CIVIL SOCIETY INVOLVEMENT IN PREPARATION OF COUNTRY REPORTS FOR UNGASS 2008:

Europe and Central Asia

Report

AIDS ACTION EUROPE

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About the Project
A Civil Society Support Mechanism was set up at the end of 2007 by a Coalition of community organizations, with support from UNAIDS. It aims to provide communication, consultation, and coordination support for civil society to be meaningfully involved in the review of the implementation of the Declaration of Commitment on HIV/AIDS (2001) and the Political Declaration on HIV/AIDS (2006).
The Coalition was formed by the African Council of AIDS Service Organizations (AfriCASO), AIDS Action Europe, the Asia-Pacific Council of AIDS Service Organizations (APCASO), the Latin America and the Caribbean Council of AIDS Service Organizations (LACCASO), the International Council of AIDS Service Organizations (ICASO), and the International Women's Health Coalition (IWHC).

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Regional and international Civil Society Support Groups made of up diverse civil society organizations and representatives will provide the leadership and direction for the support mechanism, functioning as consultation, coordination and advisory groups for the different levels of activities. These will be facilitated and supported by the Coalition members, with communication also being supported by Health Development Networks and World AIDS Campaign.
The project in Europe and Central Asia is coordinated by AIDS Action Europe with the support from Eurasian Harm Reduction Network (EHRN) and ICASO.

About organization
AIDS Action Europe was established in 2004 and wants to work towards a more effective response to the HIV and AIDS epidemic in Europe and its neighbouring countries. AIDS Action Europe is a pan-European partnership of non-governmental organisations (NGOs) that works towards a more effective response to the HIV and AIDS epidemics. AIDS Action Europe addresses the needs of communities affected by HIV, by effectively linking and mobilising NGOs across Europe and advocating their concerns. It aims to be a transparent and inclusive partnership, and encourages greater involvement of people living with and affected by HIV in tackling the epidemic. AIDS Action Europe supports and links European NGOs, mobilises and advocates NGOs around key issues and facilitates the exchange of knowledge and information.

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I. EXECUTIVE SUMMARY

The role of civil society and people living with HIV (PLWH) involvement is often described as central or key in effective response to the AIDS epidemic worldwide. People living with HIV and civil society organizations possess the knowledge and experience, which is a great resource both for policy planning and implementation, implementation of programs, and monitoring and evaluation, including UNGASS reporting.

Since 2001, the number of countries having submitted Country Progress Report has been increasing; however, the point of this study is to see if involvement of PLWH and civil society has become more effective, too. Analysis of information available leads to the conclusion that not all of the countries of the region see the added value of involvement of civil society and PLWH representatives, and this disbelief leads to cases of non-involvement or tokenistic involvement of civil society. The latter is even more dangerous, as in such a case resources are being spent only to demonstrate involvement, but not to actually ensure productive collaboration with civil society.

Several problems were identified preventing PLWH from becoming involved in processes affecting their lives. Probably the biggest one is lack of capacity of NGOs, including PLWH associations, to contribute effectively. Secondly, lack of conditions for effective feedback has also been reported to impede effectiveness of involvement. For example, without access to information about data collection plans, civil society and PLWH may not contribute effectively. Another problem is that not all governments followed UNGASS Guidelines and conducted a national consultation with all stakeholders. Lack of any public discussions, open to everyone, significantly limits opportunities of civil society and PLWH to be helpful; they may end up being able only to give their comments, and expect that these comments will be incorporated into the Country Progress Report. Not the least, stigma and discrimination are factors discouraging PLWH to become socially active.

The report identifies current difficulties for full involvement of PLWH and civil society organizations, and offers recommendations on how to better tackle them. While geographical coverage of the report is limited to Europe and Central Asia, its finding may prove to be effective in other parts of the world as well.

II. INTRODUCTION

Background

The role of civil society and PLWH involvement is often described as central or key in effective response to the AIDS epidemic worldwide. However, the right of PLWH to be involved in decisions affecting their lives has only recently been recognized; only recently the term *civil society* started to include PLWH caucuses.

NGOs have a relatively long history of partnership with governments worldwide in various socially significant domains (children and youth, gender, human rights, community support, environment protection, etc.), where civil society acts both as an advocate, lobbying for a positive social change, and as a service provider. Also, civil society organizations have been actively involved in research, monitoring and reporting, and have accumulated a considerable knowledgebase, which made them a valuable resource on practically any issue.

In contrast, PLWH spoke up to be involved as an equal partner quite recently; this call was first formulated in the Denver Principles of 1983, which recommended that PLWH "be involved at every level of decision-making and specifically serve on the boards of directors of provider organizations" and "be included in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge"[1].

More than a decade later, in December 1994, representatives of forty-two governments gathered in Paris to sign the Paris Declaration, which dealt with a variety of matters including the greater involvement of people living with HIV/AIDS.

