# Achieving universal access in Eastern, South East Europe and Central Asia – 2010

# An HIV community perspective













### December 2010

### **About organization**

Founded in 1997, the Eurasian Harm Reduction Network (EHRN) unites over 300 members from 29 countries of Eastern and Central Europe and Central Asia with the mission to promote humane, evidence-based harm reduction approaches to drug use, with the aim of improving health and protecting human rights at the individual, community and societal level. EHRN works toward its mission through: documentation and advocacy; technical assistance and training; and information and networking.

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### **Abbreviations**

CCM Country Coordinating Mechanism (a body required for shaping and

overseeing Global Fund-related processes at national level)

CIS Commonwealth of Independent States

CS civil society

CSS Community System Strengthening EATG European AIDS Treatment Group

ECDC European Centre for Disease Prevention and Control
ECUO East Europe & Central Asia Union of PLHIV Organisations

EECA Eastern Europe and Central Asia
EHRN Eurasian Harm Reduction Network

EU European Union

GF The Global Fund to Fight HIV, TB and Malaria

GHRN Georgian Harm Reduction Network

ICASO International Council of AIDS Service Organizations

IDU injecting drug user

ILO International Labour Organization

ITPC-EECA International Treatment Preparedness Coalition in Eastern Europe and

Central Asia

LGBT lesbian, gay, bisexual, and transgender people

M&E monitoring and evaluation MARP most-at-risk population MoH ministry of health

MSM men who have sex with men
OST opioid substitution therapy
PLHIV person or people living with HIV
RDS respondent driven sampling

SEE South East Europe

SW sex worker

SWAN Sex Workers' Rights Advocacy Network
TRIPS Trade-Related Aspects of Intellectual Rights

UN United Nations

UNAIDS Joint UN Programme on HIV/AIDS

WHO World Health Organization
WHO-EURO WHO Regional Office for Europe

# **Executive Summary**

Five years ago, governments in South East and Eastern Europe and Central Asia committed to move towards universal access to HIV prevention, treatment, care and support by 2010. With UNAIDS support, in 2006 most of the countries of these regions set targets and now, in 2010-2011, are reviewing their achievements, seeking ways to overcome challenges, and setting objectives and targets beyond 2010.

This report aims to inform global, regional and national efforts to improve work towards universal access from a civil society perspective. The report was initiated and supported by the International Council of AIDS Service Organisations (ICASO). The Eurasian Harm Reduction Network (EHRN) produced it in cooperation with other key regional networks including: the East Europe & Central Asia Union of PLHIV Organisations (ECUO); the European AIDS Treatment Group (EATG); the International Treatment Preparedness Coalition in Eastern Europe and Central Asia (ITPC-EECA); and the Sex Workers' Rights Advocacy Network (SWAN).

### State of the epidemic

Eastern Europe, South East Europe, and Central Asia were hit by the HIV epidemic later than most of the world, with the first few cases diagnosed in the mid-1980s and larger-scale outbreaks starting in the 1990s. HIV epidemics in these regions have continued to be concentrated among injection drug users (IDU) and their sexual partners, sex workers (SW), men who have sex with men (MSM), and prisoners.

The epidemics in the sub-regions of Eastern Europe and Central Asia (EECA) have characteristics very distinct from those of the epidemic in Balkans (South East Europe (SEE)), where HIV prevalence is low and sexual transmission prevails. The EECA countries continue to experience mainly concentrated epidemics with IDU being hardest hit. The EECA sub-region continues to experience an increase in new HIV infections, while incidence in most of the rest of the world is declining. UNAIDS estimates that two countries, Russia and Ukraine, account for almost 90% of all new HIV diagnosis in the region. In many parts of the region there are signs that the epidemic is stabilizing and that a growing portion of new infections are transmitted sexually.

The estimated number of people living with HIV in EECA and SEE in 2009 is 1.4 million. HIV prevalence among adults is 0.8% across the region with the highest prevalence countries being Ukraine and Russia. While data quality has improved substantially in recent years, there are a number of areas of deficiency, including quality of behavioral surveillance studies and lack of size estimates for key populations. Data on prisoners, transgendered people and migrants are often missing.

### The universal access consultation process

In 2010, a consultation process was held to review progress towards targets set in 2006-2007 and to set new targets for 2014-2016. In many countries, other activities such as national strategic planning, UNGASS reporting, preparation of Round 10 grant applications to the Global Fund to Fight AIDS, TB and Malaria, the International AIDS Conference, and the review of achievements related to the Dublin Declaration often drew the focus of political leaders, civil society and other stakeholders away from the universal access review process. The consultation process varied from country to country and usually involved face-to-face meetings and opportunities to provide feedback on relevant documents including UNGASS reports, national strategic plans,

program indicators, and reports on levels of access achieved. All but 2 countries in the region had plans for universal access review. The review process in 2010 was less elaborate than it was in 2006 – 2007, national networks were often less proactive about getting involved, and less funding was available for consultations. Though there was some level of civil society participation from all countries, including from organizations of people living with HIV, meaningful involvement of the most-at-risk populations (MARPs) was limited. While there were good examples of technical support to improve meaningful involvement, such support was not always provided.

### Targets set

Because many national consultations took place at the end of 2010, information on the review of the 2006-2007 targets was limited at the time this report was written. The 2006-2007 targets were often seen by community representatives as over-ambitious and difficult to measure. In 2010, most countries tended to use the UNGASS indicators for setting targets beyond 2010 and indicators from (draft) national strategic plans. They use indicators on funding levels, prevalence among key populations and pregnant women, levels of treatment, testing, prevention and behaviors of key populations and youth. Some set targets on care. Azerbaijan, Georgia, Macedonia and Romania did not set targets on human rights, according to their national Aide-Memoires.

### Progress on commitments and funding

The countries of the region have expressed commitments to address the HIV epidemic in a number of political declarations, but the degree to which these written expressions of commitment have been upheld varies. While funding from both international sources especially the Global Fund and from domestic sources has increased, it still is not adequate to fund the activities required for universal access. Investment in prevention is disproportionately low making up only 20% and 50% correspondingly of domestic and international HIV funding in the region; moreover, investment in programs for MARPs is extremely low (11% of all prevention funds) in proportion to the degree to which they are affected. Domestic HIV budgets allocate lower proportion of funding for MARPs than do international donors in the region. Many programs for MARPs are dependent on the Global Fund for funding which raises questions about sustainability as countries in the region become ineligible for future Global Fund support. Limited funds available in the region could be used more efficiently by lowering medicine prices (which are high in the region); prioritizing prevention, testing and treatment of MARPs in resource allocation: and investing in advocacy for human rights protection and sustaining political commitment to HIV.

### Progress on human rights

With some exceptions, national strategies and universal access reviews rarely addressed human rights issues. There has been substantial progress over the last 5 years concerning legal protection of the rights of people living with HIV. Though it is recognized that promoting human rights is a key element in ensuring greater access for MARP, the region still faces many problems related to stigma of PLHIV, LGBT, SW and IDU. Though stigma is such a widely recognized challenge, changes in stigma are not tracked. People who use drugs and sex workers continue to be criminalized and some countries continue to use drug user registries. Some progress has been seen in developing legal services for MARPs, most often run by civil society organizations with international funding.

## Progress on treatment, care and support

As of 2010, antiretroviral treatment is available in all countries in the region and coverage within countries has grown significantly. Though access to treatment is improving, the EECA region still has almost the lowest level of access in the world

among low and middle income countries with an estimated rate of only 19% coverage according to WHO, UNAIDS and UNICEF. Lack of support for treatment uptake and adherence among IDUs is the key reason for lower access in the region. Access to opioid substitution therapy, which is available at least on a small scale in most countries, remains considerably lower then the levels recommended by the WHO. There is gender disparity in access to treatment and treatment outcomes with men less likely to receive treatment and having poorer outcomes when they do. While there are good practice examples in the region of provision of treatment for co-infections like hepatitis or tuberculosis, which are among the leading causes of death of PLHIV in the region, access to treatment for these infections remains low among PLHIV. Problems with procurement and supply chain management, and in some cases with continuity of financing, have resulted in persistent HIV treatment interruptions in several countries. Though investment in treatment is improving, dependence of foreign funding and high pharmaceutical prices remain significant problems.

### **Progress on prevention**

Given that the region is home to some of the world's fastest growing HIV epidemics, access to prevention is insufficient in many countries. Prevention among key populations has developed greatly over the last 5 years, mainly with international funding and implementation by civil society. However, in most instances the coverage, diversity and quality of services for IDU, SW, MSM and prisoners remains low. Services for SW have actually been reduced in some countries and programs for MSM have not been adequately prioritized. Needle exchange, opioid substitution therapy and free access to condoms for prisoners continued to be the most sensitive and challenging for introduction and scale-up. Major advocacy campaigns with international support and participation of civil society are needed to ensure the sustainability and expansion of services for key populations, addressing legal and other barriers preventing access to services.

**Priority recommendations** [for the complete list see <u>6. Recommendations</u>]

## To UNAIDS family and technical support providers

- UNAIDS should establish minimum requirements and guidance for engagement of
  civil society and MARPs in the target setting and review processes. UNAIDS should
  employ good practices in community involvement. This could include, for example,
  holding civil society caucuses prior to meetings with governmental representatives
  so that civil society can define its priorities, and working with civil society to
  develop strategy and advocate their goals. Opportunities should be given to provide
  feedback on reports and meeting protocols.
- UNAIDS should prepare a set of indicators for countries to report on legislation
  directly affecting key populations and enforcement of those laws, which should
  define measures that protect or infringe upon human rights in the context of HIV. By
  2015, UNAIDS should support countries to use human rights indicators in national
  strategic planning and further target setting towards universal access;
- **UNAIDS and the regional Technical Support Facility** should provide platforms for policy makers, civil society organizations (CSOs) and MARP groups to have dialogue on human rights and to share good practices. They should promote available model legislation that ensures human rights protections;
- UNAIDS and technical agencies, including ECDC, CDC, EMCDDA, with engagement of the Global Fund and other major donors, should prioritize the following areas for improving quality of data:

- establishing national estimates of the size of key populations (comparable methodology and standardized definitions of populations),
- improving monitoring of coverage of MARPs with prevention services putting into practice the UN guidance on targets for IDU (WHO/UNODC/UNAIDS, 2009), as well as other relevant guidance;
- supporting countries to improve data on the HIV epidemic and progress reached among prisoners, transgendered people, and migrants (or their subpopulations);
- o reporting on probable routes of transmission and CD4 cell count;

### To national policy makers and other stakeholders:

- **National stakeholders** should use the national indicators and targets agreed on in 2010 for the universal access review process in 2015 and beyond. In the next round of reviews, before discussing general achievements, revising indicators and setting new targets, they should measure progress towards the targets set in 2010;
- **Parliaments and governments** should prioritize both prevention and treatment of HIV among MARPs and allocate adequate resources;
- Ministries of health and Principal Recipients of Global Fund projects should negotiate for lower pharmaceutical prices, as well as investigate other means to increase efficient use of limited resources;
- National HIV/AIDS commissions, together with PLHIV and other stakeholders, should study and address the reasons for the lowered impact of treatment, and gender disparities, particularly addressing men's vulnerabilities;
- **National HIV/AIDS commissions** should scale up access to opioid substitution therapy and TB and hepatitis treatment for PLHIV, according to WHO protocols;
- National AIDS commissions should develop systems of procurement and supply chain management that ensure continuous supplies of necessary medications and monitoring tests, with transparency and community involvement in those systems;
- **National governments and donors** should invest in improving the coverage, quality and diversity of services for key populations, including IDUs, SWs, MSM, and prisoners. Services for prisoners remain notably underdeveloped;
- Policy makers should use their political leadership to promote neglected evidence based services and remaining barriers to services, particularly for marginalized groups among whom the epidemics spread;
- **National, regional and local policy makers** should urgently develop mechanisms for authorities to contract NGO services, where they do not exist or do not operate;
- Those designing GF proposals should use the Community Systems Strengthening
  Framework to seek funding from the GF to improve the capacity of MARPs
  community systems to feed into national decision making processes and access
  necessary technical support to do so effectively;

# To donor community including the Global Fund and the European Community:

- **The Global Fund's Board** should review the eligibility criteria so that GF resources would be available to address the needs of MARPs living in upper- and lower-middle income countries where access is a problem;
- The European Community, along with the Global Fund's Board, should find realistic solutions for the EU and its neighboring countries to sustain funding and services when the Global Fund and other international funding expires;
- **Donors** should support and fund inclusion of legal services and other types of protection of human rights into essential services for key populations, as well as

provide low-threshold access to funds and support for strengthening of MARPs groups;

# To civil society and service providers:

- Given the relative lack of information on human rights in the universal access documents, **civil society organizations (CSOs)** should report on the human rights environment and progress independently;
- **Regional networks** should be engaged in the process of planning for and providing technical assistance to their national members for involvement in processes. Regional organizations should track progress on CSO, PLHIV and MARPs involvement in the processes, as well as progress towards universal access, particularly national funding, coverage and quality of HIV treatment, prevention among MARPs, and their human rights situation;
- **Service providers** should improve the quality and diversity of their services, as well as better engage communities served in order to reach greater impact on behavior change.

