in Eastern Europe and Central Asia (ITPCru).

We have had two aims while preparing this review. On the one hand, we wish to draw the attention of the international community and national ministries to the major terms of the PLWH community problems in achieving universal access to prevention, treatment, care and support for people living with HIV in 4 countries of the EECA region. On the other hand, to collect information about how these countries have participated in a process involving civil society in the preparation of the national reports in order to summarize the problems encountered in this process, and describe best practices in order to broadcast this experience in other countries in EECA region and in the world.

While preparing the reviews (chapters) on their countries, the authors were encouraged to adhere to a common methodology, such as a list of topics that had to be covered. The whole overview had to be based not only on a personal experience and expertise of the organization, but also on interviews of at least 3 representatives of other CSOs in countries.

Questions that needed a response can be logically divided into three groups:

1. Assessment of involvement of civil society in the preparation of National report for UNGASS in 2008-2010.

2. Major problems in prevention, treatment, care and support for HIV which the country has faced in the 2008 -2010 years, measures to address them, as well as best practices.

3. Recommended actions to address the problems and the conclusion.

It is important to say that the methodology, however, was not rigidly fixed, leaving the country teams the opportunity for creativity. In this regard, each of the chapters was given an unique, allowing, however, to draw parallels between the countries and compare both the organization of the national reporting process and the measures to achieve universal access.

We offer you short summary extracts from the heads of the document, which we hope will help you better understand the challenges faced by countries in the EECA region on this difficult path to achieving universal access.

LATVIA

Society "Association HIV.LV"

Assessment of involvement of civil society in preparation of the national reports for UNGASS in 2008 - 2010.

- The first information on the preparation of the report became known by the representatives of NGOs 16.12.2009, at a meeting of the Coordination Commission to reduce HIV infection, tuberculosis and sexually-transmissible diseases
- It was stressed that "the special role of non-governmental organizations, who need to develop a consensus on one of the sections of the report." However, it was referred only to "The National Composite Policy Index."
- The stakeholders' meeting on developing of the joint position was organized by the Regional Office of United Nations Office on Drugs and Crime (UNODC).
- All Latvian non-governmental organizations working on HIV/AIDS, were invited via the internet mailing list to participate in the meeting, but on Jan. 25, 2010 only four representatives worked on the policy index of NGOs and regional offices of WHO and UNODC.
- At the meeting of the Coordination Commission to reduce HIV infection, tuberculosis and sexually-transmissible diseases on Feb. 17, 2010 there was a briefing on the preparation of the national report on the meeting attended by only one NGO representative. After that no more questions related to the National UNGASS Report were discussed on any level with any representatives of HIV/AIDS NGOs'.
- Draft of the report was not distributed for discussion
- Representatives of GO were given passwords to an information system for monitoring the response in the countries so that they could review the progress of a national report and inclusion of data online. Thus, additional opportunities for representatives of NGOs to monitor the progress of writing the national report were provided. There was no indication that any representatives of NGOs took advantage of this opportunity
- The final version of the report was not distributed specifically.
- Regional offices of international agencies, WHO and UNODC as always played a coordinating and catalytic role.

Problems existing in the country, but not mentioned in the National report

- In Latvia, there is a Coordination Commission to reduce the infection of HIV, tuberculosis and sexually transmitted diseases (under the Ministry of Health), whose membership has been expanded considerably in 2008 and in its composition are 5 non-governmental HIV / AIDS organizations. However, the Commission is of a recommendatory nature and its protocol solutions are noted, but not binding.
- An Advisory Board for Pharmacy is acting as well under the Ministry of Health, which includes representatives of all the pharmaceutical companies. However, the interests of patients are represented by a single organization on cooperation between people with special needs "SUSTENTO". There were repeated requests to include representatives of the HIV/AIDS NGOs in the composition of the council, but this has not yet occurred.

