

# Living with HIV

## in Eastern Europe and the CIS



*The Human Cost of Social Exclusion*



## **Regional Human Development Report on AIDS**

# **Living with HIV in Eastern Europe and the CIS:**

## **The Human Cost of Social Exclusion**

UNDP Bratislava Regional Centre

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The people featured on the report cover are either living openly with HIV or members of a sero-discordant family. These include, in order of appearance from left to right:

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**Ms. Svetlana Izambaeva** – Russian Miss Positive 2005, who is married with a baby girl and currently heads the non-commercial *Charitable Fund of Svetlana Izambaeva* in Kazan, Russia.

**Ms. Svetlana Silla and her baby** – a mother of three children who currently works as a peer-to-peer consultant and a leader of a support group for women *Positive mothers* in Estonia. The picture was provided by the *Estonian Network of people living with HIV*, of which she is also a member.

**Ms. Marina Britvenko and her husband** – a discordant couple (her husband is HIV negative) who have lived together for eight years and have a son. They currently live in St. Petersburg, Russia where Marina heads the charitable fund on healthy lifestyle called *Piterskiy Most*.

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## Foreword

Presented in conjunction with World AIDS Day and the 60<sup>th</sup> anniversary of the signing of the Universal Declaration of Human Rights, this timely report elaborates the intrinsic linkages that join an effective response to HIV with the principles of human rights within a human development framework. At its core, the message is simple: the present level of stigma and discrimination associated with HIV in the region is undermining otherwise encouraging national efforts to reverse the epidemic and achieve Millennium Development Goal 6 – “Combat HIV and AIDS, malaria and other diseases”.

The spread of HIV represents a significant challenge to both individual rights and inclusive socio-economic development for communities the world over. This is equally true in Eastern Europe and Central Asia, where the number of people living with HIV continues to grow, as do the scale and consequences of social exclusion.

In this regard, the United Nations Development Programme (UNDP), through this Regional Human Development Report on AIDS in Eastern Europe and the CIS, seeks to go beyond the numbers to explore the human face of the epidemic and better understand the vulnerability and livelihood challenges confronted daily by people living with HIV in the region. Supported by a six-country qualitative research initiative commissioned for this purpose, the report calls for specific evidence-based responses to address these issues in a visible and compelling format.

It is our hope that the report will build on the success of the first Regional Human Development Report on AIDS in Eastern Europe and the CIS titled ‘Reversing the Epidemic – Facts and Policy Options’ which has received broad coverage in over 30 countries since its launch in 2004 and remains a widely referenced resource for advocacy and policy advice. This latest publication seeks to fulfill the dual objectives of stimulating policy discussion while advocating tolerance and social inclusion based on a professionally rigorous evidence base. The report is relevant for all members of society involved in or affected by HIV, or otherwise compelled to take action, including: policy makers, political leaders, academics, health service providers and administrators, educators, employers, non-governmental organizations, religious leaders and grass-roots community advocates. Most fundamentally, this audience includes people living with HIV, whose meaningful involvement in the response to AIDS is vital for success and sustainability.

Beyond the analysis and elaboration of challenges to the response, the report offers concrete solutions based on the proven experience of countries and communities where HIV prevention and care, combined with efforts to address stigma and discrimination, have produced results. We encourage state and non-state actors alike to embrace these recommendations for a collective regional response that benefits all members of society.



Ms. Kori Udovicki  
UNDP Assistant Administrator and  
Regional Director for Europe and the CIS

## Acknowledgements

This report is a product of extensive collaboration by many individuals and institutions actively involved in HIV prevention and care in Eastern Europe and the CIS. It is the result of a broader effort to identify barriers to social inclusion and full integration of people living with HIV in society – focusing on healthcare, education and employment and other sectors of society. Furthermore, the report provides linkages to broader developmental issues related to AIDS, such as human development, demographic patterns and trends, human rights, gender and migration.

The development of the report commenced with the implementation of a regional vulnerability research initiative in six countries of the region: Estonia, Georgia, the Russian Federation, Turkey, Ukraine and Uzbekistan. This process triggered national dialogue which in turn contributed substantially to the main messages and recommendations presented in the report. This research would have not been possible without the expertise and local networks of national sociological institutions in each of the countries. Special thanks go to the research teams and PLHIV association/NGO representatives, who implemented the research based on the support and guidance of UNDP. A detailed list of research team members and NGO representatives is provided in Annex 6 of the report. The entire process benefitted from the managerial support of the UNDP country offices and focal points, who were instrumental in ensuring successful national research studies which lead to the development of robust country reports: Nestan Khuntsaria (UNDP Georgia), Elena Malanova (UNDP Russia), Berna Bayazit (UNDP Turkey), Katerina Rybalchenko and Vladimir Gordeiko (UNDP Ukraine), Alisher Abdukayumov and Antonina Sevastyanava (UNDP Uzbekistan) and Aziz Khudoberdiev (UNAIDS Uzbekistan).

Key institutional partners involved in the preparation and finalization of the report include: the Eastern Europe and Central Asian Union of people living with HIV (ECUO), the Joint United Nations Programme on HIV/AIDS (UNAIDS) Regional Support Team, the United Nations Children's Fund (UNICEF), the International Labor Organization (ILO) and the Turkish International Cooperation and Development Agency (TIKA), which generously made a series of critical research team training seminars possible.

The report itself is the outcome of the efforts of and inputs from wide range of individual contributors. The principal author of the report was Don Operario, who was supported by Stephanie Solywoda both from Oxford University. The team of contributing authors includes Ralph Jürgens, Glenn Betteridge, Lee Nah Hsu, Hugh McLean, Andrey Ivanov (who was particularly instrumental in structuring and streamlining the report), Shombi Sharp, Dudley Tarlton, Susanne Milcher, Mikhail Peleah. Hugh McLean from the Education Support Program of the Open Society Institute (OSI) lead the qualitative research and elaboration of country studies. Other contributors to the report from the UNDP Bratislava Regional Centre included Anastasia Kamlyk (UN Plus), Joe Hooper, Snizhana Kolomiets, John Macauley and Jaroslav Kling. UNICEF country teams were helpful in gathering personal stories for the report. Both the research project and report production were coordinated by John Macauley UNDP Bratislava Regional Centre, with Shombi Sharp providing overall conceptual and team leadership.

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## Abbreviations

AIDS	acquired immunodeficiency syndrome
ARVs	anti-retroviral drugs
CIS	Commonwealth of Independent States
CD4	cluster of differentiation antigen 4 cell (a subgroup of T lymphocytes)
HIV	human immunodeficiency virus
IDU	injecting drug use
ILO	International Labour Organization
MSM	men who have sex with men
NGO	non-governmental organization
OECD	Organization for Economic Co-operation and Development
OHCHR	Office of the High Commissioner for Human Rights
PLHIV	people living with HIV
PMTCT	prevention of mother-to-child transmission
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNGASS	United Nations General Assembly Special Session on HIV/AIDS
UNICEF	United Nations Children's Fund
UNIFEM	United Nations Development Fund for Women
UNODC	United National Office on Drugs and Crime
WHO	World Health Organization

# Introduction:

## A region living with HIV

There are some 1.5 million people living with HIV across the cities and towns of Eastern Europe and the Commonwealth of Independent States (CIS) according to UNAIDS estimates, representing the full spectrum and diversity of the region. Some are teachers or students, lawyers or clients, mothers or fathers, sons or daughters, patients or health care workers, old, young or newborn, employees, unemployed or employers. All are very different from one another, yet all share one thing in common – the prospect of a daily struggle against the combined physical challenges associated with HIV and the equally, if not more devastating social vulnerability wrought by stigma, discrimination and social exclusion.

However, in over 25 years of global experience responding to AIDS, we have learned that this state of affairs is not necessary, that it is possible to make the dramatic improvements in the lives of people living with HIV necessary to overcome the personal challenges of the disease and to lead long, healthy and productive lives. A greater commitment to the principles of social inclusion for people living with HIV can bring about the public good of enhanced collective human capital as well as the conditions for the most effective prevention of further HIV transmission. What is good for people living with HIV and populations at risk is good for society as a whole.