By this Declaration governments solemnly declared their "determination to mobilize all of society - the public and private sectors, community-based organizations and people living with HIV/AIDS - in a spirit of true partnership", undertook to "fully involve non-governmental and community-based organizations as well as people living with HIV/AIDS in the formulation and implementation of public policies", and committed to "Support a greater involvement of people living with HIV/AIDS through an initiative to strengthen the capacity and coordination of networks of people living with HIV/AIDS and community-based organizations. By ensuring their full involvement in our common response to the pandemic at all - national, regional and global - levels, this initiative will, in particular, stimulate the creation of supportive political, legal and social environments"[2].

As involvement of civil society *and* people living with HIV in response to the epidemic proved to be effective in different contexts, nationally and globally, the 2001 Declaration of Commitment on

HIV/AIDS has acknowledged "the particular role and significant contribution of people living with HIV/AIDS, young people and civil society actors in addressing the problem of HIV/AIDS in all its aspects, and recognizing that their full involvement and participation in the design, planning, implementation and evaluation of programmes is crucial to the development of effective responses to the HIV/AIDS epidemic"[3]. It emphasized that, "Leadership by Governments in combating HIV/AIDS is essential and their efforts should be complemented by the full and active participation of civil society", and called to "conduct national periodic reviews with the participation of civil society, particularly people living with HIV/AIDS, vulnerable groups and caregivers, of progress achieved in realizing these commitments, identify problems and obstacles to achieving progress, and ensure wide dissemination of the results of these reviews".

In 2002 the UNAIDS Secretariat, in collaboration with UNAIDS Cosponsors and other partners, developed a series of core indicators to measure progress in implementing the Declaration of Commitment on HIV/AIDS. While the Declaration of Commitment on HIV/AIDS reflects global consensus on a comprehensive framework to achieve the Millennium Development Goal of halting and beginning to reverse the HIV epidemic by 2015, the indicators were developed as a tool of measuring success. In order to explain the indicators and the reporting process, Guidelines on Construction of Core Indicators[4] were developed; they were reviewed for 2005[5] and 2008 reporting[6]. The latter were influenced by recent documents, promoting GIPA in the region of Europe and Central Asia, in particular 2007 Bremen Declaration on Responsibility and Partnership – Together Against HIV/AIDS.

In this context, the Guidelines point out that "the wide range of strategic and tactical expertise within civil society organizations makes them ideal partners in the process of preparing National Progress Reports. Specifically, civil society organizations are well positioned to provide quantitative and qualitative information to augment the data collected by governments. They can provide a valuable perspective on the issues included in the National Composite Policy Index. They are also equally well positioned to participate in the review and vetting process for progress reports"[7]. Agencies, which were assigned to coordinate country progress reporting, have to seek maximum input from civil society, including nongovernmental organizations, faith-based organizations, trade unions and community-based organizations, for their reports on the core national-level indicators underlying the UNGASS Declaration of Commitment on HIV/AIDS. "The importance of securing input from the full spectrum of civil society, including people living with HIV, cannot be overstated; civil society speaks with many

voices and represents many different perspectives, all of which can be valuable in the monitoring and evaluation of a country's AIDS response"[8].

2008 UNGASS Guidelines set a number of criteria to be met during the preparation of Country Progress Reports. So, in order to have a productive relationship of Governments with civil society during the preparation their of reports on the core indicators, they are recommended to provide civil society organizations with easy access to their plans for data collection, as well as a straightforward mechanism for submitting and evaluating information for the Country Progress Report. "As part of this effort, these organizations should also be invited to **participate in workshops at the national level** to determine how they can best support the country's reporting process. In addition, civil society in every country should have sufficient opportunity to **review and comment on the Country Progress Report** before it is finalized and submitted" (emphasis added). The report submitted to UNAIDS "should be **widely disseminated** to ensure that civil society generally has ready access to it. UNAIDS staff at the country level are available to help facilitate input from civil society throughout the process. In particular, UNAIDS country-level staff are available to brief civil society organizations on the indicators and the reporting process; provide technical assistance on gathering, analysing and reporting data, including focused support to people living with HIV; and ensure the dissemination of reports, including, whenever possible, reports in national languages"[9].

UNGASS guidelines give further instructions as to the content of the report:

"The report should highlight successes as well as constraints and future national plans to improve performance, especially in areas where data indicate weaknesses in a country's response. This report should also include a short explanatory note for each indicator, stating how the numerator and denominator were calculated and assessing the accuracy of the composite and disaggregated data. […]Country Progress Reports should […] refer to each indicator in these guidelines, regardless of whether or not data are submitted on the indicator. In 2008, countries are expected to provide a comprehensive report on all of the national indicators that are applicable to their response.