- In Latvia there are acting "Recommendations for a rational pharmacotherapy of HIV infection in a limited state budget condition", they do not comply with the recommendations for the HIV/AIDS treatment published by the World Health Organization in 2009 (in particular, **ARV treatment is appointed by the number of CD4 cells below 200** or in the presence of concomitant diseases of the C category). An offer of non-governmental organizations to establish a reasonable period of limitations on the appointment of antiretroviral therapy was not accepted
- The ability to use generic medicines prequalified by WHO, in order to reduce the cost of HIV treatment and significantly increase an access to treatment in Latvia is not even considered.
- The State recognizes that treatment in Latvia should be provided for 700 up to 1200 patients, but the relevant authorities do not take measures to attract patients for treatment. **Budget allocations for HIV treatment cover only 50% of the required amount.** Currently 483 patients receive antiretroviral therapy.
- Only 3169 patients were observed by doctors out of 4702 reported PLWH in Latvia (at 1 May 2010) - it is 67,4% of registered cases. Although one third of all PLWH is not observed by the doctors, responsible agencies believe that this is the problem of the patients themselves, and not even consider the possibility of finding these people.
- Secondary testing of pregnant women, as well as re-testing of prisoners in penitentiaries is not held out and is not specified in the regulations, which creates a risk for the spread of infection through vertical transmission and in conditions of prison life.
- State funding for primary and secondary HIV prevention, as well as in programs to limit the spread of HIV infection in 2009 - 2013 years, is extremely inadequate

Recommended actions to address the problems:

1. Non-governmental organizations should develop a joint long-term advocacy plan to address the above problems.
2. Include professional lawyers in the "Coordinating Commission to reduce HIV infection, tuberculosis and sexually-transmissible diseases" to legally correct protocol decisions for their further advancement in decision-making structures.
3. Include HIV NGOs representative in the Advisory Council for Pharmacy in order to increase the ability to influence pricing of the pharmaceutical market in the country.
4. Propose to the Ministry of Health to establish a reasonable period of "Recommendations on rational pharmacotherapy of HIV infection in a limited state budget conditions", beyond which the recommendations of WHO automatically come into effect
5. Need to develop a program to improve adherence to treatment and social support, adopt the best practices of neighboring countries, to implement these programs in low-threshold centers with appropriate funding from the state.
6. Arrange peer counseling cabinet in the Latvian Infectology Center.
7. Develop practical guidance for family doctors on the management of patients with HIV infection and include ambulatory care of patients with HIV in the quality criteria of the family doctor.

8. Introduce mandatory training for general practitioners on specifications of diseases in PLWH.
9. Take practical steps to organize integrated services.

Also the recommendations of the positional Letter of the Baltic Positive Commonwealth to the heads of Latvia, Lithuania and Estonia should be implemented:

1. Prevention programs among vulnerable groups (including harm reduction programs) should be a priority because HIV prevention is a much cheaper than a treatment of HIV infection and dealing with the consequences.
2. Treatment for HIV infection should be appointed solely on medical conditions, on the basis of clinical protocols on HIV treatment for the WHO European Region, because HIV treatment is proven to be a best prevention.
3. Create conditions for implementation of patient-centered integrated services in order to use available resources with the highest possible efficiency.
4. To apply to the international institutions and foundations requesting financial support for programs of prevention, treatment, care and support for people living with HIV on the grounds of reduction of available State recourses
5. To include the obligation to limit the spread of HIV infection, as a state function into a legislation of local municipalities.

LITHUANIA

Lithuanian national network of PLWH «Pozityvus gyvenimas»

Assessment of involvement of civil society in preparation of the national reports for UNGASS in 2008 - 2010.

- There was no involvement of CSOs in the preparation of the national UNGASS report from the government side.
- Engagement was assured only through the UN agencies in Lithuania. By the initiative and with the direct mediation of UNODC representatives of three Lithuanian organizations participated in the national report preparation.
- Lithuania has not conducted a poll on the National Composite Policy Index.
- Once the report was finished, the drafts and the final version were not presented to civil society.
- When completing the report, civil society representatives pointed out that the formulation of questions and suggested answers in the report are too superficial, and do not presuppose a realistic picture of the situation in the country and predispose the freedom of interpretations.
- In preparing the report, representatives of the civil society and international organizations have faced the problem of inconsistency of some data, in particular the amount of HIV in prisons, the total number of AIDS cases in comparison to those who have died of AIDS in previous years and in 2009.