Many countries of the region have shown noticeable and commendable progress in their response to HIV. Yet the epidemic continues to outstrip the response as it evolves. The most visible successes have naturally come in the areas of least social resistance. But as the number of people living with HIV in the region grows daily, the scale of stigma, discrimination and rights violations, deplorable at the individual level, takes on massive proportions in the aggregate, serving to undermine those hard-won achievements.

This report endeavours to go beyond the numbers and describe the human face of the epidemic, show the nature of HIV vulnerability in the region as people live from day to day, and

propose effective policy measures to overcome this increasingly urgent challenge. In this regard, epidemiological trends play a supporting role in helping to understand the broader context and scope of vulnerability. The analysis is underpinned by the findings of an innovative six-country research study conducted in collaboration with local social research institutes in representative countries from the Caucasus (Georgia) Central Asia (Uzbekistan), the Western CIS (Russia and Ukraine), the European Union/Baltics (Estonia) and a European Union candidate country (Turkey), covering the range of epidemiological profiles in the region: higher-level concentrated, emerging concentrated and low-level epidemics. Findings of this study, presented throughout this report (in special green colour-coded boxes), convey a remarkable similarity in the nature of vulnerability for people living with HIV across a diverse range of socio-economic and political contexts.

The target audience for this report includes all members of society involved in or affected by HIV, or otherwise compelled to take action. This includes policy makers, political leaders, academics, health service providers and administrators, educators, employers, non-governmental organization staff, religious leaders, and grass-roots community advocates. Most fundamentally, this audience includes people living with HIV, whose involvement in the response to AIDS is vital to ensuring success and sustainability.

Within its mandate as a UNAIDS co-sponsor, the United Nations Development Programme works with partners to understand and respond to the social, economic and political forces that influence the HIV epidemic, building on and complementing action within the health sector. UNDP also supports partners in understanding and mitigating the consequences of AIDS – visible in multiple sectors and across many communities, and most profound in the day-to-day lives of individuals affected by and living with HIV.

The faces and voices of people living with HIV often go unnoticed. In some cases, they are ac-

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tively excluded and silenced. This report aims to bring light to the experiences, thoughts and aspirations of people living with HIV. In so doing, it places an emphasis on the humanity underpinning human development. The perspectives of people living with HIV in Eastern Europe and the CIS will be considered alongside reviews of epidemiological and policy research on the region. At the same time, the report consults the views of people representing 'mirror institutions' in three key sectors, which reflect the structural basis for vulnerability in the lives of many people living with HIV: health care (doctors, nurses and other staff), education (administrators and teachers) and the workplace (employers and co-workers). Together, these sources can provide more comprehensive insights into the challenges associated with HIV faced within the region, and the need for state responses to address this set of issues.

The overarching issues raised in this analysis concern stigma, discrimination and social exclusion, as well as the need to protect the basic rights to health, education and employment for people living with HIV and members of most-at-risk populations. Compromises in these domains are elaborated upon by respondents in our primary research. Notably, narratives from people living with HIV indicate that the social challenges associated with HIV equal or even surpass the health challenges associated with HIV illness.

In this regard, the analysis presents a set of challenges that the region must address. First, there is no simple profile of HIV in the region; policy and intervention responses cannot be guided by simplistic stereotypes about populations at risk. Second, there is substantial variability within the region in terms of national development indicators, health and social service infrastructures, legal protection, leadership and cultural beliefs about HIV and associated risk behaviours. Third, the regional epidemic is ever-changing: people living with HIV are living longer due to improved medical treatment, and HIV is increasingly associated with women and children as well as men. Fourth, policy debates around HIV are becoming more complicated, due in part to the multiple sectors affected by the epidemic. As a consequence of this variety and evolution, streamlined responses might be more difficult to achieve.

Despite these challenges, this report and analysis advances a set of core principles to guide responses throughout the region. First is the call for each setting to 'Know Your Epidemic'. That is, rather than follow generic blueprints for HIV prevention, education, testing and treatment policy, local and national responses must invest in activities to gather rigorous, accurate and up-to-date information to characterize their unique HIV epidemic. This should include biological and behavioural indicators, augmented by other forms of information (such as qualitative research) to adapt evidence-informed responses to the local setting. Second is the mandate for state and civil society partners to develop and collaborate on strategic policy responses to HIV. In particular, people living with HIV and members of most-at-risk populations must be involved to assure feasibility, success and longevity of programmes and policies to reduce HIV transmission and improve the well-being of affected populations. Third is the principle of 'Universal Access' to HIV prevention, education, testing and treatment. This principle underscores the basic right of all individuals to the best standard of care available, and challenges processes that exclude historically disadvantaged members of society. Fourth is the need to recognize that HIV affects women as well as men, and to respond to the underlying social and economic dynamics that render females increasingly vulnerable to HIV infection and the deleterious consequences of AIDS in the family and community.

This report advocates for all readers to recognize the human face and the human experience of HIV, rather than view the epidemic as a medical or political abstraction represented through numeric data and quantitative figures. By seeing HIV through the eyes of affected individuals, it is clear that responses must be simultaneously rooted in principles of public health, human rights and human development. Only such an integrated approach will successfully halt and reverse the spread of HIV in the region and tackle the devastating impact of HIV. Strong work on public health and human rights is required to respond effectively to AIDS. Fortunately, strong and effective responses will in turn contribute more broadly to public health, human development and human rights goals across the region.

*The regional epidemic is ever-changing: people living with HIV are living longer due to improved medical treatment, and HIV is increasingly associated with women and children as well as men*

# Chapter 1: The epidemic in numbers – populations at risk

The 2004 UNDP Human Development Report for Eastern Europe and the CIS<sup>1</sup> warned about the growing threat of a regional HIV epidemic.<sup>2</sup> Now, four years following the publication of that report, HIV has established strong roots throughout the region. While the global epidemic appears to have stabilized at current prevalence levels, Eastern Europe and the CIS remains one of the few regions where HIV prevalence continues to rise.<sup>3</sup> Although some countries carry a higher burden of disease than others, especially in the European CIS, no country in the region remains unaffected. It is fair to view the region as one that is now ‘living with HIV’ in ways similar to individual people who live with HIV. Much as HIV transforms the lives of people living with HIV – who must come to terms with their HIV-status, identify coping and health promotion strategies, and comply with life-saving treatment regimes – so too must states in the region undergo transformations in the ways they operate and care for their populations for generations to come.

But the metaphor of the region ‘living with HIV’ comes with the caveat that national responses to the epidemic must also incorporate macro-level considerations spanning the political, economic, cultural, demographic, international, developmental and public health domains. Whereas the foundations for addressing needs for individual people living with HIV are more clearly articulated – based on principles of human rights and universal access to care, treatment and prevention<sup>4</sup> – guidelines for states to formulate, implement and monitor these principles are less resolved and are further encumbered by multiple macro-level considerations.

## Know your epidemic

As the epidemic evolves globally, UNAIDS and other leading international actors have increasingly promoted the fundamental necessity to ‘Know your epidemic’ in order to fashion effective national responses based on local realities.<sup>5</sup> This is perhaps most important in areas with relatively low prevalence or with concentrated epidemics, such as the countries of Eastern Europe and the CIS, where investing resources in targeted interventions and services for populations at risk yields significantly more effective and cost-efficient public policy results. Knowing your epidemic allows policy makers to make the choices necessary to achieve universal access to care, treatment and support, as well as assessing the degree to which public resources invested in the response are matched with the need on the ground. In the following pages we outline the key drivers of HIV spread in the region that lay the foundation for an effective response.