As discussed previously, and as required by the Declaration of Commitment on HIV/AIDS, civil society, including people living with HIV, should be involved in preparing the Country Progress Report. […] UNAIDS strongly recommends that national governments organize a workshop or forum to openly present and discuss the findings of the Country Progress Report before it is submitted to UNAIDS. Where appropriate, the final report should reflect the discussion at this event. Joint UN Teams on AIDS are available in most countries to facilitate this discussion process"[10].

Therefore, analysis of international standards and guidelines allowed to identify a set of requirements of effective involvement of PLWH and civil society organizations. So, it has to be:

Voluntary: Every PLWH and civil society organization may seek involvement in crucial processes, in which they have interest, experience and/or expertise, such as development and implementation of national AIDS plans and strategies; participation in monitoring and reporting country progress, etc. No person or organization may be forced to participate or make input;

Respectful: A stigma-free atmosphere has to be created. No person or organization may be treated without due respect;

Equal: PLWH have to have an equal voice and standing with other participants;

Representative: Selection of PLWH has to be done by the community of PLWH based on open and transparent procedures; selection of civil society representatives has to be done based on an open announcement and selection procedures;

Professional: Adequate conditions and resources have to be provided in a professional manner.

Enabling: A supportive atmosphere has to be created; PLWH may have additional needs in order to be able to fully contribute – these needs have to be taken into account and, where possible, addressed;

Meaningful: Input from each participant has to be welcomed and taken seriously; conditions should be created to ensure that every participant can and does contribute. Practices of tokenistic involvement of PLWH and civil society representatives should be eradicated.

In order to evaluate effectiveness of civil society and PLWH involvement in preparation of Country Progress Reports, as well as other activities related to HIV/AIDS (program planning and implementation, monitoring and evaluation, etc.), one has to thoroughly analyze, to what extent this involvement meets the above requirements.

Goals and Objectives of the Study

The International Council of AIDS Service Organizations (ICASO) has entered into an agreement with UNAIDS to establish a mechanism to support the involvement of civil society organizations in the 2008 AIDS Review processes at national, regional and country levels. ICASO is partnering with AIDS Action Europe and Eurasian Harm Reduction Network (EHRN) to carry out

the activities required for the project in the European and Central Asian region, with specific focus to Eastern Europe and Central Asia.

The main goal of this project, which has started at the end of 2007, is to support civil society and facilitate its meaningful involvement in the processes related to UNGASS 2008. The project entailed establishment of a Regional Civil Society Support Group and assignment of a project coordinator working in the region of Europe and Central Asia.

This study is aimed at determining the level and quality of civil society and PLWH involvement in this process. To this end, the study was to answer a set of questions on **overall assessment** (background to the HIV epidemic in the region, including an overview of relevant issues, such as treatment, prevention, voluntary counselling and testing (VCT), and human rights; an overview of the processes used to consult and prepare the progress report, particularly assessing the quality of the involvement of the community sector; and an overall regional assessment of the quality of the reports, e.g. their being complete, inclusive and truthful); **involvement process** (how did the review/reporting process start; how was the "community sector" defined and who was included in this definition; who defined the community sector; what other sectors were involved; what support did they receive from other stakeholders in order to be involved, etc.).

To facilitate this process, a consultant was hired to:

1. Read and analyze country reports submitted by United Nations (UN) member states to UNAIDS on the progress of Declaration of Commitment
2. Analyze quality of the country reports
3. Identify main targets of the reports (universal access, civil society involvement, PLWH involvement, etc.)
4. Analyze quality of civil society and people living with HIV involvement in preparation of country reports: highlight main challenges, successes, what worked well, etc.
5. Develop structure of the report and write it.

The report was submitted to the Eurasian Harm Reduction Network on 31 March 2008.

III. METHODOLOGY

In order to obtain accurate and full information, the consultant used a combined methodology, consisting of three major methods of data gathering:

1. **Desk review,** covering a wide range of resources, including, but not limited to, Declaration on Commitment on HIV/AIDS and 2006 Political Declaration; UNGASS Guidelines on Construction of Core Indicators; 30 country reports, shadow reports (Russia, Ukraine), advocacy materials (UNAIDS[11], ICASO[12], EHRN, etc.), UNAIDS reports, as well as other research and data.

2. **Questionnaires** were developed in English and Russian in order to supplement information received from desk review. The questionnaires were sent to representatives of civil society and PLWH organizations, involved in UNGASS reporting at the country level, in the following European and Central Asian countries:: members of Eastern European and Central Asian Union of PLWH Organizations (ECUO) (Armenia, Belarus, Kazakhstan, Lithuania, Latvia, Estonia, Moldova, Poland, Tajikistan), also to Belgium, Finland, France, Germany, Kyrgyzstan, Macedonia, Portugal, Romania, Russia, Turkey, Serbia, Sweden, Switzerland, The Netherlands, Ukraine, and United Kingdom. Answers were received only from 6 countries: Armenia, Belarus, Estonia, Kazakhstan, Lithuania, and Romania.