## 1. Introduction

[We] commit ourselves to pursuing all necessary efforts to scale up nationally driven, sustainable and comprehensive responses to achieve broad multisectoral coverage for prevention, treatment, care and support, with full and active participation of people living with HIV, vulnerable groups, most affected communities, civil society and the private sector, towards the goal of universal access to comprehensive prevention programmes, treatment, care and support by 2010.

UN General Assembly (2006). Political Declaration on HIV/AIDS (A/Res/60/262)

Five years ago, governments committed to move towards universal access by 2010, and extended the pledge to 2015 during a recent review of Millennium Development Goals. With UNAIDS support, in 2006, most of the countries in Eastern Europe, South East Europe and Central Asia set universal access targets and now, in 2010-2011, are reviewing their achievements, seeking ways to overcome challenges and setting new objectives and targets beyond 2010.

Universal access is understood as more than merely scale up of services. As the International Council of AIDS Service Organizations (ICASO) notes, "it should result in the ability of all people to have equal access to the quality services or commodities that they need to meet their HIV prevention, treatment, care and support needs." (ICASO, 2010) There are vital lessons to be learned from the achievements and challenges that led to current levels of access, which can inform actions to speed further progress toward universal access.

This report aims to inform global, regional and national efforts to improve work towards universal access from a civil society perspective. It assesses how civil society groups are involved in setting and reviewing national targets, particularly the involvement of those most affected by the epidemic including people living with HIV (PLHIV), injecting drug users (IDU), men who have sex with men (MSM), sex workers (SW), prisoners, and migrants. National commitments are assessed as is the allocation and use of funds. The report reviews progress over the last 5 years as well as lessons learned from national commitments, the development of services and how they respond to epidemiological trends, and the human rights situation and response. Finally, a set of recommendations is provided for governments, United Nations (UN) bodies, international organizations, donors, and civil society organizations on what should be done to keep universal access on the agenda and speed progress towards achieving it.

The report was initiated and supported by the ICASO with funding from the Canadian International Development Agency as part of the global project, "Achieving Universal Access: supporting community sector involvement and advocacy." The Eurasian Harm Reduction Network (EHRN) in cooperation with other key regional networks including: the East Europe & Central Asia Union of PLHIV Organisations (ECUO); the European AIDS Treatment Group (EATG); the International Treatment Preparedness Coalition in Eastern Europe and Central Asia (ITPC-EECA), and the Sex Workers' Rights Advocacy Network (SWAN) cooperated to produce the report. This report builds on regional analysis conducted in 2006 and published in a report entitled "Demonstrating the impact of civil society involvement in the target setting process for universal access: Eastern, South East Europe and Central Asia."

### Methodology

Guidelines for creating the report were provided by ICASO and an approach to creating the report for the region was developed by the report authors in consultation with EHRN and its regional partners. EHRN invited cooperation of other key regional civil society networks, which reviewed the methodology and content of the report.

The main sources of information were:

- knowledge and opinions of national and regional experts who were surveyed using questionnaires developed for the regional report [see <u>7.1. List of</u> <u>interviewees</u> for names and organizations of experts interviewed];
- desk review, particularly of the UNGASS 2010 country reports; Aide-Memoire with national report on universal access review where available; global reports on universal access; national reports provided by key informants;
- national community reports on universal access review in Kazakhstan, Romania and Ukraine;
- additional information and written input was sought from experts.

The region focused on in the report includes the non-EU countries of the WHO European region, as well as Bulgaria and Romania and all countries carried out universal access target setting and review processes. In accordance with ICASO guidelines several countries were selected for in-depth review. These countries were chosen to represent the diverse characteristics of the region in terms of epidemiology, civil society development, and the response to the epidemic. Moreover, they represent various subregions: Kazakhstan from Central Asia; Georgia from the Caucasus; Belarus and Ukraine from the European CIS countries; and Albania, Republic of Macedonia, and Romania from South East Europe. The characteristics of the national 2010 universal access review processes were not taken into account in selecting countries since limited information about those processes was available when the assessment began in September-October 2010.

There were some notable gaps in data available, particularly on prisoners, transgender populations, and migrants.

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# 2. Overview of regional trends

# 2.1. Epidemiological characteristics<sup>1</sup>

Eastern Europe, South East Europe and Central Asia were hit by HIV epidemic later than most of the world with the first few cases diagnosed in the mid-1980s and larger outbreaks beginning in the 1990s. The epidemic in the sub-regions of Eastern Europe and Central Asia (EECA) has characteristics very distinct from those of the epidemic in the Balkans (South East Europe (SEE)).

Most countries of the EECA region continue to experience concentrated epidemics, with injecting drug users (IDUs) being hardest hit. In spite of some signs of stabilization, the region continues to experience an increase in new HIV infections, while rates of new infections in most of the rest of the world are declining. Ukraine has the highest prevalence of HIV infection in the region (1.1% of the adult population according to UNAIDS). The predominant route of transmission among cumulative cases is sharing unsterile injecting equipment. However, in Belarus and Ukraine, where the epidemic started earlier than in other countries, sexual contact now contributes an estimated 77.6% and 52% of newly reported HIV cases respectively. In Ukraine, many cases of sexual transmission involve a sexual partner who is an IDU. HIV prevalence at the end of 2009 reached approximately 91.1 per 100,000 population in Belarus and 220.9 in Ukraine.

The situation is quite different in the Balkan sub-region (South East Europe), where reported HIV prevalence is low and sexual transmission prevails. Each country has some peculiarities in reported HIV cases. Some countries report that a significant proportion of people acquire HIV while abroad; in Albania, 54% of all cases are associated with migration or travel. In Romania, more than 10,000 children were infected in healthcare settings between 1987 and 1992, and they are now young, increasingly sexually active adults; most newly diagnosed HIV cases in the country are among young adults through heterosexual contact (75%). Men who have sex with men make up around 10% of new and cumulative cases in the three SEE countries analyzed in this report, while their neighbors register higher proportions of HIV cases among MSM (e.g. almost 50% in Croatia). There is a general tendency that more new cases are registered each year, however there are exceptions: Republic of Macedonia registered fewer cases in 2009 than in 2008 (20%, or 2 fewer cases).

Registered HIV cases in selected countries: cumulative cases by the end of 2009 and newly registered cases in 2009.

Sub-region	Country	Cumulative number of registered cases (# per 100,000)	Number of new registered cases in 2009 (# per 100,000)	Increase/ decrease in prevalence (based on registered cases) in 2009 since 2008
South East	Albania	365	61	+24.5%
Europe		(n.d.)	(n.d.)	
	Republic of	120	8	-20%
	Macedonia	(n.d.)	(0.3)	
	Romania	16,162	428	-2%
		(24.7)	(0.7)	
Eastern Europe	Belarus	10,690	1,072	+21.7%
		(91.1)	(11.1)	
	Ukraine	161,506 (220.9)	19,840	+5.7

 $<sup>^{\</sup>rm 1}$  This and the next sections are built mainly on country UNGASS reports, Global AIDS update 2010

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			(43.2)	
Caucasus and	Georgia	2236	385	+9.7%
Central Asia		(51.1)	(8.8)	
	Kazakhstan	13,784	2,081	-10.9%(but
		(73.1)	(13.3)	+5.2% in
				comparison with
				2007)

Sources: Country UNGASS 2010 reports.

Number of new cases reported for Georgia and Kazakhstan: ECDC/WHO-EURO: HIV/AIDS surveillance in Europe 2009.

In all countries analyzed for this report, most HIV cases are among the adults aged between 18 and 49. A few countries, including Belarus, Kazakhstan and Romania, report that a majority of people are under 30 when their HIV was diagnosed, but the picture is mixed across the region . Among people in non-EU countries for whom HIV was newly diagnosed in 2009,² 44% of males were in the 30-39 year age range, while a majority (57%) of females were of the same age or slightly younger (25-39 years old). (ECDC/WHO-EURO, 2010) The epidemic remains predominantly male, as it is in the rest of Europe where 70% or more of all people diagnosed with HIV so far were males. The portion of females among new HIV cases is increasing though it remains under 50%.

### 2.2. Prevalence, undiagnosed cases and main groups at risk

The estimated number of people living with HIV in the EECA and SEE region in 2009 is 1.4 million (estimates range between 1.3-1.6 millions). (*UNAIDS, 2010*) HIV prevalence among adults is 0.8% across the region with the highest prevalence countries being Ukraine and Russia. An estimated 130,000 Eastern Europeans and Central Asians, half of them living in the most populous country, Russia, became infected in 2009 alone.

There is a large difference between numbers of registered HIV cases and estimates, which suggests that some countries have large numbers of people who have not been tested for HIV and do not know about their positive status. For example, Ukraine estimates that only 28% PLHIV know their status and the rest are not aware of it. Belarus, Georgia, and Kazakhstan estimate a better situation with awareness of HIV status. In Georgia, yet another problem is seen: late presenters who are diagnosed with advanced HIV comprise an average of 45% of all new cases since 2004. AIDS rates continued to increase there in 2009 and reached 6.5 cases per 100,000 population, the second highest rate in the entire European and Central Asian continent.

HIV prevalence in the general population, IDU, SW, MSM, and prisoners in 2009 in selected countries.

Country	Adult population % (estimated number)	IDU, %	SW, % (female)	MSM, %	Prisoners, %	Other
Albania	n.a.	0.0	n.a.	0.8		0.3 Roma (#)
Belarus	0.3 (17,000)	13.7	6.4	2.7	2.4 (\$)	
Georgia (*)	<0.1 (3,390)	2.1	1.4	3.7	1.4	
Kazakhstan	0.1 (15,000)	2.9 (0.4- 6.4%)	1.3	0.3	2.4 (0-7.6)	
Republic of	n.a.	0.8	0	2.8	0	

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<sup>&</sup>lt;sup>2</sup> The analyzed region in this report is non-EU countries of the WHO European region and Bulgaria and Romania. The region is defined by where the UNAIDS reported universal access target setting and review processes to take place.

Macedonia						
Romania	0.1 (16,000)	1.1	1	4.4	2.1 (&)	
Ukraine	1.1 (360,000)	22.9	4	8.6	15	

 $Sources: \textit{Global report: UNAIDS report on the global AIDS epidemic 2010 \& \textit{UNGASS 2010 country reports}}$ 

- (\*) Georgia National HIV/AIDS Strategic Plan for 2011-2016; most of them are different from the UNAIDS report
- (#) FHI 2005 Behavior and Biological Surveillance Study Albania
- (\$) Belarus UNGASS Report 2010 [in Russian]
- (&) Kazakhstan average & Romania prison data: ECDC, 2010.

Levels of HIV among most-at-risk populations (MARP) vary but the groups most affected are similar across countries. These are injecting drug users, men who have sex with men, sex workers, also prisoners, street children including adolescent IDUs, SW and MSM. Some countries (Albania, Romania) identify Roma populations as more vulnerable due to low access to health care, social exclusion and higher rates of injecting drug use and sex work.

The highest estimated national prevalence of HIV among **IDUs** in the countries studied are in Ukraine (22.9%), and Belarus (13.7%). Albania did not find any HIV cases among IDU in its last biological survey but identified the first case among IDUs in 2009.

Lower rates are reported among **sex workers**, among whom the most vulnerable are those working on streets and highways. Few countries in EECA report overlap among IDU and sex workers. No HIV cases are associated with sex workers in Macedonia. Georgia, Kazakhstan and Romania all report prevalence between 1-1.3% among SWs. Higher rates are recorded in Ukraine (4%) and Belarus (6.4%). Albania has not conducted surveillance among SWs but a study made by the Albanian Institute for Public Health and Aksion Plus concluded that, "Out of the 24 women living with HIV/AIDS in Albania, 4-5 have probably been infected through CSW." (*SWAN*, *2008*)

Although only a few cases of transmission among **MSM** are officially reported in EECA, prevalence studies reveal high rates among MSM, for example, 3.7% in Georgia, and 8.6% in Ukraine. Other countries, with the exceptions of Albania and Kazakhstan, estimate HIV prevalence among MSM above 1%. The large discrepancy between registered cases and prevalence rates revealed by research suggests that data about MSM community is incomplete, that the MSM community may not be reached adequately by HIV testing and counseling efforts and that fear of stigma may lead people to conceal their sexual orientation.