Using UNDP programmatic classifications for the purposes of this report, the region of Eastern Europe and the CIS consists of five sub-regions: European Union member and candidate states, the Western Balkans, the Western CIS (Belarus, Moldova, Russian Federation, Ukraine), the Caucasus and Central Asia. The CIS as a region comprises the Western CIS, the Caucasus and most of Central Asia. Sub-regions and their constituent countries differ in history, language, cultural and religious traditions and development trajectories. Owing to the diversity within the region and within states, no two countries experience the same

*Eastern Europe and the CIS remains one of the few regions where HIV prevalence continues to rise*

*Investing resources in targeted interventions and services for populations at risk yields significantly more effective and cost-efficient public policy results*

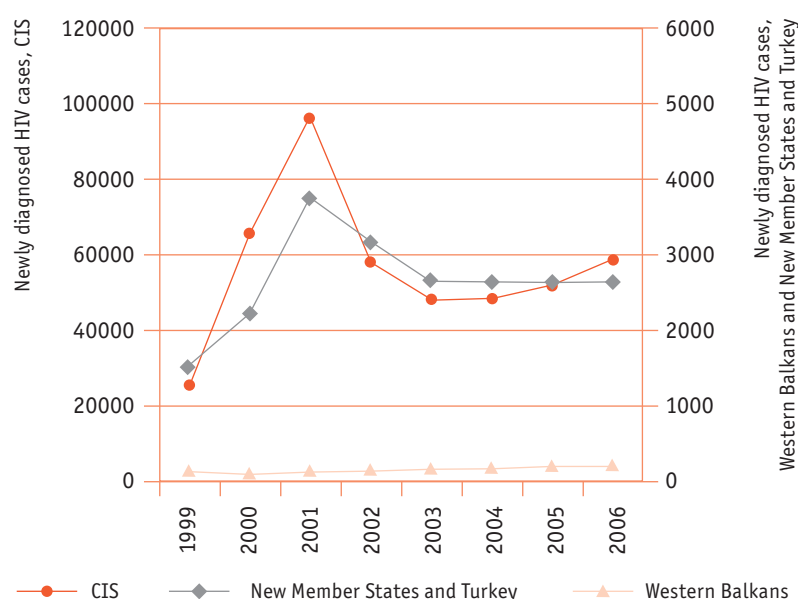
1 CIS countries are Armenia, Azerbaijan, Belarus, Georgia, Kazakhstan, Kyrgyzstan, Republic of Moldova, Russian Federation, Tajikistan, Turkmenistan, Ukraine and Uzbekistan. The new EU member states and Turkey group includes Bulgaria, Cyprus, Czech Republic, Estonia, Hungary, Latvia, Lithuania, Poland, Romania, Slovakia, Slovenia and Turkey. Western Balkan countries are Albania, Bosnia & Herzegovina, Croatia, F.Y.R. Macedonia, Montenegro and Serbia. This classification applies throughout the report if not stated otherwise.

2 UNDP, ‘HIV/AIDS in Eastern Europe and the Commonwealth of Independent States. Reversing the epidemic: Facts and policy options’, UNDP: Bratislava, 2004.

3 UNAIDS, ‘2008 Report on the Global AIDS Epidemic’, UNAIDS: Geneva, 2008.

4 UNAIDS, ‘International guidelines on HIV/AIDS and human rights’, UNAIDS: Geneva, 2006. See also WHO/UNAIDS/UNICEF, ‘Towards universal access: scaling up priority interventions in the policy sector: progress report’, April 2007, UNAIDS: Geneva, 2007.

5 UNAIDS, ‘Annual report 2007: knowing your epidemic’, UNAIDS: Geneva, 2007, available at [http://data.unaids.org/pub/Report/2008/jc1535\\_annual\\_report07\\_en.pdf](http://data.unaids.org/pub/Report/2008/jc1535_annual_report07_en.pdf)

**Figure 1.1. Newly diagnosed cases of HIV in the region, 1999-2006**

Source: EuroHIV, 2006a, Report No. 75.

**Table 1.1. Regional epidemic overview (UNAIDS estimates)**

	2001	2007
<b>Eastern Europe and the CIS</b>		
Adults and children living with HIV	0.63 million [0.49–1.1 million]	1.5 million [1.2–2.1 million]
Adults and children newly infected with HIV	230,000 [98,000–340,000]	150,000 [70,000–290,000]
Adult prevalence (%)	0.4 [0.3–0.6]	0.9 [0.7–1.2]
Adult and child deaths due to AIDS	8000 [5500–14,000]	55,000 [42,000–88,000]
<b>Western and Central Europe</b>		
Adults and children living with HIV	0.62 million [0.5–0.87 million]	0.76 million [0.6–1.1 million]
Adults and children newly infected with HIV	32,000 [19,000–76,000]	31,000 [19,000–86,000]
Adult prevalence (%)	0.2 [0.1–0.3]	0.3 [0.2–0.4]
Adult and child deaths due to AIDS	10 000 [<15 000]	12 000 [<15 000]

Source: UNAIDS, 2007 AIDS Epidemic Update. Brackets show low to high estimates.

epidemic, and no single approach to HIV policy and advocacy can be uniformly implemented.

The estimated number of people living with HIV in Eastern Europe and the CIS has grown from 630,000 in 2001 to 1.5 million as of 2007, a 150 percent increase.<sup>6</sup> According to UNAIDS data, 87 percent of newly reported HIV cases in the region were from the Russian Federation (66 percent) and Ukraine (21 percent). Prevalence of HIV in Estonia is also alarmingly high. In Central Asia and the Caucasus, the number of newly reported HIV diagnoses is also rising, with Uzbekistan having the largest number of newly registered infections in Central Asia.

The HIV epidemic in the European region has expanded steadily over the past 10 years, with 86,912 officially registered new HIV cases in 2006, out of which more than two thirds are registered in Eastern Europe. In Eastern Europe and the CIS, the rate of newly diagnosed cases of HIV infections peaked in 2001 at 342.4 per million and then declined to 174.3 per million in 2003. Since then the rate has steadily increased to 210.8 per million reported in 2006. By contrast, in most of Central and Southeast Europe, the rate of newly diagnosed cases of HIV infection has remained stable since 1999 at less than 10 per million.<sup>7</sup>

## Concentrated or generalized?

Categorizing the AIDS epidemic is important from a policy perspective. Researchers have argued that it is important to be highly specific when describing epidemics, to make policy recommendations, risk communication and containment strategies more effective.<sup>8</sup> Such descriptions should include the precise nature of disease burden and distribution; the number of cases; the case fatality rate; the area affected; the communicability and any associated risk behaviours. Thus, although AIDS is clearly a pandemic associated with one disease, it is perhaps best described to be a set of cultural/context-

6 UNAIDS and World Health Organization, 'Eastern Europe and Central Asia: AIDS epidemic update: Regional Summary,' UNAIDS: Geneva, 2008, available at [http://data.unaids.org/pub/Report/2008/jc1529\\_epibriefs\\_eeurope\\_casia\\_en.pdf](http://data.unaids.org/pub/Report/2008/jc1529_epibriefs_eeurope_casia_en.pdf)

7 EuroHIV, 'HIV/AIDS Surveillance in Europe: End-year report 2006,' Institut de veille sanitaire: Saint-Maurice, 2007. No. 75.

8 Green, M., T. Swartz, E. Mayshar, B. Lev, A. Leventhal, P. Slater, J. Shemer, 'When is an Epidemic an Epidemic?' in *Israel Medical Association Journal*, 4, 3-6 (2002). See also Wilson D., D. T. Haperin, "'Know your epidemic, know your response": a useful approach, if we get it right' in *Lancet*, 372, 423-6 (2008).



specific epidemics.<sup>9</sup> Public health and policy responses must take appropriate heed of local factors that determine effective prevention, treatment and intervention.

UNAIDS and the World Health Organization<sup>10</sup> have provided guidelines for classifying AIDS epidemics according to a three-tiered typology: low-level, concentrated or generalized (see Table 1.2). This framework states that different levels and types of epidemics warrant different responses, a pillar of the ‘Know your epidemic, know your response’ approach. For example, Family Health International, basing its reasoning on UNAIDS guidelines, recommended that “at the concentrated stage, countries should continue sero-surveillance activities in the populations where infection is concentrated and begin monitoring HIV in the general population, especially in youth.”<sup>11</sup> Countries with concentrated epidemics are urged to prioritize biological and behavioural surveillance on populations showing the highest risk of infection, and to develop targeted prevention interventions and treatment programmes while also combating social stigma against those populations. Countries with generalized epidemics are urged to maintain rigorous antenatal and population-based surveillance techniques to monitor the epidemic, to develop programmes to change social norms and to invest in infrastructures for accommodating the treatment needs of large affected populations.