3. While the above two approaches are usually very effective, they are highly time-consuming and, against short deadlines, may return insufficient information. Therefore, in order to save time, certain methodological procedures had to be skipped (e.g. questionnaire pre-testing), and information gaps had to be filled by using another method, namely **follow-up in-depth interviews**. These were carried out with questionnaire respondents, as well as additional respondents, who were unable to fill in the questionnaire, but were available for an interview (face-to-face, telephone or email). The aim was to supplement the two previous methods of information gathering; the interviews were particularly relevant, when Country Progress Report was missing necessary information (e.g. about PLWH involvement in report writing process), while questionnaire had not provided enough details.

Challenges and difficulties

There were several difficulties faced by the research team during the development of this report. A major problem was shortage of time. A proper consultation process is time consuming, but it is indispensable to ensure high quality of research.

Another difficulty was low rate of responses. As a result, only few countries were properly analysed. However, critical remarks of respondents reflect not only their own country's situation, but are illustrative of common patterns in the region.

Coverage of the report

This study covers countries of Europe and Central Asia. The term *Europe* is used in a broad political sense: it includes countries, which should geographically be considered as Asian (e.g. Southern Caucasus). Therefore, the study covers the following countries, which submitted their Country Progress Reports (it should be noted that the list of countries was taken from the official UNAIDS web-site[13]):

1. Albania	**9. Georgia**	**17. Macedonia**	**25. Slovenia**
2. Armenia	**10. Germany**	**18. Moldova**	**26. Spain**
3. Belarus	***11. Greece***	**19. Montenegro**	**27. Sweden**
4. Belgium	**12. Ireland**	**20. Netherlands**	**28. Switzerland**
5. Bulgaria	**13. Hungary**	**21. Poland**	**29. Tajikistan**
6. Croatia	**14. Kazakhstan**	**22. Romania**	**30. Turkey**
7. Estonia	**15. Latvia**	*23. Russian Federation*	**31. United Kingdom**
8. Finland	**16. Lithuania**	**24. Serbia**	
Highlighting code: **Bold – submitted a CPR in 2008*** Underlined – submitted a CPR in 2005 *Italics – submitted a shadow report in 2008**			

* Information as of 31 March 2008. The deadline for submitting reports was 31 January 2008, but it is possible that more countries will still submit their national and/or shadow reports.

While the study covers the entire region of Europe and Central Asia, special attention has been drawn to Eastern Europe and Central Asia. This is explained by a more difficult situation in this part of the continent, as compared to Western Europe.

The region represents a variety of cultures; various integration processes of the 20th and 21st centuries remapped it significantly. Unification of Western Europe after World War II, and emergence of the Socialist block divided Europe into two confronting camps. With the collapse of the Soviet

Union, countries of Central and Eastern Europe re-oriented themselves towards democracy and market economy, but they still, though to a different extent, have certain commonalities, which may be seen both in general economic and political situation, and in particular, in their HIV epidemics.

In the 1990s, all countries of Eastern Europe and Central Asia suffered huge economic and political crisis. Those countries, which were geographically located closer to developed Western Europe, opened themselves to the European integration. As a result, they accelerated political and economic reforms, but they became equally vulnerable in the face of typical Western ways of HIV transmission: mainly homo- and hetero-sexual transmission, with a smaller share of infections among injecting drug users (IDUs).

Countries farther to the East faced a more devastating crisis and overwhelming poverty; their role as transit countries for drug trafficking and exporters of cheap labour, has not only preconditioned high rates of the epidemic in the most at-risk populations (mainly IDUs), but also influenced significantly on HIV prevalence in Western Europe, which increased due to inflow of labour migrants from former Socialist countries.

Besides, all former Socialist countries are comparatively new to the very idea of civil society; capacities of NGOs are usually much smaller than those of their Western counterparts, and they most often need considerable external support in order to become sustainable. PLWH organizations have to cope with additional difficulties. Firstly, it is the notorious stigma, which is attached not only to people living with HIV, but also to their associations, and which brings about discrimination in form of tokenistic involvement (involving someone, who does not represent the community of PLWH or is incapable to actively engage), ignoring feedback, under-resourcing (providing insufficient time and resources to contribute effectively), etc. Stigma also prevents many HIV-positive professionals from going public, and thus limits capacity of PLWH organizations.

Prevailing HIV epidemic among IDUs coupled with poverty and low incomes in the countries of the Commonwealth of Independent States (CIS) poses another potential threat to very existence of these organizations, e.g. when organization's management starts actively using drugs. Add to this lack of experience as a civil society group – and oftentimes, of basic education – of the majority of PLWH, and it will become obvious why "Governments and donors should prioritize initiatives to build and sustain the capacity of community organizations and networks of people living with HIV to respond to the epidemic[14]".