The limited number of studies among **prisoners** show great variation in HIV prevalence: from 0% in Macedonia to 0-7.6% in Kazakhstan and 15% in Ukraine. Belarus diagnosed 21% of all its HIV cases through inmate testing. Thus some prisons in Kazakhstan and Ukraine contain HIV epidemics; this is unsurprising based on reports regarding the mass incarceration of people who use drugs, and higher concentrations of injecting drug use, unprotected sex, HIV and other diseases in prison settings across developed, transitional and developing economies. (*WHO-EURO*, 2007)

### 2.3. Availability and quality of data

The availability and quality of data has improved substantially over the last 10 years. A European and Central Asian HIV database, which covers the region analyzed, is maintained by the WHO Regional Office for Europe (WHO-EURO) and the European Centre for Disease Prevention and Control (ECDC). However, not all countries provide

data and not all national data are complete. It is essential to "implement case-based national reporting systems for HIV and AIDS cases and ensure data completeness and timeliness;" and "to improve the quality of data reported, especially regarding probable routes of transmission and CD4 cell count." (ECDC/WHO-EURO, 2010)

There are inconsistencies in reported HIV cases from different sources. For example, while Albania reports 36 new HIV cases registered in 2009, ECDC/WHO EURO report this number as 29. Furthermore, data on coverage, particularly the estimates of population sizes in need of services, is another area where data require substantial improvement and more consistency. At least two civil society respondents noted that different numbers are used depending on what they will be used for. Higher numbers of people in need were used when fundraising and lower numbers of people in need were used when reporting on progress. Cross-checking of population size and coverage rates for selected countries in UNGASS country reports and the Global Fund's national HIV project reports confirmed this inconsistency. There are also inconsistencies between the 2010 UNAIDS report on the global AIDS epidemic and national UNGASS reports.

The countries examined in this report have introduced or are in the process of introducing second-generation surveillance. Studies have been performed among the groups at highest risk of HIV infection concerning behavior, knowledge, and prevalence. However, some countries indicate that their data is not always representative due to the sample size or the method of selecting study subjects. Often only current clients of services were recruited for studies, meaning that findings may not be generalizable to the broader population. The main groups where such data is available are IDUs, SWs, and MSM. However, not all countries have data on all those groups, and data on SWs are limited to female SWs.

Given that prisoners are not included in the UNGASS reporting system, less information is available about this large HIV-affected group. The European and Central Asian complementary reporting on implementation of the Dublin Declaration used the UNGASS indicators and added data on prisoners, as well as some groups of migrants. This could set an example for global reporting, since prisoners are a group at risk on other continents as well. Limited data is available about vulnerable migrants. Part of the challenge is that the definition of migrants varies across Europe and Central Asia making it impossible to produce comparable data. (*ECDC*, 2010) Data about transgender is almost absent.

### **Conclusions**

- HIV has continued to spread across the region, particularly in Eastern Europe and Central Asia. Most of the countries examined in this report in Eastern Europe and Central Asia experience concentrated epidemics, while in South East Europe HIV prevalence remains very low. The epidemics continued to be concentrated among IDUs (and their sexual partners), SW, MSM and prisoners, and prevalence among these groups has risen.
- While data quality has improved substantially, there are a number of areas that require strengthening, including behavioral surveillance studies and population size estimates..
- Data on prisoners, transgender, and migrants are poor. Indicators on them should be recommended within the UNGASS monitoring framework and countries should be supported to report on them. Indicators on these groups and methods of collecting information on them could be adapted from the Dublin Declaration monitoring process.

# 3. Universal access target setting and review processes

On 18 February 2010, the UNAIDS Executive Director issued a call to countries to undertake a review of progress towards universal access and requested UNAIDS offices to "facilitate and support countries for an inclusive stakeholder process". According to the report 'Universal Access' approved at the 27th Meeting of the UNAIDS Programme Coordinating Board, Geneva, Switzerland, 8-10 December 2010, the review should:

- Analyze universal access achievements to date under national targets;
- Analyze existing approaches to HIV prevention, treatment, care and support, and what is required to achieve targets that have not been achieved;
- Analyze data about who contracts HIV and how those populations may have changed over time (such populations include women, young people, migrants men who have sex with men, transgender people, people who inject drugs, prisoners and pre-trial detainees, and sex workers) according to 'Know your epidemic and Know your response'
- Identify current obstacles to achieving universal access, such as those mentioned above and how to overcome these:
- Define how to accelerate progress where it is lagging and
- Set new targets as necessary. (UNAIDS, 2010b)

In line with programmatic strategies, frameworks and tools, UNAIDS noted that the reviews should:

- Be nationally owned and led;
- Involve the full participation of all stakeholders at all levels, including all branches of government (executive, legislative, judiciary), donors at country level, UN system and intergovernmental agencies and civil society;
- Be fully inclusive, making efforts to include those living with HIV, women, young people and those marginalized
- Reflect on legal, social, funding and programming environments affecting the response to HIV; and,
- Promote the human rights and health of all those vulnerable to HIV infection and living with HIV (UNAIDS, 2010b)

In 2010 the national reviews of progress towards universal access were one of a few competing though linked processes and events at global and national levels. All of the countries analyzed had processes to review their UNGASS progress in early 2010. Five of the seven countries analyzed worked on new national strategic plans. Additionally, many stakeholders participated in International AIDS Conference in 2010, which for the first time focused on the region. All but one of the countries analyzed prepared and submitted proposals to the Global Fund's Round 10 funding stream. Much attention was also given to the review of Millennium Development Goals, to the Global Fund's replenishment and the review of Dublin Declaration implementation, which concluded in 2010 as well.

Throughout the region, the consultation process to establish, review and adjust national indicators and targets took on varied forms as did the participation of civil society in the process. In 2010 all but 2 countries in the EECA region planned to have some universal access review. The process of review evolved over time with some countries undergoing a more elaborate process in 2010 than was undertaken in 2006 when the indicators and targets were first established, while in other countries the process was less emphasized. The simultaneous processes around national strategic planning, GF proposals and

UNGASS review sometimes led to linkage of these elements, but in other cases it led to a lack of clarity for CS organizations as to where to focus their advocacy efforts.

### 3.1. National level involvement

Since 2006 many countries in the region have experienced significant developments related to the '3 ones,' (ONE national coordinating authority, ONE monitoring and evaluation system and ONE national action framework) (UNAIDS, 2004) [See Section 5.1 below] which in turn impacted universal access processes including the review and establishment of new indicators and targets. Civil society experience and structure also evolved with impact on participation and outcomes of participation. In some respects. civil society involvement and impact became more pronounced, as for example in Belarus where CS entered the process with a well developed strategy and effectively pursued opportunities to advance its agenda. In other countries, however, many of the same barriers to CS influence seen in 2006 remained. These include: a lack of participation of representatives of most at-risk populations; lack of geographic diversity of representatives: lack of awareness about the process among CS: lack of motivation to participate; lack of capacity building activities for CS structures; lack of opportunities to provide feedback on key documents; CS representatives participating in process being chosen by governmental or UN officials instead of their own constituencies; lack of coordination among CS organizations; and lack of adequate informational platforms for wide distribution of relevant information.

As mentioned above, when the process was often combined with other processes such as national strategic planning or Global Fund proposal preparation, there was less clarity about universal access, making it harder for civil society organizations to strategically participate and focus specifically on the targets and indicators.

In Albania, the UNGASS report was available for comment as was the national strategic plan. In Macedonia, UNAIDS synthesized comments from governmental institutions and civil society in the final version of the targets and respondents noted that all issues they raised were included in the report. In Belarus, draft indicators were shared by UNAIDS in advance of a consultation and CS held a caucus to define priorities and an advocacy strategy. The minutes of the consultation was not made available for review so it was not clear at the time of the writing of this report whether CS suggestions were taken into account. The UNGASS report in Belarus was open for feedback. In Georgia the review process was done together with the development of the national strategic plan, which involved a 9 month process with 3 consultations and opportunities to give feedback. Interviewees noted that most CS proposals were taken into consideration. They were also given opportunities to review the UNGASS report. In Kazakhstan, only 2 CS organizations were given an opportunity to review the national UNGASS report. The report was not distributed for more broad review. (*ITPC*, 2010).

The process of civil society involvement in setting national indicators and targets in 2006-2007 demonstrated that, in countries where the influence of SC was strong and meaningful (e.g. Romania, Ukraine, and Belarus), the following factors were crucial to supporting CS engagement:

- Technical support for CS organizations to understand the process and define their priorities;
- Financial support for meetings;
- Support for national level networking;
- Opportunities created by UNAIDS for CS to engage in direct dialogue with governmental structures;

- Use of existing communication structures to distribute relevant information; and
- Opportunities to provide feedback on key documents. (Schonning & Stuikyte, 2007)

In many countries, Country Coordination Mechanisms (CCMs) set up to oversee Global Fund (GF)-funded programs were engaged in the process. Civil society, including people living with HIV, are usually represented on CCMs. Respondents from Albania. Kazakhstan and Macedonia mentioned that CCMs were active, though in Kazakhstan it was noted that selection of CS representatives in the CCM was not done in accordance with CCM rules, and participation in processes by some groups was consequently limited. In some cases, such as in Georgia, the process was linked with the development of the national strategic plan. The involvement of CCMs is particularly important because activities are usually linked to budgeting, providing an often unique opportunity for civil society to directly influence financing. Moreover, as GF proposal preparation is increasingly linked to national strategic plans, involvement in CCMs is potentially influential. The GF as well as by for exampleand groups such as the Global Network of People Living with HIV/AIDS (GNP+) have produced guidance to civil society on effective participation in CCMs. May of the recommendations in this guidance would be useful for supporting transparent and democratic CS influence on indicators and targets as well.

There was some level of impactful CS participation, including PLHIV, in all countries [see Section 3.3 below]. Meaningful involvement of MARPs was limited, even though there were explicit instructions that the process be "fully inclusive, making efforts to include those living with HIV, women, young people and those marginalized". CSOs which provide services to MARPs were involved but did not always insist on direct MARP participation. In Belarus, only one former drug user and no SWs participated in universal access consultations. In Georgia, MARPs were not directly involved, though there is a registered organization of people who use drugs with a strategic plan that could have participated. Some of their views may have been expressed by other CS representatives involved in the process, but the absence of direct participation is problematic.

There are no MARPs on the Georgian CCM and respondents noted that the GF does not provide funds for advocacy work, and impediment to building necessary capacity. Within the GF's new Community Systems Strengthening Framework, which was instituted starting with Round 10, community leadership development may gain greater resources, though the framework does not include many indicators related to advocacy activities. Drug policy (in particular criminalization of people who use drugs) is a barrier to meaningful involvement in Georgia. No MARPs are members of the Kazakh CCM; only organizations working with them are. In Macedonia, there is a new SW organization, STAR, and a drug user organization, neither of which were involved in the consultation process. Meetings in Macedonia were held in English which limited possibilities of meaningful involvement. In Ukraine, while PLHIV are well organized and represented, MARPs are less organized and have less technical and financial support and therefore have less meaningful involvement. Natalia Leonchuk from ECUO noted also that young PLHIV need more support to become meaningfully involved. In Romania, many CS organizations were involved including organizations representing PLHIV, MSM, and IDU. Sex workers and prisoners were not involved.

### 3.2. Regional level involvement

The region is home to a number of regional-level CS networks that have been involved in universal access processes, including: the Eurasian Harm Reduction Network (EHRN);

the East Europe and Central Asia Union of Organisations of PLHIV (ECUO); the International Treatment Preparedness Coalition (ITPC); and the European AIDS Treatment Group. All regional networks provided their members and participants in their communication networks with information about the process, distributing relevant news, reports, etc. They have also participated in activities such as the preparation of the current report and one published in 2007 on universal access processes.

EHRN participated in the Global Steering Committee on the Universal Access Initiative in 2005 and was also represented in the Task Force to prepare for the 2006 UNGASS High Level Meeting on AIDS, in which it participated as well. EHRN and ECUO participated in regional consultations held for the CIS in Moscow, and EHRN and EATG participated in consultations for the Balkans in Bucharest in 2007. In 2007 groups of PLHIV including ECUO, ITPC, EATG and the Russian Community of PLHIV organized with cooperation and support of UNAIDS and WHO a consultation in St Petersburg designed to encourage PLHIV involvement in universal access processes and build capacity. During the UNGASS review meeting in 2008 EHRN championed MARPs issues and helped participants representing MARPs to have their voices heard. ITPC and EHRN have also provided technical and financial support to their members to write shadow reports, and in 2007 EHRN led a partnership of regional organizations to research and draft a report on civil society involvement in the universal access processes.

Regional networks can support their members to be more strategically involved in national processes, identify good practices in involvement, help CS country representatives identify advocacy priorities, and highlight targets for advocacy among regional and global target audiences, such as donors and UN agencies. UNAIDS officials noted in January 2011 that a regional consultation will be held in March 2011, which will hopefully provide an opportunity for reflection on the situation in the region and discussion of how to support greater community involvement in future review processes.