Estonia, Russia and Ukraine, while considered ‘concentrated epidemics’ show increasingly generalized characteristics in some sub-national regions. In Ukraine, for example, 3 out of 27 regions have recorded prevalence among pregnant women exceeding 1 percent.<sup>12</sup> According to UNAIDS estimates, HIV prevalence in these countries may have surpassed the 1 percent adult population threshold.<sup>13</sup> In these settings, both targeted and population surveillance techniques are necessary to monitor trends in epidemiologic distribution, and interventions should address broadening transmission dynamics in order to contain the epidemic’s growth. However, the same report demonstrates that HIV in these set-

**Table 1.2: Guidelines for determining the type of epidemic**

Low-level epidemic	<1% prevalence in the general population and populations at risk
Concentrated epidemic	<1% prevalence in the general population and >5% prevalence in populations at risk
Generalized epidemic	>1% prevalence in the general population, sustained primarily through sexual transmission

tings remains concentrated largely among people who inject drugs, other populations at risk and their sexual partners, indicating that a generalized epidemic has not appeared at the national level in any country in the region. Experts speculate that there is also considerable infection among men who have sex with men, which has likely been under-reported due both to lack of focused research and to social taboos against reporting such behaviour. These settings demand ‘combination prevention’ activities – those that combine behavioural, community, structural and biomedical approaches to target key sub-populations that are most at risk, while simultaneously addressing the potential for transmission throughout the general population.<sup>14</sup>

In concentrated epidemics, public health and social policy approaches must prioritize the health needs and rights of the populations most affected and at risk, while raising awareness and reducing stigma and discrimination among the general population. Populations at highest risk include people who inject drugs, men who have sex with men, and sex workers. Partners of individuals who belong to these populations must also be prioritized. Other vulnerable populations may include prisoners, migrants and ethnic minorities. Efforts to intervene on behalf of these populations must face the difficulty of navigating historical challenges brought on by the stigma, marginalization, poverty, discrimination and moral judgment aimed at them.

*Although AIDS is clearly a pandemic associated with one disease, it is perhaps best described to be a set of cultural/context-specific epidemics*

*Public health and social policy approaches must prioritize the health needs and rights of the populations most affected and at risk, while raising awareness and reducing stigma and discrimination among the general population*

9 Lancet, ‘HIV/AIDS: not one epidemic but many,’ editorial in Lancet, 365, 1-2 (2004).

10 UNAIDS/WHO working group on global and STI surveillance, ‘Guidelines for Second Generation Surveillance’ (2000), available at <http://www.unaids.org/en/KnowledgeCentre/HIVData/Epidemiology/epiworkinggrp.asp>

11 Family Health International, ‘Behavioral Data Collection in HIV-Related Risk Behaviors,’ available at <http://www.fhi.org/en/HIVAIDS/pub/fact/behavdatacol.htm>

12 Draft ‘Comprehensive External Evaluation of the National AIDS Response in Ukraine’, UNAIDS, 2008, p. 21.

13 UNAIDS and World Health Organization, ‘Eastern Europe and Central Asia: AIDS epidemic update: Regional Summary,’ UNAIDS: Geneva, 2008.

14 Merson, M. H., J. O’Malley, D. Serwadda, C. Apisuk, ‘The history and challenge of HIV prevention,’ in Lancet, 372, 475-88 (2008).

## HIV transmission routes in Eastern Europe and the Commonwealth of Independent States

The principal means of HIV infection for the majority of new cases in the region is through injecting drug use (IDU). However, the pattern

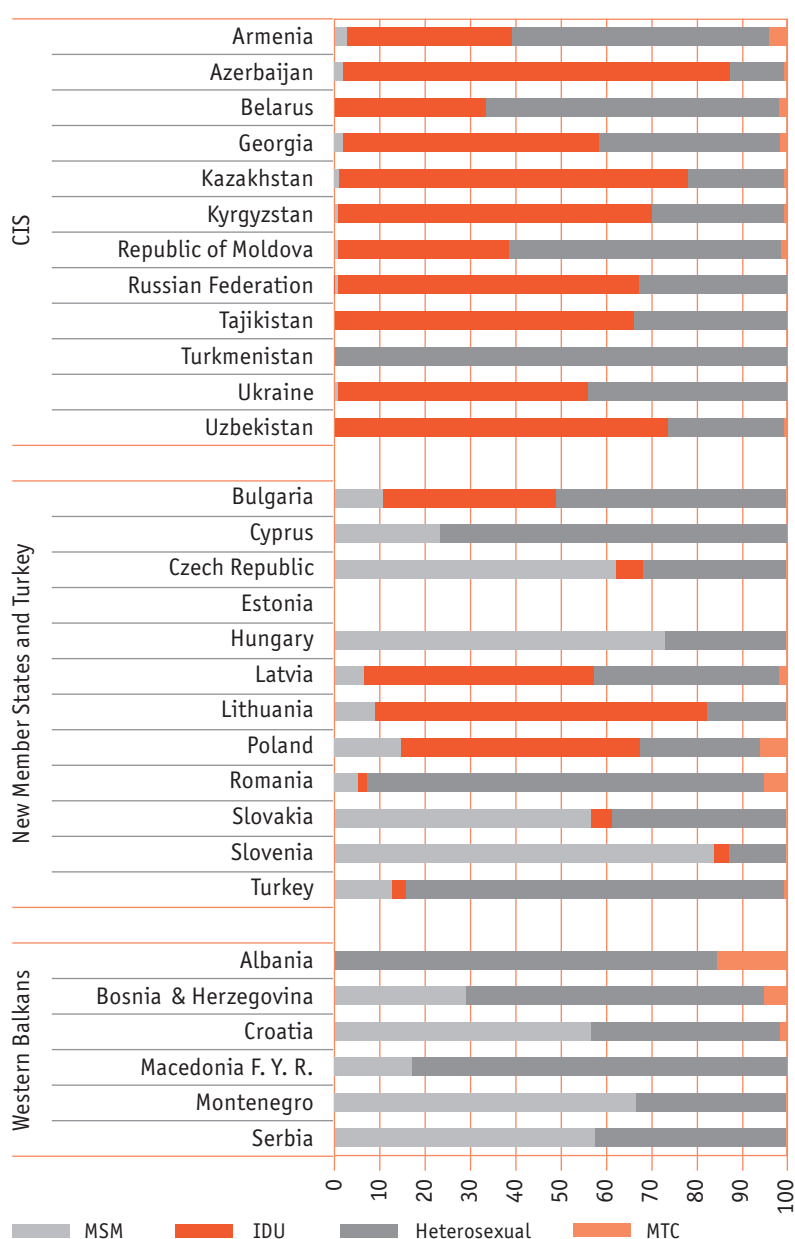
of epidemic growth throughout the region as a whole can be conceptualized according to three waves: first, an explosive spread among the people who inject drugs, followed then by a slower but more general growth through sexual contacts and thirdly through mother-to-child transmission which data have recently revealed (Figure 1.2).

### Injecting drug use

Injecting drug use represents the dominant mode of transmission in 11 countries of the region. Of the 59,866 newly diagnosed cases reported in 2006 (a rate of 210.8 per million), 62 percent were among people who inject drugs.<sup>15</sup> The 2001 peak of new HIV infections in Eastern Europe was caused by new HIV diagnoses reported among people who inject drugs, with the majority reported in the Russian Federation and Ukraine. HIV prevalence estimates among people who inject drugs in the region vary greatly by country. In many Central European countries, HIV prevalence is low and the proportion of new HIV diagnoses reported among people who inject drugs is usually less than 10 percent and decreasing. In some countries, particularly in Eastern Europe, the epidemic spread intensively in the late 1990s, leading to a large population of people living with HIV. Increasing heterosexual HIV transmission in Eastern Europe is partly attributed to transmission between HIV-positive injecting drug users and their sexual partners.