Problems existing in the country, but not mentioned in the National report

- There are doubts about the veracity of the data provided to the national report on HIV infection by regions, as far as the data submitted by the Lithuanian Centre for AIDS and communicable diseases were utilized using the registration of residence, not place of residence and receiving of services by a patient with HIV/AIDS. Therefore, there is a reasonable doubt in the reality of the shown situation and the geographical distribution of HIV in Lithuania.
- Once started in April 2009 a reform in the health care system in Lithuania, the situation has become catastrophic in terms of access to treatment, as well as HIV care and support and testing.
- In Lithuania, access to treatment with ARVs to all who need it is limited by the existing HIV treatment protocols. Being guided by these methods, **HIV treatment in Lithuania may be initiated when the CD4 count is less than 200.**
- Funding for the purchase of antiretroviral drugs is not increased, while demand for treatment has increased significantly. Due to lack of funding, ARV treatment initiation for new patients will not be possible.
- Since January 2010 not only with shortages of ARV medicines started, but as well with an immunological analysis of blood for patients with HIV. **The funds provided to carry out immunological studies of blood in patients with HIV, were used for the purchase of vaccines against influenza.** In 2010 free blood test is not available for PLWH in Lithuania.

- Every citizen of Lithuania, who was diagnosed with HIV infection, automatically receives health insurance. The amount of health insurance for PLHIV includes free medical consultation, diagnostics, ARV therapy, and only 2 days of hospitalization. Such aid does not meet the needs of PLHIV.
- At the present day no funds are allocated for the prevention and treatment of opportunistic diseases in Lithuania. The cost for the prevention and treatment of these diseases is to be fully covered by the patient.
- In Lithuania, the state does not fund programs to provide peer counseling services, psychosocial support for PLWH and adherence to treatment. Anonymous HIV testing is also to be paid by the client and the tests costs about \$ 10. Testing centers are located only in the administrative centers of districts.
- There are no programs aimed at prevention among men who have sex with men (MSM) in Lithuania since 2008.
- The cost of providing medical services for prisoners is fully covered by the Ministry of Justice of Lithuania. MoJ is unable to cover the costage of purchase the ARVs medicine for those all in need of treatment in penitentiary. For the Ministry of Justice tender, ARV drugs are considered as a subject to an increased rate of state tax, comparing to the Ministry of Health. Due to insufficient funding ARV treatment in detention for PLHIV is very exceptional.

Recommended actions to address the problems:

1. Treatment, care and support for HIV / AIDS

1. Provide patients with HIV / AIDS approach to quality health care for at least 40 hours per week.
2. To ensure and guarantee the free, regular screening of blood for patients with HIV / AIDS.
3. Ensure continuity of treatment of patients with HIV / AIDS quality ARVs.
4. Provide prevention and treatment of opportunistic infections in patients with HIV / AIDS.
5. To ensure control, prevention and treatment of co-infections.
6. To ensure public support for providing peer counseling, psychological care and social support.

2.Groups particularly vulnerable to HIV

1. Provide an approach to free HIV testing for persons in the risk of infection.
2. Provide an opportunity for HIV testing using rapid tests in the low-threshold offices and during social events.

3. Ensure risk approach to safe, counseling, psychological and social assistance to low-threshold offices.
4. Provide an approach to the means of harm reduction for drug users (needle exchange, provision of security tools, educational materials, etc.)
5. Provide drug treatment patients substitution therapy in prisons.
6. Ensure continuity of treatment of patients with HIV / AIDS in prisons.
7. Provide an approach to HIV prevention in prisons.

3. NGO sector

1. To ensure and guarantee the participation of NGOs in the implementation of national policies for prevention and control of HIV / AIDS and harm reduction.
2. Ensure the involvement of NGOs in prevention work with vulnerable groups
3. Involving representatives of PLWHA and civil defense in the coordinating committees of national programs for prevention and control of HIV / AIDS and drug addiction.

TAJIKISTAN

Assessment of involvement of civil society in preparation of the national reports for UNGASS in 2008 - 2010.

- The National report states that non-governmental organizations participated in the development of the national report, but what exactly has been done is not specified.
- It is not known who came up with the initiative to invite those organizations, as it is still not clear if any organizations did participate in preparation of the above mentioned report.
- The country has conducted a poll on the national composite policy index, since this problem was posed in the past, in the national report from 2007. Not all organizations have participated in the discussion of NCPI, and the results distributed to public as well as the final version of the NCPI have not been published.
- Community organizations had no opportunity for input to the numerical data while developing the report. The report includes only the official data of the Ministry of Health sentinel surveillance data and the results of studies carried out by the MoD and the Ministry of Health, although many studies and projects that are carried out by NGO's in RT they may have been interesting and they also could be included in the National report.
- Draft of the National report was not available. The report itself and its final version was posted at the UN website.
- International agencies have been fairly passive in terms of attracting a wide range of NGOs. There is a lot of mailings in the country, which could be used to inform NGOs and people living with HIV, but these resources have not been used. There are also NCC, MHAIDS, UN websites, where the information from report development could be posted, but these resources have not been used.