### 3.3. Issues raised & impact

In the countries studied, the CS representatives raised important issues but the impact of their advocacy efforts varied. In Belarus, CS representatives raised several issues, including the scientific validity of approaches to monitoring and evaluation. interruptions to CD4 testing access, changes in ARV regimens, and the need for more emphasis on care and support for PLHIV. It is not yet clear whether these issues will be reflected in the final universal access review documents. In Macedonia CS representatives raised issues including: political commitment; forced testing of SW by police: the need to plan for sustainability after GF projects conclude: quality and accessibility of drug dependence treatment; drug treatment and syringe exchange in prisons and the quality of services for MARPs. Most issues raised by CS were included into the report. In Georgia, issues raised included: legal issues and human rights; services to improve coverage of MARPS (e.g. mobile VCT services for female IDU). In Romania CSOs raised a number of issues including: the need to strengthen the national coordination mechanism; improving the M&E system to better address the needs of MARPs; need for national funds for prevention activities targeting MARPs; and continued monitoring of ARV treatment. Many issues raised were included but sometimes not at the levels recommended by CS.

### Case study: Multi-stage preparation processes in Belarus

In the 2007, an ICASO/EHRN report entitled, "Demonstrating the impact of civil society involvement in the target setting process for universal access in Eastern, South East Europe and Central Asia," highlighted practices in Belarus that were worthy of replication in other countries. The country's multi stage preparation process, which involved capacity building exercises for civil society representatives and opportunities for them to formulate and express their positions, was singled out in particular. Again in 2010 Belarus stands out as a country with interesting lessons to share.

Initially, only a limited number of NGOs were invited to participate in the consultation process, but civil society successfully lobbied for more representatives to be invited. UNAIDS selected a meeting facilitator who was recommended by civil society. Prior to the meeting, UNAIDS made available a preliminary document on indicators and coverage. The Ministry of Health (MoH) did not provide any information in advance. On the eve of the national consultation process, the Belarusian PLWH Community in cooperation with the Belorussian Association of Non-profit Organizations Countering HIV/AIDS (the BelAIDS Network) organized (with financial support from UNAIDS) a civil society caucus, during which civil society representatives reviewed national data and developed concrete positions on 5 indicators. They strategized about how to present their positions during the national consultation, selecting people to present on each of the chosen indicators.

Civil society raised issues related to adherence, access to treatment as well as issues related to the needs of MSM and SW. "In the beginning of the meeting, all of the officials spoke, telling about how good everything is, and then Lena and others from the PLHIV network started to raise issues about changing ARV regimens and access to viral load testing," noted Oleg of BelAIDS Network. MoH representatives promised to address their concerns. Civil society representatives tried to push for higher targets for ARV treatment indicators, but their suggestions were countered by the MoH, which cited budget constraints as a barrier. In other cases CS representatives advocated the inclusion of lower, more realistic indicators, but their proposals were rejected by the MoH which was reluctant to include lower targets than those in the previous set. CS representatives raised the issue of the need to use a more scientific approach to tracking achievements toward universal access. For example, CS representatives pointed out that the data used to draw the conclusion that 88% of MSM know the routes of HIV transmission in Belarus could not be used to draw that conclusion since only service users were questioned and that similar problems existed with data on levels of access among IDU and SW. CS representatives suggested using methodologies such as Respondent Driven Sampling (RDS) that enable more accurate measurement of rates of access among a given population group (including people who are not service users). Civil society representatives also raised issues such as the need to correct interruptions in access to CD4 tests.

Although the overall process in Belarus was good, it was not ideal. MSM were represented but sex workers were not and do not even have an organization. There was a representative of an organization of former drug users present but not active drug users. Respondents noted that some of the responsibility lies with civil society itself. "There are opportunities to participate but to use them we need activism," said Oleg from BelAIDS Network. He also noted that considerable work needs to be done to develop leadership skills and teach people about their rights. "Its not enough just to train them about AIDS. They know about their responsibilities but not about their rights." He also noted that since sex work was illegal, it was not possible for them to register an organization and openly participate in the process. There are also no

organizations of drug users. Other factors which may negatively impact the influence of CS involvement include the fact that the protocol of the meeting will be seen by CS only after approval by the MoH. It is not yet clear whether their suggestions that were accepted during the meeting will impact the final documents.

### **Conclusions**

- Civil society was involved in universal access processes and had positive impact when it did.
- The degree and impact of involvement varied from country to country, and the process in 2010 was less clear than in 2006 due in some cases to the universal access review being combined with other national and global processes such as UNGASS reporting or national strategic planning, and given less direct focus.
- MARPs were underrepresented in universal access review throughout the region.
   CSO representatives from services for MARPs often participated, but did not insist on direct MARP involvement. Advocacy by CSOs and MARPs for involvement has been insufficient.
- Communities in many countries do not yet have adequate capacity to make the most of opportunities to be represented in decision making processes.
- While there are good examples of technical support to improve meaningful involvement of populations affected by HIV, that support is not universally available.
- While there are good examples of MARP groups getting involved proactively, other MARPs groups do not assert themselves.

# 4. Universal access targets agreed

In 2006-2007 countries set targets towards universal access through national processes. Regional civil society networks analyzed these processes in selected countries in the report Demonstrating the impact of civil society involvement in the target setting process for universal access: Eastern, South East Europe and Central Asia.3 The study showed that each country used their own indicators and often adjusted them once clearer guidance was received from UNAIDS in 2007, encouraging countries to use UNGASS and other nationally used indicators. The quantity of indicators varied greatly from country to country (from 10 in Moldova to 38 in Armenia). There was also variation in ways they were formulated (as percentages or a number of people to be reached). The issues addressed also varied greatly. All countries assessed in 2007 set targets on treatment and prevention among the general population and youth, prevention of vertical transmission, as well as prevention among one or more key populations. Fewer countries set targets on political commitment; those that did mainly focused on levels of national funding (in Belarus, Russia and Ukraine). Even fewer countries set targets for human rights, mainly on levels of stigma of people living with HIV (Belarus, Russia, Ukraine) or establishing a human rights monitoring body (Albania). Few countries reported integration of the indicators in other programs. For example, in Macedonia the same indicators and targets were set within the Global Fund's program, and respondents from Central Asia reported in 2007 that indicators were integrated into national program planning.

At the time data was collected and analyzed for this report, complete information on the 2010 review of national targets was not yet available as most national consultation

<sup>&</sup>lt;sup>3</sup> The analysis was done for the following countries for which national consultation reports were received: Albania, Armenia, Belarus, Moldova, Romania and Ukraine, as well as Russia (basing on draft report) and taking a note of Macedonian report that was received at late moment. The set of countries is geographically representative for SEE and EE but not for Central Asia.

reports had not vet been produced. That said, CS informants interviewed for this report. indicated that they were not fully informed about the review process and had limited access to data on the targets. National consultation reports summarized in so called "Aide-Memoires"<sup>4</sup> were obtained for Azerbaijan, Georgia, Macedonia and Romania. Romania was the only country with reports from both the 2007 and 2010 consultations. This limited information points to the tendency for countries to update indicators with those used in UNGASS reporting<sup>5</sup> by creating a sub-sample on impact, treatment, prevention and behaviors of key populations and young people, and funding levels. One country (Georgia) introduced an indicator on support for PLHIV. None of the four countries for which Aide-Memoires were available added indicators on human rights. There were examples of more strict definitions of indicators on behaviors (e.g. the percentage of IDUs who used condoms during last intercourse and who used clean injecting equipment during last injection, percentage of SWs who consistently use condoms, percentage of young people who use condoms during first sexual intercourse). Three out of the four countries for which national review reports were available added indicators on prisoners.

Moreover, a comparison of the summary indicators for Romania in the national consultation report from four years ago and the recent progress review shows that the number and wording of indicators was changed , making them difficult to compare. The country indicators on various marginalized and vulnerable groups, including IDUs, SWs, MSM, inmates, disadvantaged communities (primarily Roma communities), and youth. Those indicators are also integrated into the draft national strategy. Additionally, Romania introduced more specific indicators on service development, for example, it set separate indicators on the percentage of IDUs accessing needle exchange services and those eligible for and accessing opioid substitution therapy. There are 8 specific indicators on MSM and 5 indicators on prisoners with an emphasis on access to quality HIV prevention services.

While in 2006-2007 countries set very ambitious targets that projected major growth of services and changes in risk behaviors, targets developed in 2010 are, on the contrary, substantially less ambitious with regard to behavior change and access to testing and treatment. Respondents from Belarus and Georgia stated, however, that the 2010 targets were still too ambitious. Elena Grigorieva from the Belarus PLHIV Network, commented that the ambitious nature of the targets set four years ago was counterproductive in some of the 2010 discussion, since government officials tend to want to seem progressive and therefore seek more ambitious targets even though doing so may not be realistic.

Georgian, Belarusian, Macedonian, and UNAIDS respondents noted that it was challenging to review progress towards targets which were expressed as a percentage of a population having a certain characteristic because the denominators (total population size) has not been adequately assessed. This is especially true for marginalized populations.

### Conclusions

 Limited information was available about the targets set in 2006-2007 and reviewed in 2010 because national reviews were under way at the end of 2010.

<sup>&</sup>lt;sup>4</sup> Aide Memoire is a product of the universal access reviews at country levels and is prepared internally by each UNAIDS country office according to suggested template covering country consultation process, key successes, key gaps/obstacles, and recommendations for future action.

<sup>&</sup>lt;sup>5</sup> For more see: UNAIDS (2009). Monitoring the Declaration of Commitment on HIV/AIDS: guidelines on construction of core indicators: 2010 reporting

- In 2010, most countries tend to use the UNGASS indicators for setting targets beyond 2010. They use indicators on funding levels, prevalence among key populations and pregnant women, levels of treatment, testing, prevention and behaviors of key populations and youth. Some set targets on care. Azerbaijan, Georgia, Macedonia and Romania do not have any targets on human rights, according to the national Aide Memoire.
- In many countries there was recognition that some of the targets set in 2006-7 were not well formulated (overambitious and/or hard to measure), so instead of conducting in-depth reviews of the degree to which they were achieved, efforts were dedicated to developing new indicators and setting new targets.

# 5. Progress on achievement by 2010

## 5.1. Commitment and funding

The countries of the region have expressed commitment to address the HIV epidemic in a number of political declarations,<sup>6</sup> but the degree to which these written expressions of commitment have been upheld varies.

# 5.1.1. The 'three ones' and integration of universal access targets and processes

In most countries in the region, the 3 ones (one national decision-making body, one national strategic plan, and one monitoring & evaluation (M&E) system) have been implemented. In Albania, the 3 ones have been achieved with the CCM functioning as the national decision-making body. Albania is in the midst of its 2008 – 2014 national strategic plan. In Belarus, respondents noted that the 3 ones are being implemented though there are problems with the M&E system, including inaccurate estimations of coverage and challenges related to research quality. Additionally, there is both a CCM and a Coordination Council in Belarus. Also noted was the fact that the Coordination Council included representatives of PLHIV (who had specifically requested to be part of the group) though MARPs were not represented (and may have not asked to be included). In Georgia, the 3 ones are being implemented, with the CCM serving as the key national body for multiple diseases including HIV; a national strategic plan for 2011-2016 is developed and awaiting approval. In Macedonia, the three ones are being implemented. Until recently, there were two national decision-making bodies - a National AIDS Commission and a CCM – though the Commission does not currently function and the CCM occupies that role, though respondents noted that it is not quite the same as a national AIDS coordination body. In Ukraine, Kazakhstan, and Romania the three ones have also been implemented.

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<sup>&</sup>lt;sup>6</sup> Starting with the 1972 Alma-Ata Declaration in which, though it predates the HIV epidemic, countries expressed commitment to provide primary health care for all. All countries in the region are signatories of numerous declarations of commitment. They are all signatories of the UNGASS declaration of 2001 explicitly committing themselves to achieving the goal of universal access. In 2004, they signed the Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia (2004) in which they explicitly committed themselves to scale up access for MARPs. Also in 2004, many countries became signatories to the Vilnius Declaration on Measures to Strengthen Responses to HIV/AIDS in the European Union and in Neighboring Countries and in 2007, many became signatories to the Bremen Declaration 'Responsibility and Partnership – Together Against HIV/AIDS' in which commitment to cooperate to ensure affordable treatment was expressed.

# 5.1.2 Integration of universal access indicators and targets with national strategic plans and budgets

The regional UNAIDS office noted that most national programs use the principles of universal access to build their national strategies. In Albania, the indicators were used in the national strategic plan and this strategic plan was in turn used in the GF Round 10 proposal. In Belarus, the indicators were integrated, with some minor discrepancies, into the national program for 2011 – 2016. They were also integrated into the National HIV prevention program 2006 - 2010, as well as the national strategic plan for 2004-2008. In Georgia, the indicators were integrated into the national strategic plan, but the national strategic plan is not very tightly linked to HIV program budgets. (Chikanovani, 2010). In Macedonia, discussion of indicators and targets was linked with discussion of the national strategic plan. In Ukraine, where the national strategic plan is now undergoing a mid-term evaluation (the program will be completed in 2013), the indicators and targets were integrated into it. In Romania, the targets are integrated into a national strategic plan, which was awaiting official endorsement by the MoH at the time of this writing. In 2007, the indicators were integrated with the national strategic plan for 2008 - 2013, which has not been fully endorsed by the government. The national strategic plan currently awaiting approval is not linked with a budget or operational plan and therefore, as national activists point out, "will not automatically ensure the implementation of HIV prevention programs, access to ARV treatment for everybody in need without interruption, the existence of psycho-social services for PLHIV or any other services in HIV/AIDS."