It is important to note regional and within-country differences in rates of HIV among people who inject drugs, as large national studies can mask the variability between regions or cities. Many cities and regions in Eastern Europe have reported HIV prevalence exceeding national prevalence estimates, suggesting localized HIV outbreaks in specific populations injecting drugs (Figure 1.3). For example, in Russia HIV prevalence among samples of injection drug users ranges from three percent in Volgograd to 14 percent in Moscow<sup>16</sup>. By

**Figure 1.2. Newly diagnosed cases of HIV by route of transmission (% share) , 2006**



**Source:** own calculations based on EuroHIV, 2006a, Report No. 75

**Note:** the share of mother-to-child transmissions for 2006 in Russia and Ukraine were not reflected by this source. The latest national UNGASS progress reports indicate that 8,000 and 3,430 children were born to women living with HIV in Russia and Ukraine, respectively. The majority of these children will not be infected with HIV. In Ukraine for example, 257 children born in the previous 18 months had an HIV-positive diagnosis confirmed in 2007

<sup>15</sup> EuroHIV, 'HIV/AIDS Surveillance in Europe: Mid-year report 2007', Institut de veille sanitaire: Saint-Maurice, 2007. No. 76; data on transmission group missing for 23,936 cases.

<sup>16</sup> EuroHIV, 'HIV/AIDS Surveillance in Europe: Mid-year report 2007', Institut de Veille Sanitaire: Saint-Maurice, 2007. No. 76, p. 12 and Annex 1.4. pp. 28-29 (refers Russia study, Rhodes T, Platt L, Maximova S, Koshkina E, Latishvskaya N, Hickman M, et al., 'Prevalence of HIV, hepatitis C and syphilis among injecting drug users in Russia: a multi-city study'. *Addiction* 2006;101:252-66.

contrast, in Ukraine, in 9 out of 10 cities where HIV was assessed among people who inject drugs, prevalence was higher than 20 percent, indicative of a widespread epidemic in this population.

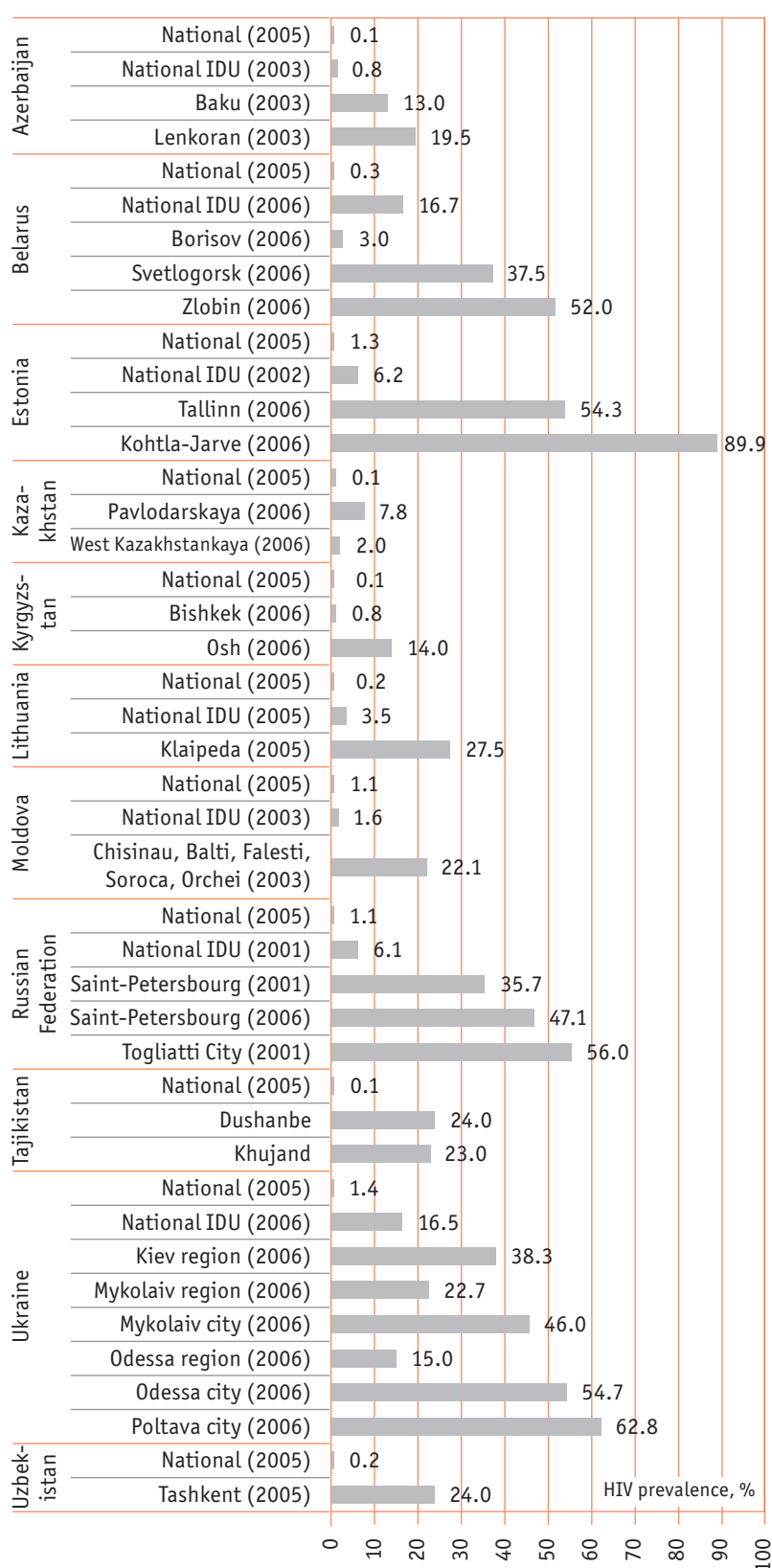
## Heterosexual transmission

Heterosexual transmission is reported to be the second largest mode of HIV transmission in the region. Data on new HIV cases suggest that the principal routes of transmission are shifting and that the epidemic has started to spread from people who inject drugs to their sexual partners. The proportion of people living with HIV who inject drugs in the CIS declined between 2002 and 2006 from 79 percent to 62 percent,<sup>17</sup> whereas during that same time the proportion of HIV infections through heterosexual contact increased from 20 percent to 37 percent.<sup>18</sup> Figure 1.4 (on page 8) depicts a trend that is indicative for the region as a whole – the proportional decline in HIV infections among injecting drug users and the proportional rise in HIV infections through sexual transmission in Ukraine between 1987 and 2007.

This trend has an explicit gender dimension by rendering women increasingly vulnerable to HIV infection. Historically, most registered cases of HIV in the region have occurred among men, reflecting the greater numbers of men who inject drugs. Yet, in 2006 women comprised 41 percent of 59,862 new HIV infections in Eastern Europe and the CIS. Some of these women themselves inject drugs and/or have multiple partners through sex work. The increasing proportion of women affected, however, probably indicates growing heterosexual transmission of HIV, especially from male drug users and bisexual men to their female partners.<sup>19</sup>

For example, the 2005 Russian UNGASS report noted that 65.3 percent of male injecting drug users engage in sex with women who do not inject drugs.<sup>20</sup> Further research is necessary to

**Figure 1.3. Regional and local disparities in HIV prevalence rates among IDU samples**



**Source:** HDR2007/2008 for national prevalence, EuroHIV, 2007, Report No. 76 for prevalence among people who inject drugs.

<sup>17</sup> EuroHIV, 'HIV/AIDS Surveillance in Europe: End-year report 2006,' Institut de veille sanitaire: Saint-Maurice, 2007. No. 75; own calculations. Includes only cases for which transmission route is known.

<sup>18</sup> Ibid.

<sup>19</sup> Ibid.

<sup>20</sup> Russian Federation, UNGASS report 2005.



better determine this relationship in order to target prevention efforts appropriately.