There is no need to conduct research to reveal a dependence between, on the one hand, country's economic well-being and democratic governance, and, on the other hand, activeness of civil

society organizations. But it becomes difficult to reveal any correlation between national economics and politics on the one hand, and effectiveness of involvement of PLWH in country-level UNGASS monitoring and reporting processes.

Research findings therefore reveal several major factors, which pre-condition effectiveness of civil society involvement in UNGASS reporting, namely:

a) presence of **goodwill** to collaborate. When authorities see the benefit of involving civil society and/or PLWH in national response to the epidemic, they do not try to keep civil society and/or PLWH away from politics (international politics, if we take UNGASS processes) and policy-making. When governments see the benefit of involving civil society and/or PLWH in monitoring and reporting country progress, they do not restrict or limit NGOs and PLWH, but rather take measures to maximize civil society's input. At the same time, goodwill and commitment of civil society organizations are just as important, meaning their willingness to contribute as much as possible of their expertise and experience, time and resources.

b) **ability** of civil society, including PLWH, to contribute. Lack of access to information about UNGASS reporting may significantly obstruct effectiveness of civil society and PLWH involvement. Ability of civil society can be easily increased by targeted support from the Government and international organizations, and it depends enormously on the previous factor – the goodwill of the Government.

c) **capacity** of civil society organizations and, in particular, PLWH associations and networks, to contribute. This factor is more difficult to address, as it includes availability of qualified human resources; knowledge of, and ability to use, reporting methodology; communication and presentation skills, etc.

d) **technical support** available. The Declaration of Commitment urges UNAIDS to play a facilitating and coordinating role; however, to what extent is this support provided?

The region, when looked at through the prism of these factors, reveals further differences among countries. So, even neighbouring countries may be antipodes in terms of political will to partner with civil society and PLWH; capacity of NGOs to contribute may also vary drastically. Finally, support provided by UNAIDS and other UN agencies was reported to be from "none" to "100%"

IV. FINDINGS

Analysis of Country Progress Reports shows that their quality varies significantly, mostly depending on how the report writing took place. Countries, where a wide spectrum of organizations and people were engaged, have provided better reports in terms of their comprehensiveness, completeness and inclusiveness; and vice versa, the smaller the circle of participants and contributors, the lower would be the quality of the final product (data or opinions are missing, information on certain issues may be insufficient, etc.). However, this is true only when all stakeholders are equipped with a solid knowledge of reporting procedures, and are willing to contribute. Another important factor is leadership, ie who led the process of CPR writing, and endorsed the report.

In general, it should be emphasized that countries are doing better in terms of reporting on indicators: the number of indicators reported is growing, while monitoring techniques are becoming more uniform. Notably, Georgia presented a recommendation to add two more indicators to the list (at least for countries where injecting drug use remains to be the major transmission route):

- IDUs coverage with substitution therapy (numerator: number of drug addicts who started therapy during the reporting period/denominator: estimated number of drug addicts by the end of the reporting year);
- Hepatitis C patients coverage with specific antiviral therapy (numerator: number of Hepatitis C patients who started specific antiviral therapy during the reporting period/denominator: estimated number of Hepatitis C patients in need of specific antiviral therapy by the end of the reporting year).

Also, countries report developments on most indicators; improvements can be seen both in scaling up country response to HIV, and in quality of monitoring.

Countries of the region vary substantially in terms of their commitment to collaborate with NGOs and PLWH. For instance, **Finland** may be taken as an example of a high-quality good report, produced as a result of intensive joint work of the Government, NGOs and PLWH.

According to the Country Progress Report[15], the report writing process was initiated in spring of 2007. On June 8, 2007, a coordination meeting of key governmental agencies was held, where participants discussed and divided responsibilities. At the meeting, it was decided to involve civil society not only as respondents at the report data collection stage, but also through two specific consultation and coordination activities. The Finnish HIV-network (a network of Finnish national and multilateral

NGO/Civil Society actors) was assigned to coordinate completion Part B of the National Composite Policy Index (NCPI). Upon completion of the first draft of the report, it was distributed among NGO partners and discussed at a half-day session in November. Feedback from the civil society was incorporated into a new draft, which was shared for final review with other relevant NGO, civil society and governmental stakeholders. The feedback was incorporated, and in January 2008 the Country Progress Report was submitted to UNAIDS.

The report acknowledges the contribution of a number of NGOs – "important players within the Finnish HIV/Aids field"[16], who "have involved themselves actively in the data collection, evaluation and drafting during all steps of the reporting process". Notably, number two in the list of contributors is the Finnish Body Positive Association (FBPA), a peer organization and the only association of people with HIV in Finland.