# 5.1.3. Commitment and Funding

### 5.1.3.1 Sources of Funding (domestic v. international)

The most sincere expression of commitment to address the HIV epidemic by a state is the allocation of funds for appropriate services and commodities. By analyzing where money for national HIV programs comes from and how it is used much can be said about commitment.

In the region overall, spending has increased in the period since the establishment of UA targets and there has also been an increase in the proportion of money available from domestic sources for HIV work (see table below). Of the countries surveyed, Belarus had the highest level of domestic investment with 75.2 % of funds for HIV coming from domestic sources. In Georgia, the proportion of HIV funding coming from domestic sources is the lowest despite an increase in the proportion of funding from domestic sources from 17.5% in 2008 to 24.1% in 2009. The increase was largely due to the change in household expenditure, which grew from 2.1% to 9.4% of total HIV spending during the same period. This is a dangerous tendency as it means that affected households are beginning to bear the burden of the costs of the epidemic which is likely to only further contribute to their vulnerability and limit access for those not able to pay. Belarus has seen a recent increase in domestic funding though it was not due to an expansion of HIV programs, but rather to sector-wide increases in salaries of governmental employees. By 2013, Belarus will be required to fund 50% of activities funded by the GF. In Macedonia, in 2008, the level of domestic spending was 4% above the amount targeted in their universal access indicators for that year.

Proportions of funding from domestic and foreign sources, as reported in national

**UNGASS Reports**<sup>7</sup>

Country (year)	Domestic sources reported in national UNGASS reports (Domestic sources reported in UNAIDS Report on the Global AIDS Epidemic 2010)	Foreign sources
Belarus (2008)	75.2 % (72.7%)	24.8 %
Georgia (2008)	17.5 % (15.8%)	82.5 %
Kazakhstan (2009)	71.4%	28.6%
Macedonia (2008)	56.45%	43.54%
Ukraine (2008)	29.29% (59.5%)	70.71%

### 5.1.3.2 Allocation of Funding

Analysis of the types of activities funded reveals some disturbing tendencies: 1) a strong tendency to underfund prevention; and 2) a strong tendency to underfund activities targeting MARPs. These problems are a larger issue in domestic funding than in programs funded from international sources. Over 90% of all funding for work with SW and clients, IDU and MSM in the EECA region comes from international sources (Broun, 2010). While approximately 50% of international funds in the EECA region are used for prevention, less than 20% of domestic funds are used for prevention. Only 11% of all prevention program funds are spent to target MARPS8 (Schonning, 2010). Moreover, spending on treatment is growing much faster than spending on prevention, having increased by approximately 14% between 2008 and 2009 while spending on prevention increased by approximately 2% in the same period (Broun, 2010). In Georgia, for example, "analysis of national strategic plan's spending on strategic priorities reveal that the share of funds spent on treatment and surveillance are increasing at the cost of declining share for prevention" (Chikanovani, 2010). In Romania, the national government provided very limited financial support for work by CSOs and prevention services for MARPs are almost exclusively supported by the Global Fund (through 2010) and other international donors.

The lack of state support for prevention programs and activities targeting MARPs is especially dangerous for the region as international funding decreases over time. As noted in the recent Lancet review article entitled, *Financing of HIV/AIDS programme scale-up in low and Middle-income countries, 2009-2031,* "...middle-income countries with low burden of HIV/AIDS will gradually be able to take on the modest cost of their HIV/AIDS response..." (*Hecht, 2010*). All countries in the EECA & SEE region are or will soon become "middle-income" countries. Belarus, Kazakhstan, Bosnia Herzegovina and Macedonia are now categorized as "upper middle-income" countries and therefore will likely not to be eligible for Global Fund support of HIV programs in Round 11. Russia has not been eligible for GF funds for HIV for several years already, and all of the (new) EU member states are ineligible.

Civil society representatives that were surveyed for this report displayed awareness of this dynamic and advocated for more robust funding for programs targeting MARPs during the process of review of universal access targets. In Belarus, there was some discussion of possible state funding for work with MARPs, but no specific figures were

<sup>&</sup>lt;sup>7</sup> It should be noted that in some cases there were discrepancies between data reported in national UNGASS reports and data reported in the Global AIDS Report. In Belarus and Georgia the estimate of domestic spending was around 2% lower in the Global AIDS Report than it was in the national UNGASS report (Belarus - 75.2 % in national report vs 72.7% in global report and Georgia 17.5 % in the national report vs 15.8% in the global report. In Ukraine the difference was very significant, with domestic investment estimated at 29.29% in the national report while the global report estimated it at 59.5%.

<sup>&</sup>lt;sup>8</sup> Data based on the last year data available to UNAIDS in 2010.

mentioned and no promises were made. "The share of HIV funding for MARPs should be higher than it is now," said David Otiashvili, Chair of Georgia's Harm Reduction Network and Director of the NGO Alternative Georgia. He noted that during discussion of the national strategic plan, their suggestion to expand services for MARPs in order to increase coverage was considered but not fully funded due to budget constraints. In Macedonia too, CS representatives advocated for increased support for MARPs. including sex workers, prisoners MSM, and IDU. Hristijan Jankuloski of the NGO Healthy Options Project Skopje (HOPS) acknowledged significant government spending but noted that state money is not spent well. MoH money was spent on strategic information, testing, and work in schools, but no money was allocated for NGOs, which are not funded from the state budget at all. In 2009, HOPS requested an allocation for needles, condoms, and lubricant, which was added to the text but not the budget. The same request was made in 2010 for the 2011 budget. Similarly, the NGO Equality of Gay and Lesbian requested 6000 sets of condoms and lubricant for MSM. The 2011 budget had not been approved at the time of the writing of this report. The GF was the only funder of MSM work in 2011. Considerable advocacy will be needed to bring spending in line with needs.

Another critical issue in terms of allocation of funding is pharmaceutical pricing. According to a report produced by EATG, ECUO, ITPC-EECA and EHRN in 2007, the prices paid for pharmaceuticals in the EECA region are very high compared with other regions. (*ECUO*, 2007) Pharmaceutical companies try use the middle or upper-middle income status of many of the countries in the region to seek greater profits. Governments and notably CS in most countries do not pursue lower pharmaceutical prices through competition among manufactures. The flexibilities allowed in Trade-Related Aspects of Intellectual Property Rights (TRIPS) Agreement allowing countries to use compulsory licensing to obtain cheaper medications have never been used in the region. Moreover there are cases in which prices for medicines purchased with domestic funds are higher than those for medicines purchased with GF funds. This occurred in Ukraine (*ECUO*, 2007) and recently in Russia (*Cantau*, 2010). With such high pharmaceutical prices, scarce resources are feeding company profits rather than being directed at needed programming.

### 5.1.3.3 Sustainability?

The countries in the region are still heavily dependent on foreign funding. This problem is especially pronounced in relation to prevention funding. Some countries will face considerable difficulty continuing to finance progress toward universal access, while others are in better shape. Albania is in the midst of carrying out its national strategic plan for 2008 – 1014. It has a Round 5 grant which will conclude in 2012; Olimbi Hoxhai of the Albanian Association PLHIV expressed concern stating that "the sustainability of this objective will be an obstacle in the future as financial resources from the state budget are very limited." Albania's application to Round 10 was not approved, meaning there will likely be a shortfall in funding for planned activities. Of the countries studied, Belarus, with its relatively high proportion of funding coming from the state, might be in a relatively strong position for sustaining funding. But limited or no state funding for programs targeting MARPs and the rejection of their Round 10 GF proposal (which targeted MARPs) likely means there will be significant shortfalls in funding for critical programs in the next 5 years. Belarus is likely to not be eligible for Round 11 due to its status as an upper middle-income country. Georgia has had GF grants in Rounds 2, 6 and 9. As stated above, state funding accounts for a small proportion of funding. The state program for 2011 - 2015 has been developed and is awaiting approval. Its Round 10 proposal targeting MARPs was conditionally approved (category 2). In Romania, the sustainability of HIV funding is at risk as international donors have withdrawn after Romania joined the European Union. But EU funding mechanisms have been

inaccessible for most CSOs and difficult to manage for those that have received EU funds. Moreover, in the midst of the current economic crisis, funding for social programs is being radically reduced. Macedonia's Round 10 Global Fund proposal targeting MARPs was approved unconditionally (category 1). According to Hristijan Jankuloski of HOPS, funding should be adequate through 2016. The governmental will be obligated to match funding within that grant agreement and in fact had already taken up funding of treatment in 2009. Macedonia will not be eligible for GF funds in Round 11 under current eligibility criteria.

### **Conclusions**

- While funding from both international sources (especially the GF) and from domestic sources has increased, it still is not adequate to fund the activities required for universal access.
- Investment in prevention is disproportionately low.
- Investment in programs for MARP is extremely low in proportion to the degree to which they are affected.
- The proportion of domestic HIV funding that is allocated for prevention and for programs for MARPs is lower than the proportion that international sources allocate for prevention and for programs targeting MARPs.
- Some countries in the region are likely to become more reliant on local funding as GF eligibility criteria exclude them from future grants.
- Medication prices in the region are high and governments and civil society have yet to take action to lower them so that resources can be made available for priority programming such as prevention among MARPs and advocacy work.

# 5.2. Human rights

In the context of HIV/AIDS, an environment in which human rights are respected ensures that vulnerability to HIV/AIDS is reduced, those infected with and affected by HIV/AIDS live a life of dignity without discrimination and the personal and societal impact of HIV infection is alleviated.

UNAIDS International Guidelines on HIV and Human Rights 2006

During the last 5 years, all countries studied except Macedonia and Romania had reviewed and updated their **legislation related to HIV**. Revised laws have mainly moved towards a more protective environment for PLHIV. In Ukraine, HIV-based travel restrictions were removed in 2010. Albania's law adopted in 2008 addresses not only labor rights and the right to confidentiality but also promotes the establishment of safe places where affected

In the last five years, many countries looked into their HIV/AIDS legislation. [There would be many examples,] the region's tendency is that laws become more positive towards people living with HIV.

Nataliya Leonchuk, ECUO

people have access to life saving treatment, and a complaints mechanism. However, as Albanian respondents noted, the law is not sufficient: relevant regulation and support needs to be provided. In contrast, Romania, where legislation that prohibits discrimination on the grounds of sexual orientation and health status is in place, dedicated one of the four goals described in the national HIV strategy to social protection and the rights of PLHIV.

An exception to these positive trends is Belarus, where the current draft of legislation on "socially dangerous diseases" foresees mandatory treatment for HIV and some

provisions that would endanger the confidentiality of people's HIV status. Elsewhere, elements of criminalization of HIV exposure and transmission are still in place, for example in Kazakhstan and Macedonia.

Fewer legislative changes have been reported for protection of rights of the key populations. The Charter of Fundamental Rights of the European Union<sup>9</sup> prohibits discrimination on the grounds of sexual orientation and disability, and thus could be applied in Romania, which is part of the EU, and in the future in the countries that want to join the EU. Georgia too has legislation against discrimination on grounds of sexual orientation (*de Lussigny et al, 2010*). After extensive discussions, similar provisions were not foreseen in Macedonia.

In Georgia, no positive changes have been achieved on human rights in the last years with a few exceptions and declarations. In the drug policy field, it has just worsened with everyone being tested for drugs and imprisonment of drug users.

David Otiashvili, GHRN & Alternative Georgia

On **drug policy**, we see tendencies in sharp contrast to those related to legislation on HIV. Normative acts are sources of a prohibitive environment for people who use drugs. In Georgia, drug use continues to be a criminal offence. This contributed to Georgia now having one of the world's highest portions of its population in prison. Civil society groups mobilized society and collected support from more than 58,000 citizens in order to initiate legislative changes to the Criminal Code (*Georgian Harm Reduction Network*, 2008), but for more than two years proposed legislative changes have not been reviewed by the Parliament, according to Koka Labartkava of the NGO New Vector. In the next 5 years, the country plans to revisit drug policy as part of its implementation of the national HIV strategic plan and road towards universal access.

Drug possession for personal use is a criminal offence in most countries. Recently Ukraine undid their progressive regulative changes of two years ago that increased the amounts of drugs that one may legally possess from trace amounts of drugs to the size of small doses that users would actually use. Civil society groups commented that this reversal of policy effectively criminalizes drug dependence (*International HIV/AIDS Alliance in Ukraine, 2010b*). Moreover, its narcotic and psychotropic substance regulation creates obstacles to the broader implementation of opioid substitution therapy (OST). Each day OST patients must pick up their dose personally from a specialized clinic, thus restricting working hours and freedom to travel. OST programs have also attracted special police attention: police harassment and arrests of doctors and patients have been documented in a number of cities.