### Sex work

The number of sex workers in Eastern Europe and the CIS has risen due to social, economic and political changes that led women (as well as some men) to turn to sex work as a means of income. Sex workers who do not use condoms consistently are at risk of infection due to their high frequency of sexual encounters and to maintaining multiple concurrent partners. Sex workers also are at risk due to drug use and needle sharing, which have been shown to be prevalent among sex work populations in the region.<sup>21</sup> It is also important to note that sex work affects the spread of HIV from one country to another. Both sex workers and clients of sex workers can travel internationally. Some sex workers migrate voluntarily for a number of reasons, including

the potential to increase earnings. In addition, there has been a considerable growth in the number of women and girls from the region who become victims of international human trafficking, often to end up involved in the sex industry in Western or Central Europe or the Middle East.<sup>22</sup>

### Sex between men

Men who have sex with men (MSM) as an umbrella term refers both to men who self-identify as gay, as well as those who do not, but engage in sex with other men in specific contexts. Though a long established population at risk in Western Europe, the situation among men who have sex with men is less clear in Eastern Europe and the CIS due to inferior data and behavioural information as compared to other populations at risk.

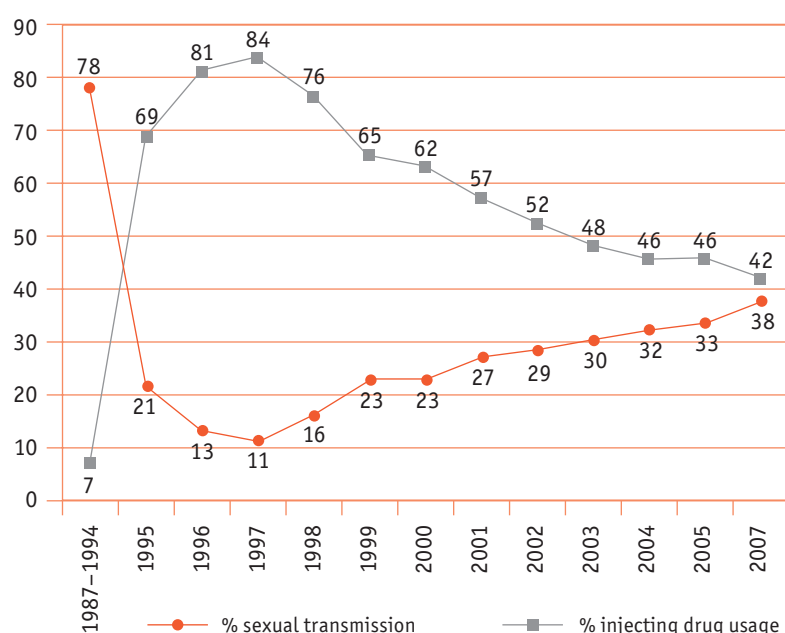
Nonetheless, there is increasing evidence of a hidden epidemic among men who have sex with men in Eastern Europe and the CIS, who are often driven underground by severe stigma, discrimination and even persecution. Decriminalization of same-sex relations is a relatively new development in most countries of the region, with the exception of Turkmenistan and Uzbekistan, where criminal prohibition remains in force.<sup>23</sup> As a result, men who have sex with men are less likely to access services despite being a population at higher risk. For example, estimated 60 percent of men who have sex with men in Ukraine remain untested for HIV.<sup>24</sup>

Table 1.4 (on page 10) presents a compilation of existing survey data on HIV prevalence among men who have sex with men since 1996, demonstrating both the likelihood that the epidemic among men who have sex with men in the region is at a concentrated level and the need for more systematic and nationally consistent data-gathering to drive appropriate targeted responses.<sup>25</sup>

It is also important to recognize that some men who have sex with men also have sexual relations with women, in some cases due to social

*There is increasing evidence of a hidden epidemic among men who have sex with men in Eastern Europe and the CIS, who are often driven underground by severe stigma, discrimination and even persecution*

**Figure 1.4. Patterns of HIV infection in Ukraine from 1987 to 2007**



**Source:** Vulnerability Assessment of People Living With HIV in Ukraine, Third Draft Report, 10 December 2007.

21 EuroHIV, 'HIV/AIDS Surveillance in Europe: Mid-year report 2006,' French Institute for Public Health Surveillance: Saint-Maurice, 2007. No. 74.

22 Zimmerman C., K. Yun, I. Shvab, C. Watts, L. Trappolin, M. Treppete et al, *The health risks and consequences of trafficking in women and adolescents. Findings from a European study*, London School of Hygiene and Tropical Medicine: London, 2003.

23 WHO, 'Progress on implementing the Dublin Declaration on partnerships to fight HIV/AIDS in Europe and Central Asia,' 2008, p.14.

24 Ibid, p.95.

25 Table reproduced from a presentation made by the WHO Collaborating Centre on HIV surveillance, Zagreb, Croatia, June 2008.

pressures to conform to traditional norms.<sup>26</sup> This has important implications in the need to target prevention services for men who have sex with men to stem both same-sex and heterosexual transmission.

## Prison settings

High HIV prevalence among prisoners reflects the co-occurring rates of injecting drug use and unprotected sex in this population. It is estimated that the prevalence of HIV in prisons is 3.5 to 10 times higher than that in the general population. As of January 2007, the Ukrainian penal system had 4,695 documented HIV-positive inmates,<sup>27</sup> and HIV prevalence among prisoners in Ukraine increased from six percent in 1999 to 14 percent by 2006.<sup>28</sup> HIV prevalence among prisoners in the Russian city of Samara was also high, estimated at 12.2 percent in 2005, though this is not nationally representative.<sup>29</sup> Other HIV prevalence estimates among prison populations in the region are presented in Table 1.5 (on page 11).

## Unsafe blood transfusion

Few recent cases of HIV infection transmitted through blood transfusion have been reported in this region, although recent outbreaks in Kazakhstan and Kyrgyzstan have been linked to blood transfusions. In Eastern Europe, the prevalence of HIV identified in blood donations (i.e. blood provided by donors) has increased dramatically from less than one per 100,000 blood donations in 1995 to 37.6 per 100,000 blood donations in 2006; this increase underscores the continued need to screen, monitor and regulate blood samples.

This trend stands in sharp contrast with that in Western European countries, where the prevalence of HIV among blood donations has declined from 5.2 per 100,000 donations in 1990 to 1.2 per 100,000 donations in 2006. In Central European countries, during the same period, the prevalence of HIV among blood do-

**Table 1.3. HIV, injecting drug use and condom use among female sex workers in some Eastern and Central European states and cities, 2000-2005 (data from different sources using different methodologies)**

Country	Year (n)	Percentage of IDUs among female CSWs	Prevalence of HIV	Condom use (% and indicator)
<b>Azerbaijan</b>	2003 (n=200)	1%	9%	9% indicator not specified
<b>Georgia</b>				
<i>Tbilisi</i>	2002 (n=158)	1%	0%	72% last month
<b>Kazakhstan</b>	2005 (n=1,960)	12%	2%	72% at interview
<b>Kyrgyzstan</b>				
<i>Bishkek, Osh</i>	2004 (n=352)	5%	2%	82% at last contact
<b>Latvia</b>	2002 (n=92)	80%	16%	80% last month
<i>Riga</i>	2004 (n=93)	53%†	18%	
<b>Lithuania</b>	2005 (n, not reported)		0%	70% at last contact
<b>Republic of Moldova</b>				
<i>Chisinau</i>	2003 (n=151)	11%	5%	82% at last contact
<b>Russian Federation</b>				
<i>Yekaterinburg</i>	2003 (n=149)	27%	15%	68% at last contact
<i>Moscow</i>	2003 (n=135)	5%	14%	96% at last contact
<i>St. Petersburg</i>	2003 (N=108)	93%	48%	93% at last contact
<i>Togliatti</i>	2001 (n=77)	100%	62%	
<b>Ukraine</b>	2001 (n=646)	35%	20%	
<b>Uzbekistan</b>	2004 (n, not reported)		10%	53% at last contact
<b>Bulgaria</b>	2005 (n=874)	16%	2%	
<b>Poland</b>	2002 (n=400)	2%	2%	89% at last contact
† Percentage of injecting drug users among HIV-positive respondents.				

Source: EuroHIV, 2006b. Surveillance in Europe: Mid-year report 2006 No.74.

26 WHO, 'Progress on implementing the Dublin Declaration on partnerships to fight HIV/AIDS in Europe and Central Asia,' 2008, p.107.

27 State Department of Ukraine for Law Enforcement Issues, 2007.

28 UNDP, 'Vulnerability Assessment of People Living With HIV in Ukraine', UNDP: Kiev, 2008, p. 15

29 Drobniewski, F. A. et al, 'Tuberculosis, HIV seroprevalence and intravenous drug abuse in prisoners,' in *Eur Respir J*, 26(2): 298-304 (2005).