Unfortunately, only few countries of the region (mostly in Western Europe) have followed all the recommendations of the UNGASS reporting guidelines; a majority of countries fall short in one respect or another.

According to **Kazakhstan** civil society and PLWH activists, the report was prepared fully in line with UNGASS Guidelines. However, the Kazakhstan's CPR is not as inclusive and comprehensive as the Guidelines suggest.

In **Estonia**, civil society and PLWH were involved in the process of CPR writing; however, the initiator of such involvement was not the Government, but the Estonian PLWH Network, which addressed the Estonian Ministry of Social Affairs with a proposal to organize a meeting and to involve PLWH in the process of development of the Country Progress Report. Network leadership expressed their doubts that they would have been involved at all, if they were not proactive, But even so, they believe that the potential of civil society was not used to the full extent, because "civil society in Estonia is passive" and "not united".

The situation in Belarus was even more complicated, Belarusian PLWH Association reports that, "during the preparation of the Country Progress Report, we were purposefully ignored (just like in other processes, important for PLWH, such as preparation of the GFATM application, country-level monitoring and reporting, etc.). […] Our only involvement was limited to a proposal, received through a listserv, to fill in a questionnaire for civil society. So we did. However, our suggestions have not been taken into consideration yet […]. UNAIDS [country office] found it sufficient to get in touch with the Belarusian Association of AIDS Service Providers in order to collect feedback from civil society; the Association held a meeting of members to discuss the CPR […]. However, Belarusian PLWH

Association, not being a member of the named Association, was not informed about the date and venue of the meeting, and therefore could not take part in this event […]. Later on we found out that the presentation of the final draft of the Country Progress Report took place at the CCM session, but the PLWH representative, who is a member of our organization and an official CCM member, was not invited. We discussed this issue both with the Healthcare Ministry and UNAIDS, but they answered: "Nothing important for you was discussed there; we will invite you next time"". Interestingly, the Belarusian PLWH Association said that "only those PLWH were involved, who would respond *correctly* or would just keep silence. Discussions were built on the principles of quasi-transparency. Well, an outsider may have an illusion that all rules are observed…". As a result, when asked to assess the quality of the Country Progress Report, the Belarusian PLWH Association indicated that the report was *not complete, partly inclusive and not truthful*. The main gap of the report was said to be "human rights and HIV".

Another example of tokenistic involvement of PLWH can be seen in Lithuania. The CPR states that it was prepared "by national AIDS centre in collaboration with other sectors, involved in HIV/AIDS prevention programme implementation. The report was publicly presented to civil society in press conference in January 2008 and on the website of Lithuanian AIDS Centre www.aids.lt, discussed in a large forum with key representatives working in the area of HIV, people living with HIV, including representatives working in education, health, social, academic sectors, non-government organizations, organizations of people, living with HIV/AIDS". Also, the report refers to wide involvement of civil society and PLWH in other areas as well, such as monitoring and evaluation

However, a questionnaire returned by PLWH activists indicates certain difficulties, which significantly reduced effectiveness of PLWH and other civil society involvement:

The part of the [questionnaire], intended for completion by civil society representatives, was not translated into Lithuanian, and for this reason, many people just could not fill it in, as they did not speak English. No conditions were created for the civil society to participate, PLWH initiative groups from the regions were not aware about the [report] preparation [process] at all. The Lithuanian Gay League was completely ignored".

"The Program Coordination Board plays only a representative function […]. Despite the fact that one representative of PLWH is a member of the Board, the problem that he raises has so far been ignored, and no follow up action has been taken".

"The final version of the report does not even mention violations [of rights of PLWH], the fact that anonymous testing is not available free of charge in Lithuania; lack of prevention and treatment of opportunistic infections of PLWH is only mentioned briefly."

"Only information received from those NGOs, which were either created under the Lithuanian AIDS Centre or being loyal to it, was taken into consideration. Also, the final version of the report contains only information, which does not discredit accomplishments of Lithuania in HIV/AIDS prevention. Comments of State bodies, related to the lack of concrete numerical indicators of services, consultations, etc. During the preparation of the report, the Lithuanian AIDS Centre has only provided the participants with data in per cents. […] We could not find out, what was taken as the totality for calculating these percents. Data were collected mainly in the capital of Lithuania; apart from the office of our organization [Asociacija "Pozityvus gyvenimas"] in the city of Klaipeda, there are no other PLWH activities in the regions. There is also a self-support group in Siauliai, but they were not involved in preparation of the report. Therefore, in no way it can be called a country progress report".

"The report lacks indicators of PLWH's access to medical and psychosocial services; nor does it present quantitative and qualitative indicators of provision/non-provision of services. Problems of PLWH are hardly covered at all".