Problems existing in the country, but not mentioned in the National report

- The National report widely describes the social work, mentioning the figures held activities among the population (number of distributed information materials, outreach workers, women, youth, etc.), but on the other hand outlines the effectiveness of work among the vulnerable communities, for example, did not sanctify the problem of interaction GO and state structures, no concrete examples of project-oriented and the problems associated with the use of HAART, the quality of life of PLWHA, IDUs, MS, MSM.
- The problems described in the report mainly relate to government services and have the problem of highlighting the problems of the representatives of the communities, all current research and best practices are aimed at assessing of the financial resources, that clearly show the need to fight with the spread of the epidemic in the whole country and ignores the needs of specific vulnerable groups.
- The national report failed to mention the problem of rehabilitation of drug addicts, the problems of lack of free treatment in clinics in the country, for IDUs (PLHIV) are not highlighted.
- The problem of drawing needed healthcare resources such as a social worker, psychologist, outreach workers in public health facilities and the problem of juvenile law (in ongoing work with homeless children or conducting prevention in schools) were not pointed out.

- There is a lack of medical care for HIV infected persons. PLHIV do not have the funds to obtain medical services, as all services are paid to be paid for. Medical services for people living with HIV has not been developed. There are no specialists and services such as dentistry, ultrasound diagnostics or surgery. While the law regulates the free assistance to HIV-positive patients, payment is still required for everything. Even with disclosure status, health facilities are still not free for people living with HIV, as there is no funding provided.
- There is a lack of coordination in NGO activities. Donor agencies have created a non-competitive system of grants. This results in an unhealthy competition in the country and lack of coordination and cooperation between NGOs in the country. Donor agencies have become dominant in the decision-making process in all respects.
- The information about grants is closed, and not widely spread. For more than 12 years, there have been representatives of the DPP, working on HIV prevention, and millions of dollars on HIV prevention have been allocated since. But all are repeating that NGO capacity is low. The question is what have donor agencies been doing, if for more than 12 years they could not do anything about the potential of NGOs? Why are the best practices in the country not shown in the report?
- The information provided in the report is often one-sided. For example, the report states that the potential of CSOs is low. Meanwhile, no one has investigated the quality of services provided by CSOs, as well as research on the potential of the service providers does not exist.
- The lack of monitoring and assessing of the quality of the service providers. There is no common mechanism, for assessing of the quality of the services.
- The pre-test counseling is not carried out frequently. Several researches have been held in the country to prove this. The counselors' knowledge and skills for this topic are below the appropriate levels. Counseling in prisons and among pregnant women is not carried out most of the time.

Recommended actions to address the problems:

1. It is necessary to create a unified exchange system on the state of affairs in civil society , with the necessary exchange of statistical data with its calculation, basic data (target groups, human resources, services, customer needs, level of satisfaction), common information exchange system or databases are seriously needed.
2. Properly timed exchange of information with government agencies on clients database and services that can be provided to the every specific client, is also required
3. The DPP representatives who participate in the development of certain documents, or who are the representatives of the NCC , need to be known, in order to understand and on what basis decisions are made or certain requests are allocated. The participation of DPP should not be overly formal.
4. The legislative framework for regulation of Defense and representatives of ministries and agencies, is necessary, as otherwise there is no possibility to sign the memorandums and the agreements for working together, as a status of OO does not match the status of the ministry.
5. It is important to develop and implement a mechanism for monitoring and evaluating the service of the providers.

6. Active involvement of the community in decision-making process is important. Groups of representatives of PLHIV, injecting drug users, are established in the country, who can and are willing to openly address the problems and share experiences.
7. Ensuring adequate and unbiased attitudes towards those DPP, who do not share the views of donor agencies.
8. Expansion of HR programs, and quality implementation of the methadone program.
9. Piloting the methadone program for one small group. Provide an integrated approach to the GP.
10. Helping to improve the potential of AIDS service organizations. Assess the needs and requirements of service providers and respond to their needs.