**Table 1.4. HIV prevalence among men who have sex with men since 1996**

Country and year when survey was done	Survey method	Sample size	Est. HIV Prevalence
Armenia, Yerevan, 2007	Snowball	100	2
Belarus, Minsk, 2007	Convenience	279	0
Bulgaria: Sofia and Varna, 2006	Convenience	199	0
Croatia, Zagreb, 2006	RDS	360	4.5
Estonia, Tallin and Harju, 2007	RDS	59	5
Georgia, Tbilisi, 2005	RDS	70	4.2
Kazakhstan, several sites, 2007	Convenience	450	0
Kyrgyzstan, Bishkek, 2006	Convenience	100	1
Latvia, Riga, 1998	Convenience	242	5.4
Moldova, Chisinau, 2007	Convenience	94	4.8
Poland, several sites, 2004	Convenience	404	4.7
Russian Federation: Tomsk, 2003	Convenience	114	0
Yekaterinburg, 2003	Convenience	124	4.8
Moscow, 2005	TLS	303	0.9
St Petersburg, 2005	TLS	217	3.8
Krasnoyarsk, 2006	RDS	267	0.8
Perm, 2006	RDS	239	2.2
Nizhniy Novgorod, 2006	Convenience	108	9.3
Slovakia, Bratislava, 1996	Convenience	170	5.4
		124	1.6
Slovenia, Ljubljana, 2006	Convenience	136	2.1
Turkey, Ankara, 2006	Convenience	166	1.8
Ukraine: several sites, 2007*	RDS	359	9
Kiev		90	4.4
Kryviy Rig		100	8
Mykolaiv		100	10
Odessa		69	23.2
Uzbekistan: Tashkent, 2006	Convenience	102	10.8

\* The median value across four cities was 9.0%.

**Source:** Bozicevic I, Voncina L, Munz M. HIV Among Men Who Have Sex with Men in Central and Eastern Europe: A Review of 27 Countries. WHO Europe 2008. Draft.

nations rose slightly from 1.6 per 100,000 in 1990 to a maximum of 3.8 per 100,000 donations in 2006. The most dramatic rise in the number of HIV positive donations has occurred in Ukraine, where the rate of HIV-positive donations has increased from 2.1 per 100,000 donations in 1995 to 128.4 in 2004, and has since stabilized with a reported prevalence of 127.1 per 100,000 in 2006.

Concerns regarding the safety of blood supplies in the region are emblematic of the significant deterioration of the healthcare infrastructure in the CIS during the years of the transition period. Countries have experienced difficulties ensuring the proper screening of blood for HIV, implementing quality-assured testing and improving blood donation performance standards. A recent study from Central Asia showed that sensitivity for detecting HIV in the blood centre laboratories was only 55 percent.<sup>30</sup> Even more concerning, some health facilities in Central Asia do not test blood donations at all.<sup>31</sup>

## Vertical transmission

Most children living with HIV acquire the infection through mother-to-child transmission, which can occur during pregnancy, labour, delivery or breastfeeding. According to the World Health Organization, in the absence of any intervention the risk of such transmission could be as high as 30 percent in non-breastfeeding populations, with breastfeeding by an HIV-positive mother increasing the risk to a total of 45 percent.<sup>32</sup> While mother-to-child transmission has been rare in previous years, the number of new cases is growing due to the increasing numbers of women living with HIV in the region. For instance, in Russia 43 percent of new HIV cases in 2004 were among women,<sup>33</sup> 90 percent of which were among women of reproductive age. The number of childbirths in 2007 among women living with HIV in Russia and Ukraine was 8,000 and 3,430, respectively.<sup>34</sup> In Ukraine the seroprevalence rate among pregnant women rose from 0.12 percent in 1998 to 0.34 percent in

30 World Bank, *Blood Services in Central Asian Health Systems: A Clear and Present Danger of Spreading and Other Infectious Diseases*, World Bank: Washington, DC, 2008, available at <http://siteresources.worldbank.org/INTECAREGTOPHEANUT/Resources/cabloodbankstudy.pdf>, accessed 10 June 2008.

31 Ibid.

32 WHO, *Antiretroviral drugs for treating pregnant women and preventing HIV infection in infants: towards universal access: recommendations for a public health approach*, WHO: Geneva, 2006, available at <http://www.who.int/entity/hiv/pub/guidelines/pmtctguidelines3.pdf>

33 <http://www.hivpolicy.ru/topics/?id=48>

34 2007 UNGASS national progress reports for Russia and Ukraine

2004.<sup>35</sup> Recent calculations attribute 24 percent of HIV infections among pregnant women to injecting drug use and 39 percent of HIV infections to sexual transmission.<sup>36</sup>

Implementation of complex prevention of mother-to-child transmission (PMTCT) measures (including administering antiretroviral medications to women during pregnancy and labour, elective caesarean delivery, and complete avoidance of breastfeeding) could significantly reduce risk of vertical transmission from 20–45 percent down to 1.2 percent.<sup>37</sup> PMTCT measures in Russia and Ukraine are showing promising results with increasingly high coverage of services (84 percent and 93 percent, respectively)<sup>38</sup> and declining mother-to-child transmission.<sup>39</sup>

However, three elements needed for successful interventions are less broadly available in the region than in high-income countries: readiness of public health systems to take risk-alleviating steps, prepared medical personnel and informed women.

## Mobility and HIV vulnerability

Migration and population mobility as a whole form important and growing dimensions of HIV vulnerability in Eastern Europe and the CIS. Migrants represent about nine percent of the population of developed countries,<sup>40</sup> and Eastern Europe and the CIS region is no exception. If one excludes movements between industrialized countries, the region accounts for over one third of the total world emigration and immigration.<sup>41</sup> In 2007, Russia received the second largest number of migrants in the world (13 million); Ukraine was fourth with 7 million. Migrant groups are prone to multiple layers of so-

**Table 1.5. HIV prevalence studies in prison samples**

Country	Population	N tested	%HIV+	Notes
Bulgaria, Sofia (2005)	Injecting drug users in prisons	115	2.6	Diagnostic Testing
Armenia (2002)	Prisoners	438	5.5	Seroprevalence study, HIV prevalence among IDU prisoners 10%
Kazakhstan (2006)	Prisoners	22428	1.6	Diagnostic testing 45% prisoners inject drugs
Latvia (2006)	Prisoners	2600	4.4	Diagnostic testing. Proportion of inject drug users among HIV+: 60–90%

Source: EuroHIV, 2007, Report No. 76.

cial vulnerability. They often lack status, power, information, economic independence and access to services. They are also vulnerable to HIV. Migrants tend to depart from their country of origin with relatively sound health records, a phenomenon known as the ‘healthy migrant effect’.<sup>42</sup> However, migrant populations may experience greater risk of HIV infection when they travel to countries with significantly higher HIV prevalence levels, in turn increasing the risk of transmission to their partners when they return home.<sup>43</sup> The risk of ‘bringing communicable diseases home’ is exacerbated by structural barriers for migrants to access health services and have symptoms treated in their host countries.<sup>44</sup> In Azerbaijan, for example, 45 percent of official HIV cases are reportedly due to infection abroad. In Tajikistan, 56 percent of HIV infections are reportedly among seasonal workers who travel abroad, and a recent study suggested that the

*Migrant populations may experience risk of HIV infection when they travel to countries with significantly higher HIV prevalence, and in turn, these same migrant populations may increase HIV risk of their partners when they return home*

<sup>35</sup> World Bank, *Socioeconomic Impact of HIV/AIDS in Ukraine*, World Bank: Washington, DC, 2006.

<sup>36</sup> Own calculations based on EuroHIV, ‘HIV/AIDS Surveillance in Europe: End-year report 2006,’ Institut de veille sanitaire: Saint-Maurice, 2007. No. 75.

<sup>37</sup> Cooper, E. R. et al, ‘Combination antiretroviral strategies for the treatment of pregnant HIV-1-infected women and prevention of perinatal HIV-1 transmission,’ in *J Acquir Immune Defic Syndr*, 29, 484–94 (2002).