There are many other problems mentioned in the questionnaire that are not reflected in the CPR, such as in particular lack of effective pre- and post-test counselling, lack of free-of-charge anonymous testing, the fact that medical staff is writing "HIV" on the front page of HIV-positive patients' medical cards, lack of efforts to ease the access of PLWH to services and to protect them from possible stigma and discrimination. Thus, the respondents conclude, the CPR is "too abstract, not truthful, and it only partially reflects the situation in certain regions, but not that of the country".

In **Armenia**, efforts were made to involve all stakeholders, including civil society and PLWH.

"During the preparation of a Country Progress Report […], all representatives of civil society, who are members of the CCM, including our [PLWH association], were involved. Besides, the working draft of the report was published on the official web-site of National Centre for AIDS Prevention, and everyone could get familiarized and give feedback, which was or was not then considered by the CCM working group, depending on how objective that feedback was".

"The process of CPR development was transparent and practically all interested parties had an opportunity to contribute. The problem was that many civil society representatives did not have enough knowledge, skills and will to participate productively. The State, bi- and multi-lateral partners

did not pay due attention to developing capacities of civil society in order to enable it to effectively contribute to/influence on preparation of the CPR"

According to the respondents, a major problem in Armenia was the fact that UNAIDS hardly played a role in the process of CPR drafting. "Some of the direct duties of UNAIDS were taken over by the CCM working group", while UNAIDS was almost not involved at all: they limited their involvement by providing technical support in collection, analysis and presentation of information.

Romania presents different problems. First off, "There is not enough coordination between local and central level, and some small organizations working in HIV/AIDS cover very limited part of the HIV work. For example, the human rights organizations declare their limited capacities to work with HIV/AIDS cases and/or vulnerable groups. There are only few court cases initiated by the HIV affected persons/groups since the epidemic began in Romania".

"HIV/AIDS indicators are not widely distributed and most of the organizations do not include in their workplans the collection of specific indicators needed for reporting. In addition, because the national M&E system do not include a detailed workplan and timeline with reporting needs and indicators that should be collected, many organizations define their own indicators (that are more or less in line with the UNGASS proposed indicators for example)"

It is also worth to mention **Kyrgyzstan**. While the country organized the process, collected and analyzed information with involvement of civil society, the officially endorsed Kyrgyz CPR was not submitted to UNAIDS. Reportedly, there are other countries, which have submitted their CPRs, but this has not been reflected at the UNAIDS web-site. It should also be noted that proper analysis of country reports available at UNAIDS website a significant difficulty. Most of reports are posted without annexes, sometimes missing very important information; such as the description of consultation/preparation process for the country report on monitoring the progress towards the implementation of the Declaration of Commitment on HIV/AIDS.

V. CONCLUSIONS AND RECOMMENDATIONS

A major conclusion of this research is that the region is progressing in responding to HIV pandemic. At the same time, monitoring and evaluation systems, while not available everywhere, are developing as well, and there is clear commitment on behalf of governments to keep on working in this direction. All country reports clearly recognize the impact of Global Fund-supported activities in all areas, be that epidemiology, provision of services, monitoring and evaluation, or institutional capacity

building. At the same time, the region, particularly its Eastern part, still largely suffers from tokenistic representation of PLWH in both decision making and M&E processes.

Research showed that there is a long list of factors, which affect involvement of civil society and PLWH in various processes, including CPR preparation. Some of them are caused by internal capacity problems, when PLWH organizations do not have sufficient capacity to contribute, particularly in countries where such organizations were formed recently and did not accumulate sufficient expertise and human resources. In Eastern Europe and Central Asia, Ukraine represents a unique example, where a PLWH organization was able to grow into a sustainable and well-funded network. The rest of countries face different difficulties, affecting their effective engagement.

It should be noted that more attention needs to be drawn to the way UNAIDS and UN country teams support stakeholders in providing their input on the national level. Analysis shows that UN has played different roles in countries of the region, from being completely passive and merely observing the process of CPR drafting, to being actively involved at all stages of drafting the report. It should be stressed that information about reports having been submitted was not reflected in appropriate manner internationally, i.e. on UNAIDS web-site, where only timely submitted reports (without annexes!) were posted. By the time of submission of the present report, the official UNAIDS web-page on status of CPR submissions has not been updated. In Central Asia, it was confirmed that CCMs in Uzbekistan and Kyrgyzstan have approved their country progress reports and sent them to UNAIDS; however, in the Central Asian region UNAIDS web-site presents only Kazakhstan's and Tajikistan's country progress reports, which is very unfortunate in terms of comprehensiveness of this research.

Capacity building is the key term in context of civil society involvement. Training and professional development of staff and volunteers of community and other civil society organizations, becomes indispensable when it comes to effective communication and feedback.

Only by building capacity of public officials (in particular, members of CCMs) it is possible to ensure that the Government is aware of underlying reasons for GIPA, and welcomes input from civil society and people living with HIV.