At least a few EECA countries, including Russia, Kazakhstan, and Ukraine, continue to maintain drug user registries. The names of people who seek drug dependence treatment in health institutions or who are 'caught' by police while intoxicated are included in an official registry, which frequently results in violations of economic and social rights. For example, people on the registry can be prohibited from receiving driving licenses or acquiring certain jobs. Having one's name removed from the database is difficult and requires proving that one has not used for some period of time. Georgia, in contrast, has recently removed its registry.

lex.europa.eu/LexUriServ/LexUriServ.do?uri=0J:C:2007:303:0001:0016:EN:PDF

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<sup>&</sup>lt;sup>9</sup> Article 21: Any discrimination based on any ground such as sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age or sexual orientation shall be prohibited. Available: http://eur-

For **sex workers** the major source of human rights violations is from those who should be protecting rights – the police (*SWAN, 2009*). In three countries studied - Albania, Macedonia and Ukraine - the situation is worsened by prohibition of sex work in administrative, public order, or criminal law. Genci Mucollari from Albania indicated that the illegal status of sex work creates major challenges in reaching out to sex workers. Also of note is the absence of surveillance studies among sex workers in this country. In Macedonia, legislation indicating that sex work endangers the public health has long been unenforced. However, in 2009 police conducted involuntary testing of sex workers for STIs, including HIV, based on the article. This one time action was met with quick mobilization by civil society groups which secured broad international support. The situation may change further as a result of the recent creation of a few sex worker rights groups in the region and more international support for SW rights, such as the International Labor Organization's (ILO) recommendation on HIV/AIDS (*ILO, 2010*).

Criminal laws against **homosexuality** were abolished in some countries relatively recently (e.g. 2001 in Romania). Across the region, Turkmenistan and Uzbekistan still have punishments for MSM behavior among their laws. However, MSM in various countries of the region report physical violence due to sexual orientation (10% of MSM in Georgia), and psychological violence and harassment (as high as 70% in Serbia) (*de Lussigny et al, 2010*). The biggest challenge for MSM is stigma in society, media, and even in health care settings. "You would get a service but with prejudice," summarized Zoran Jordanov, EGAL, Macedonia.

There are cases when people cannot exercise their rights due to **stigma**. In Belarus, people are entitled to financial support in the event of the death of a family member. However, in some places, death certificates that are needed to get this support indicate the cause of death, and often people would rather refuse the social benefit than disclose the HIV status of the deceased to their family.

New **instruments** that have been used **to protect of human rights** during the period under review include legal services, often through collaboration between human rights groups and service providers working with key populations. Legal services have addressed challenges that IDUs, SWs, and MSM face with law enforcement, residence registration, and lost documents. In most cases, those services are made available with international support, notably from the private Open Society Foundations. In Macedonia, the *Coalition for the Promotion and Protection of the Sexual and Health Rights of Marginalized Communities, (www.coalition.org.mk)* not only provides services but also publishes annual reports on rights conditions. Other human rights protection mechanisms noted by interviewees were:

- Court precedents: in national judicial systems or through the European Court of Human Rights (ECHR). In Georgia, the ECHR heard a case involving a prisoner in need of hepatitis C treatment;
- UN and other international human rights mechanisms: one Russian drug user complained to the UN Special Rapporteur on the Right to the Highest Attainable Standard of Physical and Mental Health about the illegality and unavailability of OST in her country;
- Citizen legislative initiatives: e.g. the abovementioned case of a petition to change the Criminal Code in Georgia;
- Tracking of and raising awareness of discrimination cases by community groups with support of human rights organizations.

Government monitoring mechanisms, including administrative measures in governmental health clinics, and use of ombudsmen, are present in some countries but

infrequently utilized. As Belarus and Macedonian respondents noted, people often don't trust government structures including state justice systems.

Community systems capable of empowering leaders and communities to stand up for their rights are at varying levels of development in the region. PLHIV groups have grown stronger in almost all countries analyzed and have advocated for human rights issues to be addressed, though PLHIV groups in some low prevalence countries have become weaker. MARPs groups tend to be less developed than PLHIV groups though there are some good examples such as the All-Ukrainian Association of OST Patients, which is working to improve the quality of services and to defend the rights of OST program clients and practitioners. A few sex worker organizations are emerging including two in the region analyzed. Organizations focused on health and rights of LGBT mainly run by LGBT leaders continued to grow in number and engagement in both services and advocacy, notably in Belarus, Georgia, Macedonia, Ukraine. MARP-led groups have limited access to funding with few donors investing into advocacy and even fewer providing support for community development. The Community Systems Strengthening (CSS) Framework of the Global Fund, designed to empower such communities, has yet to be included in the Global Fund financed work in most countries in the region.

In this environment, it is extremely useful that the universal access review process makes it possible to highlight individual cases of discrimination, and to have national stakeholders address the need of human rights protection and the factors that hamper public health objectives.

### **Conclusions**

- A number of countries have major challenges in protecting the human rights of key populations, though there is a substantial positive progress over the last five years in addressing specific rights of HIV-positive people.
- Human rights violations against stigmatized, vulnerable populations persist, though
  it is widely recognized that upholding human rights is crucial for successful HIV
  prevention, treatment, care, and support for these populations.
- Progress on human rights is not tracked in many countries and example indicators and technical support on how to use them are needed. National Strategies or universal access reviews rarely addressed it.
- Though stigma is widely recognized as problematic, there is not much being done to monitor it.
- The diversity of services related to human rights has expanded in the region with an increasing number of programs designed to provide legal support to MARPs.
- Most human rights protection mechanisms accessible to MARPs are run by civil society and funded by international donors.
- There is distrust (especially among stigmatized populations) of state services, including state mechanisms to address human rights issues.
- There are good practices in the region, in Macedonia for example where civil society has provided needed legal support to PLHIV and MARPs.
- Organizations led and run by MARPs are emerging in the region as important advocates, but further strengthening of capacity and access to funding (including the Global Fund's CSS mechanism) are needed.

### 5.3. Treatment, care and support

As of 2010, antiretroviral treatment is available in all countries in the region, which was not the case in 2006, and coverage within countries has grown significantly. But access

is far from universal. The average level of access in the low and middle income countries of Europe and Central Asia is lower than for all other regions in the world with the exception of the region of North Africa and the Middle East, with a rate of only 19% coverage compared with a global average of 36% (WHO/UNAIDS/UNICEF, 2010). The low HIV prevalence South East Europe has higher levels of access, in many cases with rates that can be considered "universal". Of the countries studied, Romania and Georgia have achieved "universal" access, both with rates of 95%, though in Romania one study estimated that access was only at 83% (Sens Pozitiv, 2010) if PLHIV who do not know their status are taken into consideration. The rates in Belarus, Kazakhstan and Ukraine were considerably lower - 48%, 49% and 16% respectively (WHO/UNAIDS/UNICEF, 2010). In Macedonia, the rate of coverage was estimated at only 5% with 442 people estimated to be in need and only 24 receiving it, according to the national UNGASS report. Data on the portion of those in need receiving treatment was not reported for Albania. In many countries estimates of coverage may be of limited reliability due to the fact that significant numbers of people do not know their status.

Low coverage in the EECA countries may be linked to inadequate access by MARPs, who

in most countries in the region comprise the majority of PLHIV. The dynamics are different in the Balkans where there are relatively few PLHIV. Several respondents mentioned that stigmatization of MARPs was a barrier to access to a wide range of services. A respondent from Georgia stated that there was not direct discrimination but that late presentation was a problem for IDU. A respondent from Albania mentioned that stigma, especially for

The main cause of low levels of access to HIV treatment in the countries where many PLHIV are IDU is repressive drug policy and lack adequate support, including opioid substitution therapy.

Daria Ocheret, EHRN

transgender, can be a barrier to access to care. In Belarus, a respondent mentioned that IDU are always last to receive services, including for example treatments for opportunistic infections. In Macedonia, a respondent stated that IDU were not discriminated against at the HIV treatment center. Repressive drug laws were cited by respondents as a barrier to access by IDU. Drug policy was identified as a barrier to treatment by 63% of countries in Europe and Central Asia that reported on progress related to the Dublin Declaration (ECDC / WHO-EURO, 2010). An important factor blocking access by IDU in most countries in the region is low levels of access to opioid substitution therapy. Less than 2% of IDU receive OST in Ukraine and less than 1% receive it in Belarus, Georgia, and Kazakhstan (Mathers et al, 2010), 10 though the WHO recommends that between 20% and 40% of IDU should have access to OST. (WHO/UNODC/UNAIDS, 2009). Though lack of access by IDU may be a major barrier to achieving universal access for many countries in the region, monitoring access by IDU is inadequate with only 4 out of 12 countries in the region reporting the number of IDU receiving treatment. (UNAIDS, 2010)

While respondents noted that access to treatment for opportunistic infections was not problematic, access to treatment for Hepatitis C was very limited. "There is very little access to treatment for hepatitis C even though our epidemics are mainly among people who use drugs, the majority of whom have hepatitis." said Natalya Leonchuk of ECUO HIV. Though limited overall, there are examples of progress being made. In the Balkans, Macedonia recently included HCV medicines in its essential medicine list. In Belarus, a few PLHIV have had access. In Ukraine, more than 400 people were treated with costs covered by a World Bank loan. In both Romania and Russia, HCV medications are available to some degree to PLHIV. The expensive medications used to treat HCV are

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<sup>&</sup>lt;sup>10</sup> Comparable data was not available for Albania and Macedonia.

rarely paid for by governments, and have generally proven too costly to be included at adequate levels in GF grant proposals. In Ukraine, only 300 HCV treatment courses were included in the GF 10 round proposal and only 400 in the Kyrgyz proposal, though the number of people in need in both countries is far greater. A notable exception in the region is Georgia, which is expected to provide treatment to 100 people in need in 2011 to adequately cover the need currently identified over the next 5 years with the GF support. Drug dependence, a common co-morbidity in the region, is a problem for which adequate treatment is woefully inadequate, leading to poor uptake of antiretroviral therapy and inadequate treatment support of many in need. Drug overdose, a leading cause of death among PLHIV in the region, remains underaddressed, though overdose prevention education and distribution of naloxone to communities of drug users is increasingly seen as an effective means to reduce overdose mortality (EHRN, 2010). The region faces continued problems with linkage between TB and HIV services leading to inadequate treatment levels. Significant numbers of PLHIV with diagnosed TB go without treatment: Belarus - 27%; Georgia - 67%; Kazakhstan -57%: Ukraine 79% (WHO / UNAIDS / UNICEF, 2010). TB is a leading cause of death among PLHIV in the eastern part of the region.

Most but not all countries in the region have treatment protocols in place. The treatment protocol developed by WHO-EURO specifically with the regions need in mind was instrumental in this process. However, implementation has been challenging. For example, HBV vaccination recommended for PLHIV is rarely available. The impact of treatment among those with access is slightly lower in the EECA region than the world average. While the average global treatment retention rate at 12 months was 82% (WHO/UNAIDS/UNICEF, 2010), the median rate among countries reporting in the SEE & EECA region was 79% (ranging from 58% - 93%). Rates for countries studied are: Belarus - 78.43%; Georgia - 81.03%; Kazakhstan - 74.89%; Romania - 93.38%; Ukraine - 84%. These somewhat low rates have been attributed to late presentation. inadequate adherence support (especially among IDU with inadequate drug dependency care), and continued need to develop adequate psychosocial support for treatment adherence. Generally, diagnostic tests are available free of charge but some barriers were reported. In Belarus, for example, in Gomel Oblast, where approximately 30% of the country's PLHIV live, there is no lab and access to viral load testing is periodically limited. It is interesting to note that women have better access and better treatment outcomes than men in many countries, which suggests that men (more commonly IDU) may be facing discrimination and innadequate support for uptake of and adherence to treatment.

Interruptions in provision of treatment have been noted throughout the region and among the countries studied in Albania, Belarus, Georgia, Macedonia, and Romania. In Albania, there have been interruptions in provision of child formulations of medicines. In Belarus, a recent interruption in the drug supply remained unresolved in December 2010 at the time of this writing, though civil society groups had taken action to seek an appropriate response by the government. In Belarus, treatment interruptions are not officially acknowledged. In Romania, the government was unresponsive to civil society appeals to alleviate treatment interruptions that were experienced in 2009 and 2010. Interruptions were attributed to inadequate allocation of financial resources by the government and also to decentralization of procurement. In other countries, interruptions have been attributed to problems with supply chain management and/or procurement. Some noted that it was challenging to forecast appropriate quantities of medicines to procure in low prevalence countries where relatively little is needed.