KAZAKHSTAN

Assessment of involvement of civil society in preparation of the national reports for UNGASS in 2008 - 2010.

- 13 October 2009 the Director General of RAC had approved the order № 26-P, of establishing a working group to prepare a national report for 2008 - 2009.
- The working group included representatives of international organizations and NGOs, such as: AIDS Foundation East West, representatives of the project to control AIDS in Central Asia, Kazakhstan Union of People Living with HIV.
- RAC claims that the questionnaires have been sent to several NGOs, but the replies have been received from only two of them. However, three of the five leading AIDS service NGOs in the country, who participated in the preparation of the previous national report, claim that they have not received any form at all.
- A wide poll on the National Composite Policy Index (NCPI) has not been done. Only five organizations, including UNAIDS and Control Project for AIDS in Central Asia, have complete the questionnaire in its part devoted to representatives of civil society organizations, bilateral agencies and UN organizations .
- The right to complete numerical data for inclusion in the report was officially given only to two NGOs.
- The national report and questionnaire on the national index of policies were reviewed and discussed at the one-day meeting, held on March 15, 2010 in Almaty. The representatives of two nongovernmental organizations: the Kazakhstan Union of PLHIV (NGOs) and the National Association of AIDS Service Organizations (NACA) were invited on the meeting. However, only one NGO, the Kazakhstan Union of PLHIV turned up on the meeting. Thus, the draft national report was received and discussed only with a national NGO.
- The final version of the report has not been widely distributed enough.

Problems existing in the country, but not mentioned in the National report

- According to NGOs survey, there is no institution of social workers focused on issues of HIV / AIDS. And all that despite the existence of the Order of the Minister of Labour and Social Welfare of the Republic of Kazakhstan dated January 26, 2009 № 25 "On Approval of qualification requirements for social workers in the field of social protection and the rules of their certification, and passed the Act on special social services". However, the law enforcement practice of law in the field of HIV remains at a very low level.
- Treatment of hepatitis remains unaffordable for most in need of it. The product "Pegintron", is registered in Kazakhstan, but a full course of treatment is not carried out. Only a short course is held, as this drug has a lack of quantity and it is very expensive.
- A fairly high level of stigma and discrimination against people living with HIV is typical in Kazakhstan, especially in the South Kazakhstan region.

- National treatment guidelines have not been updated since 2004. RAC regularly updates those guidelines, but unfortunately the awaiting of the Ministry of Health of the Republic of Kazakhstan approval causes a delay in the process.
- Serious problems with the formation of commitment during HAART. Over 70% of PLWHA receiving treatment are injecting drug users. Irregularity of the medication intake and omissions are what everybody under the treatment faces.
- There is a serious shortage of infectious specializing in the field of ART, in the country. There is no clinical basis for doctors. Altogether there can be found a catastrophic shortage of specialists in general, not to mention specialists in HIV infection. Professionals, especially psychologists and medical workers have to be provided firstly and only then the problem can be sorted.
- The prison system health care providers often simply provide HIV-positive convicts with the prescribed medicines, while those use them take them at their discretion.
- Substitution therapy works primarily as a component of adherence to ART, but still the harm reduction is very low.
- MPC (multidisciplinary teams) are practically not operating. The best practices of NGOs on the MPC are not used in practical work. Created project AFEW «Social Bureau" did not find any support from the government and are now self-supporting material base.
- There are serious problems in the registration of ARV medications. Registration can take for up to a year or even more. From all the generics suppliers in Kazakhstan only company "Rambaksi" is registered, witch means there is no competition, which, accordingly, affects the choice and the price of drugs.

Recommended actions to address the problems:

1. Coordinating Council for working with NGOs on AIDS and drug addiction in the regional and district akimats (municipalities) must abandon traditional formal work regime and start building a long-term program in cooperation with the NCBs.
2. We must begin to implement the law on social workers focused on issues of HIV / AIDS, aiming on providing them with the high quality of education and employment.
3. Public services should consider shortening the time of registration of drugs to treat HIV and viral hepatitis.
4. All interested parties should start advocating lowering the cost of drugs for the treatment of hepatitis "C".
5. Ministry of Health should revise outdated protocols for treatment.
6. Existing studies for successful multidisciplinary teams should be supported by the State and implemented as widely as possible.
7. Government and donors should allocate funds to train infection doctors as well as develop and implement programs of their training.