It goes without saying that the quality of reports in general immensely depends on the capacity of all stakeholders at country level to contribute. In this sense, more efforts should be made to promote further *coordination*, both vertical and horizontal, in the reporting processes. Efforts should be made to promote better coordination practices at country level.

Consequently, it is clear that another area for improvement is *communication*. The region presents a number of good practices in national response to HIV epidemic, in promoting GIPA, in UNGASS

reporting, Universal Access, and so on, and so forth. By improving information sharing, it will be possible to expect further improvements in country-level HIV reporting.

The following recommendations were made by respondents from the region; these seem to be valid not only in regard of one particular country, but for the region in general:

- UNGASS reporting should be further promoted in the region of Europe and Central Asia, particularly by UNAIDS and co-sponsors; a list of indicators, a clear working plan, and a timeline should be established and made available for all organizations being active in HIV/AIDS area;
- UNGASS reporting needs to be correlated with other reporting processes at country level; a unified system of monitoring and evaluation should be promoted in countries in order to ensure that indicators are measurable against each other;
- In countries, where no M&E systems exist, measures should be taken to introduce effective mechanisms and structures for monitoring and evaluation of progress achieved by the countries in the area of HIV/AIDS prevention, treatment, care and support interventions;
- It is desirable to identify one institution, responsible for the entire M&E process on a country level; where possible, this institution must have capacity and commitment to perform this function in close collaboration with all stakeholders, both governmental and non-governmental;
- Capacity of civil society, and particularly that of PLWH organizations, has to be significantly increased, so that they are able to act as partners to the Government in the field of planning, implementation, and monitoring and evaluation of programs and projects. In particular, trainings should be organized in research methodology, monitoring and evaluation, UNGASS reporting procedures, GIPA, etc.;
- UNAIDS and co-sponsors, as well as other development partners, should provide rigorous support to ensure that civil society and PLWH are actively involved in the areas, where they can contribute their expertise and experience; they should also promote a constructive dialogue between different stakeholders;
- Efforts have to be made in order to ensure that UNGASS Guidelines are available in local languages and are clear to all stakeholders, particularly to civil society and PLWH;
- UNAIDS should review the way country progress reports are published online to ensure full access to information on all countries.

Notes:

[1] Statement from the Advisory Committee of People with AIDS (The Denver Principles), 1983. Available from: http://data.unaids.org/pub/ExternalDocument/2007/gipa1983denverprinciples_en.pdf.

[2] The Paris Declaration. Paris AIDS Summit, 1 December 1994. Available from: www.unaids.org/unaids_resources/images/Partnerships/The%20Paris%20Declaration.pdf.

[3] Declaration of Commitment on HIV/AIDS. Adopted by General Assembly resolurion S-26/2 of 27 June 2001 "Global Crisis – Global Action". Available from: http://data.unaids.org/publications/irc-pub03/aidsdeclaration_en.pdf.

[4] Monitoring the Declaration of Commitment on HIV/AIDS. Guidelines on Construction of Core Indicators. UNAIDS/03.29E (English original, August 2002). Available from: http://data.unaids.org/publications/IRC-pub02/jc894-coreindicators_en.pdf.

[5] Monitoring the Declaration of Commitment on HIV/AIDS. Guidelines on Construction of Core Indicators. UNAIDS/05.17E (English original, July 2005). Available from: http://data.unaids.org/Publications/IRC-pub06JC1126-ConstrCoreIndic-UNGASS_en.pdf.

[6] Monitoring the Declaration of Commitment on HIV/AIDS. Guidelines on Construction of Core Indicators: 2008 Reporting. UNAIDS/07.12E/JC1318E (English original, April 2007). Available from: http://data.unaids.org/pub/Manual/2007/20070411_ungass_core_indicators_manual_en.pdf.

[7] Ibid.

[8] Ibid.

[9] Ibid.

[10] Ibid.

[11] UNAIDS policies and briefs, available from: http://www.unaids.org/en/PolicyAndPractice/default.asp.

[12] AIDS Advocacy Alert: High Level Meeting on AIDS – How to Get Involved (2008); AIDS Advocacy Alert: Urgent Action Now - UNGASS on HIV Country Review Process (2007); AIDS Advocacy Alert: Reviewing National AIDS Responses - How to Get Involved (2007). Available from: http://www.icaso.org/advocacy_alerts.html.

[13] Http://www.unaids.org/en/KnowledgeCentre/HIVData/CountryProgress/2007CountryProgressAllCountries.asp

[14] Declaration of Commitment on HIV/AIDS: five years later. Report of the Secretary-General. UN Doc.: A/60/736, 24 March 2006, 11(b).

[15] Finland 2008 Country Progress Report. Available from: http:/data.unaids.org/pub/Report/2008/finland_2008_country_progress_report_en.pdf.

[16] Ibid.