Even though access to medicines is quite limited in the region, few countries have taken measures to lower pharmaceutical prices. Pharmaceutical prices in low and middle

income countries are often as high as prices in the European Union. Few countries use generics though some do. In Albania and Belarus, medicines are acquired through international suppliers (UNICEF and IDA correspondingly), though it was noted by CS respondents that even in those countries it was difficult to track prices. In most countries even civil society activists have rarely included the issue of medicine pricing in their agendas. Ukraine is an exception with a leadership of PLHIV focused on using the limited available resources for buying medicines for the maximum number of people in need. Romania cannot introduce generics for most medicines as it must comply with EU regulations. As national governments take on a growing proportion of the cost of purchasing drugs some new risks will arise. Already twice, in Ukraine and Russia, a situation where the national government paid more for drugs than was paid with Global Fund's resources have been seen. Recently it came to light that the Russian government was paying 6000 USD for a medicine that was being purchased with Global Fund monies for only 3200 (*Cantau, September 23, 2010*).

### **Conclusions**

- Access to treatment in EECA is improving but the region still has among the lowest treatment rates in the world.
- The impact of treatment (indicated by survival and continuation of therapy 12 months after treatment initiation) is lower in the EECA region than the world average.
- Lack of access to testing, care and support by MARPs, especially IDU, is the biggest factor contributing to the region's low level of access.
- Men have lower access to treatment and worse treatment outcomes than women.
- While there are good practice examples in the region of provision of treatment for co-infections such as hepatitis C or tuberculosis, access to treatment for these infections remains low among PLHIV.
- Information on the comprehensiveness of treatment programs, for example appropriate care and support services, is limited.
- Access to opioid substitution therapy, which is available at the pilot level in most countries, remains considerably lower than the levels recommended by WHO. This situation impacts treatment uptake and adherence among the many PLHIV in the region who are opioid dependent.
- Treatment interruptions persist in the region, indicating problems in procurement and supply chain management and sometimes problems with continuity of financing.
- Though investment in treatment is improving, dependence on foreign funding persists, as do high pharmaceutical prices.
- In some countries, we are beginning to see individual co-payments for some services become a barrier to access to care.

### 5.4. Prevention

Key prevention messages are definitely not 'abstinence only' but also not a free choice either. Governments are focused on educating youth in schools about HIV but not so much on IDUs, prisoners and sex workers. At least not state investment. **Anna Zakowicz, EATG** 

Given that most countries studied are experiencing growing epidemics and, as UNAIDS has noted, some of the fastest growing epidemics in the world, clearly prevention has not been adequate to slow HIV's spread in EECA. The SEE countries have thus far managed to keep HIV prevalence low, though over the last 5 years they experienced

increases in HIV rates in MSM and some other key populations. Prevalence among key populations has risen. Over the period analyzed, civil society groups and other national stakeholders in both EECA and SEE report substantial progress, according to interviews, country UNGASS reports, and the universal access review processes.

### 5.3.1. Policy and priorities

As interviewees noted and as also mentioned in the comprehensive review of progress of the Dublin Declaration, governments recognize the importance of prevention in national responses, but they often prioritize programming for populations that are politically acceptable rather than supporting 'politically-sensitive' services and promoting an enabling environment for them. As David Otiashvili of the Georgian Harm Reduction Network said, "countries' priorities often depends on donor's priorities." National funding for prevention is most likely to be spent on general population awareness (and sometimes testing) campaigns and supporting programs targeting mainstream youth, as well as improving safety of blood and blood products, and safety in healthcare settings. Services for key populations almost solely depend on international funding: over 90% of funding for services for SW, MSM, IDUs come from international sources, mainly the Global Fund. (*Broun, 2010*)

The Dublin Declaration report notes two more major challenges, which are true not only of Europe and Central Asia and specifically the countries studied. Most countries report having laws, regulations or policies that present obstacles to effective HIV responses among key populations, and marginalized and stigmatized populations often lack champions in government who are willing to work to address these obstacles. The availability of prevention services which are politically acceptable is higher than for those that are less politically acceptable, such as harm reduction services in prisons.

### 5.3.2. Vertical transmission

Half of the respondents indicated that the largest success in the field of prevention is progress on preventing vertical transmission, and UNAIDS estimates the coverage of vertical transmission at 90% (though coverage is still lower than 50% in Azerbaijan and Romania and under 25% in Kyrgyzstan and Tajikistan). Albania, which according to one respondent had previous challenges with early identification of HIV cases among pregnant women, reported no HIV cases among pregnant women in 2008-2009. Romanian informants confirmed challenges with pre-test counseling for pregnant women. Other countries report introducing massive routine testing and counseling programs for all pregnant women and high rates of testing – above 85% in Belarus, Kazakhstan, and Ukraine. In Ukraine, the country in the region most affected by the epidemic, the vertical transmission rate was reduced from 27.8% in 2001 to 6.2% in 2007. Ninety-five percent of women who tested positive for HIV receive medicines for prevention of vertical transmission. However, there are some challenges including: late diagnosis of HIV (mentioned in the Georgian national report): discrimination and lack of specialized support for drug using women; and lack of comprehensive support, especially challenges with counseling (mentioned by one respondent) and low adherence (mentioned in the Belarus and Ukraine national reports).

### 5.3.3. Testing and counseling

Testing expanded substantially. Belarus, Kazakhstan, and Ukraine report high numbers of people tested among the general population. In Belarus, 36.9% of population has been

ever tested and 8% of the population is tested annually. In the Balkans, there are more voluntary counseling and testing centers that often test not only for HIV but also other STIs and hepatitis C. More cities have centers and more people have been tested. Those centers do provide confidential services. One of the remaining challenges is testing of underage adolescents, since legislation in many countries requires parental permission for those under 16.

Countries do prioritize testing in their policies and are rather eager to start providing national funding and organize it through government-based services. Sometimes this leads to funding and management challenges, as an Albanian respondent pointed out was the case when the government took over funding of testing in 2008-09. Overall, however, these developments are significant and there have been substantial increases in numbers of people tested. In Albania for example, 10 times more people were tested then 5 years ago.

The expanded testing programs do not always are target people who are the most vulnerable. For example, a UNAIDS analysis shows that the percentage of IDUs among people tested decreased from 2005 to 2009 in EECA countries (*Broun, 2010*). Of particular concern is the lack of accessibility of testing and counseling services for IDUs in Georgia, Romania, and Ukraine, for SWs in Georgia and Romania, for MSM in Georgia, and for prisoners in Ukraine. The quality of data on accessibility by MARPs is sometimes inaccurate since data is collected almost exclusively from clients of low-threshold services, and therefore does not accurately reflect accessibility among most-at-risk populations as a whole. In particular it should be noted that data about prisoners is not available for most countries.

Portion of populations who received HIV test in the last 12 months and know its result

			1	1	
Country	Adult populations	IDUs	MSM	SW	Prisoners
Albania	0.2% among	16.5%	44.9%	n.d.	n.d.
	females; 0.6%				
	males				
Belarus	16.3%	56.72%	79.85%	84.99%	n.d.
Georgia	Not relevant,	5.7%	23.53%	27.5%	n.d.
	according to				
	national UNGASS				
	report				
Kazakhstan	22.06% (2008)	56%	60%	81%	n.d.
Macedonia	2.92% females; n.d.	43.73%	55.90%	47.25%	n.d.
	males				
Romania	n.d. (no. of tests	19%	75.19%	29.21%	n.d.
	performed in 2009:				
	118,981 or around				
	.54% of all				
	population)				
Ukraine	13%	26%	43%	59%	12%

Source: Country UNGASS 2010 reports; Romanian data for IDUs: UNODC, 2010.

### 5.3.4. Key populations

Respondents stated that most countries have managed to make significant progress in developing services for key populations over the last five years, and that this is addressed in most countries' national strategic plans, though services for prisoners are frequently lacking. Introducing services for vulnerable groups is often presented among

good practice examples in national UNGASS reports from the region. This development is linked with the Global Fund's support and priorities of those limited international funds that are available in the region.

A common challenge is that despite an increase in services available and increased HIV knowledge among vulnerable groups, behavior is slower to change. Many challenges remain for vulnerable groups to realize their rights, as mentioned in the previous section, including in terms of legislation and public perceptions, such as in healthcare settings. Marginalized groups are often prohibited from receive needles in pharmacies or care in mainstream healthcare settings. Access to condoms may be limited among low income people. Respondents emphasized that coverage of services available for vulnerable groups is limited and mostly implemented by NGOs. UNGASS coverage indicators could be an important source to allow comparison between countries, but they are of limited practical value. "Coverage," for example, has been defined for IDU as the proportion who were tested for HIV and who received a condom and a clean syringe at least once during the past year, a level of engagement that is obviously not sufficient for preventing HIV among the population.

### Injecting drug users

Within the country data reported through UNGASS, the greatest progress in introducing and developing innovative services was for IDUs. All the countries analyzed have 'legalized' needle exchange and opioid substitution therapy and have at least started pilot programs in community settings, Albania, Macedonia and Romania continued to expand programs. Albanian opioid substitution therapy (OST) is implemented by an NGO, and an NGO-based OST program exists in Romania alongside similar governmentrun services. In Romania, the first needle exchange program operated by a Roma NGO began work in 2009. In Georgia, OST is partially supported by the state, but service fees may limit accessibility to economically disadvantaged IDUs. Ukraine scaled up its pilot OST programs and is now providing both methadone and buprenorphine. Countries introduced overdose prevention education and naloxone, an opioid overdose antidote. but its distribution is limited and somewhat restricted by prescribing requirements in most countries. In Romania, NGOs continued to provide sensitization training to pharmacy staff in order to improve IDU access to low-cost sterile injecting equipment. In Ukraine, there are now 108 pharmacies from the state and private sectors that provide sterile syringes and other preventive supplies to IDUs (International HIV/AIDS Alliance in Ukraine, 2010). In order to reach young and adolescent drug injectors in Ukraine, peer driven interventions were piloted, which in particular improved outreach to stimulant injectors and females. More attention was paid to underserved women who use drugs with new services in Georgia and Ukraine.

HIV knowledge is rather good among the majority of IDUs in Belarus, Kazakhstan and Ukraine, but less than 20% identify transmission routes correctly and reject major misconceptions in Albania and Romania. Countries report rather high safe injecting behavior among IDUs with 70% or more IDUs self-reporting the use of clean syringes and other equipment in Albania, Belarus, Macedonia, and Ukraine, 63% in Kazakhstan and only less than 50% in Georgia and particularly low in Romania (17%). Almost everywhere sexual behavior is less safe than injecting behavior; less than half of IDUs used a condom during last sexual intercourse in Albania, Kazakhstan, and Ukraine. Georgia and Romania report the highest percent of IDUs with self-reported safe sexual behavior (77.9% and 85% respectively). The portion of IDUs who know where to get an HIV test and who at least once per year obtained a condom and a clean needle or syringe was above 50% in all countries with the exception of Ukraine (32%) and the country with the most rigid drug policy, Georgia (11.45%). Data from Albania and Macedonia on this were not available. The levels of coverage are lower than those recommended by

UNAIDS, UNODC and WHO in their technical guidance on setting targets for 9 essential components of harm reduction programming for IDU. Most IDU services in the region do not integrate TB or hepatitis services in their programs.

IDUs: knowledge, behavior and access to prevention programs (using UNGASS

indicators)

Percent of IDUs with:	Good HIV knowledge	Safe behavior: condom use in the last sexual intercourse	Safe behavior: using clean injecting equipment in the last injection	Coverage of prevention programs (UNGASS definition)
Albania	15.2%	36% (non-regular, non-commercial)	81.60%	79.1% (know where to get HIV test)
Belarus	57.58	59.43%	87.21%	63.63%
Georgia	37.5%	77.9%	48.1%	11.45%
Kazakhstan	76.5%	46%	63%	60%
Macedonia	34.46%	50.76%	72.73%	90.98% know where to get HIV test
Romania	10%	17%	85%	50%
Ukraine	55%	48%	87%	32%

Source: National UNGASS 2010 reports; Romanian data: UNODC, 2010.

### Sex workers

UNAIDS reports that the portion of sex workers reached through prevention programs is decreasing in the region. HIV prevalence among sex workers has increased significantly in a few countries, having doubled in Belarus and Georgia, and having gone from 4% to 13% in Ukraine. (*Broun, 2010*)

In addition to the human rights environment described above, there are additional challenges in preventing HIV among sex workers. SWAN's regional survey of sex workers indicates that the confiscation of condoms was reported by SWs in Macedonia and Serbia and that the financial burden of police fines and demands for bribes restricts sex workers' choices and contributes to their decision to sacrifice condom use for increased revenue. An additional barrier to safe sex is rushed negotiations with clients due to the threat of police violence, arrest, or extortion. The SWAN survey points out that "police harassment, detention and violence can push sex workers into isolated and unsafe areas without access to HIV prevention and treatment services or outreach programs that distribute free condoms" (SWAN, 2009).

UNGASS reporting on SWs was available from all countries with exception of Albania. The coverage of services is approximately 66% in the countries analyzed with the exception of Ukraine (59%) and Romania (22%). Condom use with commercial clients is reportedly above 95% in Georgia, Kazakhstan, and Romania, which raises admiration but also leads one to question the source of the information. High rates of condom use were also reported in Ukraine (88%), Macedonia (almost 78%), and Belarus (almost 70%). HIV knowledge among SWs is, however, often poor, and is particularly low in Georgia (<9%) and Romania (<11%).

# SW: knowledge, behavior and access to prevention programs (using UNGASS indicators)

Percent of SW	Good HIV	Safe behavior: reported	Coverage of
with:	knowledge	condom use with their most	prevention
		recent client	programs

Albania	n.d.	n.d.	n.d.
Belarus	67.33%	69.98%	85.87%
Georgia	8.13%	98.8%	66.9%
Kazakhstan	69%	96%	88%
Macedonia	46.67%	77.91%	78.75% know
			where to get
			HIV test
Romania	10.89%	98.2%	22%
Ukraine	51%	88%	59%

Source: National UNGASS 2010 reports.

#### **MSM**

According to a recent regional analysis, current MSM programming in Eastern Europe includes pilot and short term programs for delivering prevention services, and much less emphasis is placed on creating an enabling environment, providing supportive interventions, and providing treatment and care for MSM. In most countries assessed, the regional report indicates that while MSM are now included in national programs and in universal access planning as one of the populations at risk, this group often receives less attention in the actual development of services and an enabling environment than other key populations.

As for other populations, HIV prevention work among MSM is almost exclusively done by NGOs. The scale and scope of prevention services for MSM have improved over the last five years, but "remain significantly inadequate to make a sustainable impact on behavior and reduce HIV transmission among MSM. No MSM programs are large enough to be considered at scale, and most could be classified as small scale boutique or pilot projects" (*International HIV/AIDS Alliance in Ukraine, 2010a*).

The regional report lists several additional behavioral risk factors: low levels of condom use; in some countries, high levels of injecting drug use among MSM (more than 9% in Georgia, 12% in Azerbaijan), especially in the Caucasus region; and high levels of MSM having sex concurrently with female partners and commercial partners. Romania is the only country among the countries assessed for this report which reports HIV prevention coverage of MSM to be lower than 60%: in Romania it is as low as 28%.

### **Prisoners**

Belarus, Georgia, Kazakhstan, and Ukraine (but not Albania, Macedonia, or Romania) have among the top 10 largest prison populations per capita in Europe and among the highest incarceration rates in the world (*Walmsley*, *2009*). As two respondents noted and a number of external reports confirm, this high population is often related to restrictive drug policy and drug users are disproportionally represented among inmates. The drug problem is increasingly recognized by prison authorities but not necessarily actual drug use and injecting in prisons, since that would mean recognition of the system's failure to prevent drugs from getting into prisons. Sex among inmates, including among males, remains controversial and therefore condom distribution and other measures to increase safety are mainly provided through health settings (i.e. one must ask doctor for a condom rather than receiving them through a freer distribution system) or in visitation rooms. In all countries the prison health system is separated from broader health care and is shaped by prison authorities under ministries of justice or ministries of interior.

Ukraine, which is among the few countries that describes the prison situation in its UNGASS report, indicates that between 13-17% of inmates have HIV and only 15% of inmates are reached by HIV prevention, which comes mainly in the form of information

and testing rather than more comprehensive harm reduction. In the last five years, harm reduction services were initiated in Georgia and Romania. Georgia piloted prison-based opioid substitution therapy; Romania has piloted both needle exchange and opioid substitution therapy and plans to expand them further after program evaluation is completed.

### **Conclusions:**

- The region has demonstrated that it can achieve great success when prevention issues are prioritized, such as prevention of vertical transmission.
- National policies lack clear priorities that would inform the use of limited resources and guide negotiations with international donors.
- There are many good practices showing that coverage, scope and quality of programs for MARPs can be achieved, but the scale is still too low to have a major impact on the epidemic.
- Prevention among key populations has developed greatly, mainly with international funding and implementation by civil society. This is particularly seen for injecting drug users. However, the availability of services for SWs has decreased. MSM groups, particularly in EECA, report not receiving prioritization. Needle exchange, opioid substitution therapy, and free access to condoms for prisoners continued to be the most sensitive and challenging interventions for introduction and pilot, though some progress has been achieved in selected countries, notably Romania.
- Major advocacy campaigns with international support and participation of civil society are needed to ensure the sustainability and expansion of services for key populations.

### 6. Recommendations

### On universal access processes:

- UNAIDS should make the process more clear to CS, MARPs and other stakeholders, and start planning for it earlier, perhaps strategically combining it with UNGASS reporting;
- **UN agencies** should to the degree possible coordinate target setting review and reporting among the UN family and the GF.
- **UNAIDS** should establish minimum requirements and guidance for engagement of SC and MARPs in the target setting and review processes. UNAIDS should employ good practices in community involvement. This could include, for example, holding civil society caucuses prior to meetings with governmental representatives so that civil society can define its priorities, and working with SC to develop strategy and advocate their goals. Opportunities should be given to provide feedback on reports and meeting protocols.
- **UNAIDS, technical support providers, regional networks, and donors** should provide financial and technical support for MARPs involvement;
- Those designing GF proposals should use the Community Systems Strengthening Framework to seek funding from the GF to improve the capacity of MARPs community systems to feed into national decision making processes and access necessary technical support to do so effectively;
- **Civil society representatives and representatives of key populations** should be proactive in becoming involved with universal access processes;

- Civil society groups not representing MARPs should make an effort to encourage direct MARPs participation in the processes rather than attempting to voice their concerns for them;
- Technical support providers including the regional Technical Support Facility should develop tools and pools of technical assistants who can provide support in developing proposals on Community Systems Strengthening;
- **Regional networks** should be engaged in the process of planning for and providing technical assistance to their national members for involvement in processes. Regional organizations should track progress on CSO, PLHIV and MARPs involvement in the processes, as well as progress towards universal access, particularly national funding, coverage and quality of HIV treatment, prevention among MARPs, and their human rights situation;
- Civil society groups, technical support providers, donors and TGF principle recipients should support the strengthening of community systems including by developing community leadership, building organizations, and supporting them to strategize;
- **National stakeholders** should use the national indicators and targets agreed on in 2010 for the universal access review process in 2015 and beyond. In the next round of reviews, before discussing general achievements, revising indicators and setting new targets, they should measure progress towards the targets set in 2010;

### On commitment and finance

- **Parliaments and governments** should prioritize both prevention and treatment of HIV among MARPs and allocate adequate resources;
- **UNAIDS** should encourage countries to report on national funding allocated for MARPs so that investment in programs for MARPs can be tracked, analyzed and fed into universal access and other processes;
- **Donors and technical support providers** should build capacity to advocate for greater investment in prevention, specifically for services targeting MARPs;
- Ministries of health and Principal Recipients of Global Fund projects should negotiate for lower pharmaceutical prices, as well as investigate other means to increase efficient use of limited resources;
- Civil society and representatives of most-at-risk populations should step up their efforts to hold their governments accountable to their commitments by identifying clear priorities and developing advocacy plans. Technical assistance should focus on developing an understanding of economic arguments based on cost effectiveness and cost-benefit;
- **The Global Fund's Board** should review the eligibility criteria so that GF resources would be available to address the needs of MARPs living in upper- and lower-middle income countries where access is a problem;
- The European Community, along with the Global Fund's Board, should find realistic solutions for the EU and its neighbouring countries to sustain funding and services when the Global Fund and other international funding expires;

### On human rights

UNAIDS should prepare a set of indicators for countries to report on legislation directly affecting key populations and enforcement of those laws, which should define measures that protect or infringe upon human rights in the context of HIV. By 2015, UNAIDS should support countries to use human rights indicators in national strategic planning and further target setting towards universal access;

- Given the relative lack of information on human rights in the universal access documents, CSOs should report on the human rights environment and progress independently;
- The newly launched HIV and Human Rights Commission should support civil society, particularly MARPs groups, to submit their reports. Along with UNAIDS, it should facilitate sharing good practice examples of changing and enforcing legislation, particularly at the regional level;
- Donors should support and fund inclusion of legal services and other types of protection of human rights into essential services for key populations, as well as provide low-threshold access to funds and support for strengthening of MARPs groups;
- The Global Fund and other donors should increase investment into protection of human rights of key populations. They should produce guidance on supportive policy and programming with regard to human rights and HIV, including by sensitization of key populations among the media and police, empowerment of MARPs organizations, promoting decriminalization and de-penalization of key populations, working on specific anti-discrimination legislation and its enforcement, and encouraging countries and other applicants to integrate such measures into their projects;
- UNAIDS and the regional Technical Support Facility should provide platforms for policy makers, CSOs and MARP groups to have dialogue on human rights and to share good practices. They should promote available model legislation that ensures human rights protections;

### On treatment

- National HIV/AIDS commissions, together with PLHIV and other stakeholders, should study and address the reasons for the lowered impact of treatment, and gender disparities, particularly addressing men's vulnerabilities;
- National HIV/AIDS commissions should scale up access to opioid substitution therapy and TB and hepatitis treatment for PLHIV, according to WHO protocols;
- **Donors and technical support providers** should support national and regional efforts to advocate for improved access to treatment;
- National AIDS commissions should develop systems of procurement and supply chain management that ensure continuous supplies of necessary medications and monitoring tests, with transparency and community involvement in those systems;
- **National AIDS commissions**, along with principal recipients of Global Fund programs and civil society groups, should work to lower pharmaceutical prices so that money saved could be used to fill gaps in access:

### On prevention

- **UNAIDS and donors** should support countries to better prioritize limited available resources from international and national sources and populations where HIV is concentrated among MARPs;
- **National governments and donors** should invest in improving the coverage, quality and diversity of services for key populations, including IDUs, SWs, MSM, and prisoners. Services for prisoners remain notably underdeveloped;
- Service providers should improve the quality and diversity of their services, as well
  as better engage communities served in order to reach greater impact on behavior
  change;
- Policy makers should use their political leadership to promote neglected evidence based services and remaining barriers to services, particularly for marginalized groups among whom the epidemics spread;

- National, regional and local policy makers should urgently develop mechanisms for authorities to contract NGO services, where they do not exist or do not operate, notably in Belarus and Romania;
- **Civil society groups** should be provided with funds and assistance in their advocacy campaigns for sustainability of services and funding;

### On data and surveillance

- UNAIDS and technical agencies, including ECDC, CDC, EMCDDA, with engagement of the Global Fund and other major donors, should prioritize the following areas for improving quality of data:
  - establishing national estimates of the size of key populations (comparable methodology and standardized definitions of populations),
  - improving monitoring of coverage of MARPs with prevention services putting into practice the UN guidance on targets for IDU (WHO/UNODC/UNAIDS, 2009), as well as other relevant guidance;
  - supporting countries to improve data on the HIV epidemic and progress reached among prisoners, transgendered people, and migrants (or their subpopulations);
  - o reporting on probable routes of transmission and CD4 cell count;
- **National M&E agencies and UN agencies** should improve the coherence of data reported by various agencies internationally and at country level;
- **UNAIDS** should improve the UNGASS M&E framework by recommending indicators on prisoners, transgender people, sub-populations of migrants, as well as improving definitions of indicators on coverage of MARPs with services.

# 7. Resources

# 7.1. List of interviewees

National informants (by sub-region and country)

Sub-region	Country	Name / organization	Focus
Caucasus &	Georgia	David Otiashvili, Georgian	IDU, drug policy and
Central Asia		Harm Reduction Network	harm reduction
		(GHRN) & Alternative Georgia	advocacy group
Caucasus &	Georgia	Nino Tseretelli, Information	MSM, sex workers
Central Asia		and Counseling on	
		Reproductive Health	
		"Tanadgoma	
Caucasus &	Georgia	Konstantine (Koka)	Drug user self-
Central Asia		Labartkava, New Vector	organization
Caucasus &	Georgia	Dato Ananiashvili, Georgian	PLHIV
Central Asia		Positive Group (answered	
		concisely via email)	
European CIS	Belarus	Lena Grigorieva, Chair of	PLHIV
		Belarusian Network of PLHIV	
		and member of Steering	
		Committee of AIDS Action	
		Europe	
European CIS	Belarus	Aleh Yaromin, Chairman of the	HIV general, MSM
		Coordinating Committee of	
		Association BelSet anti-AIDS &	
_		NGO Vstrecha	
South East Europe	Albania	Genci Mucollari, Aksion Plus	IDU, SW, prisoners,
_			Roma, transgender
South East Europe	Albania	Olimbi Hoxhaj, national PLHIV	PLHIV
		network	
South East Europe	Republic of	Hristijan Jankuloski, HOPS	IDU, SW, Roma,
_	Macedonia		prisoners
South East Europe	Republic of	Zoran Jordanov, EGAL	MSM, LGBT
	Macedonia		organization

Regional informants (by organization)

Organization, name	Individual
ECUO	Nataliya Leonchuk
EATG	Anna Zakowicz
EHRN	Daria Ocheret
ITPC-EECA	Denis Godlevskiy
SWAN	Aliya Rakhmetova
UNAIDS	Michelle Williams-Sherlock & Yekaterina Yusupova

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