<sup>38</sup> Resource Centre for HIV/AIDS Policy Research, Russia. [<http://www.hivpolicy.ru/publications/index.php?section=50&id=66>] 1.10.2008

<sup>39</sup> Resource Centre for HIV/AIDS Policy Research, Russia. [<http://www.hivpolicy.ru/topics/?id=48>] 1.10.2008

<sup>40</sup> OECD, ‘Policy coherence for development: Migration and developing countries, Executive Summary, 2007. p. 12

<sup>41</sup> Mansoor, Ali and Bryce Quilín, ‘Migration and Remittances: Eastern Europe and the Former Soviet Union,’ World Bank, January 2007. Page 3 of Overview.

<sup>42</sup> Razum O., A. Jahn, M. Blettner, P. Reitmaier, ‘Trends in maternal mortality ratio among women of German and non-German nationality in West Germany, 1980 to 1996’ in *Int J Epidemiol*, 28: 919–24 (1999).

<sup>43</sup> UNAIDS ‘AIDS in the Commonwealth of Independent States’ MAP Report, 2008, p. 66.

<sup>44</sup> Matic, S., J. V. Jazarus, M. C. Donoghoe, *HIV/AIDS in Europe: Moving from death sentence to chronic disease management*, World Health Organization, Europe: Copenhagen, 2006.

*Migrants themselves are not the cause of HIV transmission. Policies, barriers to prevention, care and treatment services, and costs increase migrants' vulnerabilities to HIV*

HIV prevalence level among returning migrants is some 20 times higher than the national average for adults. Mobility even plays a significant role in HIV transmission in Western Europe. For example, 43 percent of people living with HIV in the Netherlands were born abroad.

It is important to understand that migrants themselves are not the cause of HIV transmission. Policies, barriers to prevention, care and treatment services, and costs increase migrants' vulnerabilities to HIV. Further, given the nature of the epidemic in Europe and the

CIS, migrants tend to come from countries of relatively low prevalence and face much higher risk of infection while in the host country. However, as the region scales up Universal Access to HIV services, migrants are increasingly left behind. Harsh law enforcement policies and attitudes breed a culture of fear around HIV, with disclosure often resulting in immediate and permanent deportation and loss of livelihood. From 2003 to 2008, the majority of migrant clients of a leading legal service centre in Kyrgyzstan sought legal support in connection with the refusal by health facilities to provide HIV services. This example illustrates the discriminatory treatment of migrants and their HIV service needs. As with men who have sex with men, many national HIV surveillance systems do not explicitly examine HIV prevalence and risk among migrants, and response plans often exclude migrants entirely.

**Table 1.6. Prevention of mother-to-child transmission in countries in the region**

Country	Antenatal care coverage (%), 1997–2005*	Estimated number of HIV-positive pregnant women, 2005	% of HIV-positive pregnant women who received ARVs for PMTCT, 2007**
Albania	91		
Armenia	93	<100	
Azerbaijan	70	<100	
Belarus	100	<200	88.2
Bosnia and Herzegovina	99		
Georgia	95	<100	68
Kazakhstan	91	<500	68
Kyrgyzstan	97	<100	1.5
Macedonia, F.Y.R.	81		
Republic of Moldova	98	<500	85
Montenegro		33	
Romania	94		
Russian Federation		6800	84
Tajikistan	71	<100	<1
Turkey	81		
Turkmenistan	98		
Ukraine		2400	93
Uzbekistan	97	<500	
Notes:			
* Data refer to the most recent year available during the period specified in the column heading; empty cells reflect lack of estimates.			
** United Nations General Assembly Special Session on HIV/AIDS (2001) indicator.			

Source: Adapted from WHO, UNAIDS, UNICEF, 2007 "Children and AIDS. A stocktaking report".

## Chapter conclusion

This chapter has provided a broad overview of HIV prevalence and specific risk dynamics associated with HIV transmission in the region. The epidemiologic overview has indicated that this region as a whole is indeed living with HIV, and will continue to over the long term, but that different states within the region are experiencing different burdens of HIV prevalence, incidence, disease and stigma. Epidemiologic variability within states has been observed, as have different levels of success for various intervention programmes.

Despite the ongoing policy debates and discrepant epidemiologic trends in the region, one guiding principle offers a coherent and appropriate approach for responding to HIV for countries in Eastern Europe and the CIS: the need to 'Know Your Epidemic' and 'Know Your Response'. This principle proposes that a 'one size fits all' approach is not appropriate for this region (or for any other region), and incorporates the basic premises of capacity development and its focus on national ownership and adaptation. In practical terms, this approach means that concentrated efforts and resources are needed for understanding the distribution of the HIV epidemic, the specific local drivers of HIV transmission and the social and cultural context in which policies must be developed, elaborated and implemented.



## Chapter 2: The epidemic through voices – Impact and vulnerability

Since the diagnosis of the first cases of HIV in the early 1980s, understanding of the epidemic has evolved through several stages. While at the outset of the epidemic HIV was mainly considered a public health issue, it is now increasingly seen as a fundamental challenge to broader human development. The impact of the epidemic goes far beyond health outcomes and encompasses the broad spectrum of human development challenges, calling for a multi-sector response that not only focuses on how the virus is transmitted but that also addresses underlying structural factors that render people and communities vulnerable. In this way a human development perspective can provide a comprehensive approach to match the complexity of HIV related challenges.

### HIV as a human development challenge

The concept of human development recognizes that people are at the centre of the development process and sees them as both the means and ends of development. To develop their human potential, people must be able to make choices about their lives in a way that validates and affirms their participation in social, cultural, political and economic processes, contributing to a life of dignity, respect and well-being.

Making the human development response to HIV operational and policy-relevant requires going beyond studies of national averages to focusing on specific challenges among particular vulnerable populations. People living with HIV are one such a group, and the link between their HIV status and barriers to full social inclusion makes the concept of human development particularly relevant in the context of the HIV epidemic.

The epidemic affects not only people living with HIV, but also their families and communi-

#### Box 2.1. Advocating better understanding between AIDS and development

HIV strategies work best when there is a clear understanding of the relationship between AIDS, poverty and human development. And in 2007, UNAIDS examined this relationship and what is often called the vicious circle within which the impacts of AIDS increase poverty and social deprivation, while socioeconomic inequalities increase vulnerability to HIV infection.

The article, published in a leading journal, pointed to recent evidence indicating that AIDS is a disease of inequality, often associated with economic transition, rather than a disease of poverty in itself. New data from Africa showed that during the early stage of the epidemic, estimated incidences of HIV initially occurred not among the poorest, but among better-off members of society in this region. Many researchers now point not to poverty itself but to economic and gender inequalities as factors influencing sexual behaviour and therefore the potential for HIV transmission.

ties and the broader social structures they inhabit.<sup>45</sup> The human development burden of HIV is difficult to quantify, but the personal experiences of people living with HIV show that a supportive national and local environment is fundamental both to their individual welfare and to the advancement of human development in HIV-affected societies.

A reciprocal relationship exists between development and social health risks, and this relationship is manifested in the ways in which HIV is distributed within and across societies. Global statistics generally suggest the existence of a correlation between lower human development indices and higher HIV prevalence though this appears to be more a function of inequalities within societies rather than absolute poverty – a relationship that seems to hold true for Eastern Europe and the CIS. Box 2.1 excerpted from the 2007 UNAIDS Annual Report discusses this dynamic.

*A human development perspective can provide a comprehensive approach to match the complexity of HIV related challenges*

45 Dzenovska, Dace, Nadia Rasheed and BjNrg Sandkj r, 'HIV/AIDS and Human Development,' Thematic Guidance Note, UNDP.

*If adequate systems of human development are put in place, which allow people to use their full human capacities, then both the human cost of HIV and the incidence of HIV may decline over time*

Determinants of low human development (such as low education, insufficient income, disempowered women, social gender biases, inadequate health systems and weak governance systems) also contribute to higher HIV prevalence. Once the epidemic has gained momentum it can start exerting a direct negative impact on human development, bringing about lower economic productivity, weakened community and family networks and overburdened health, educational and social service systems.

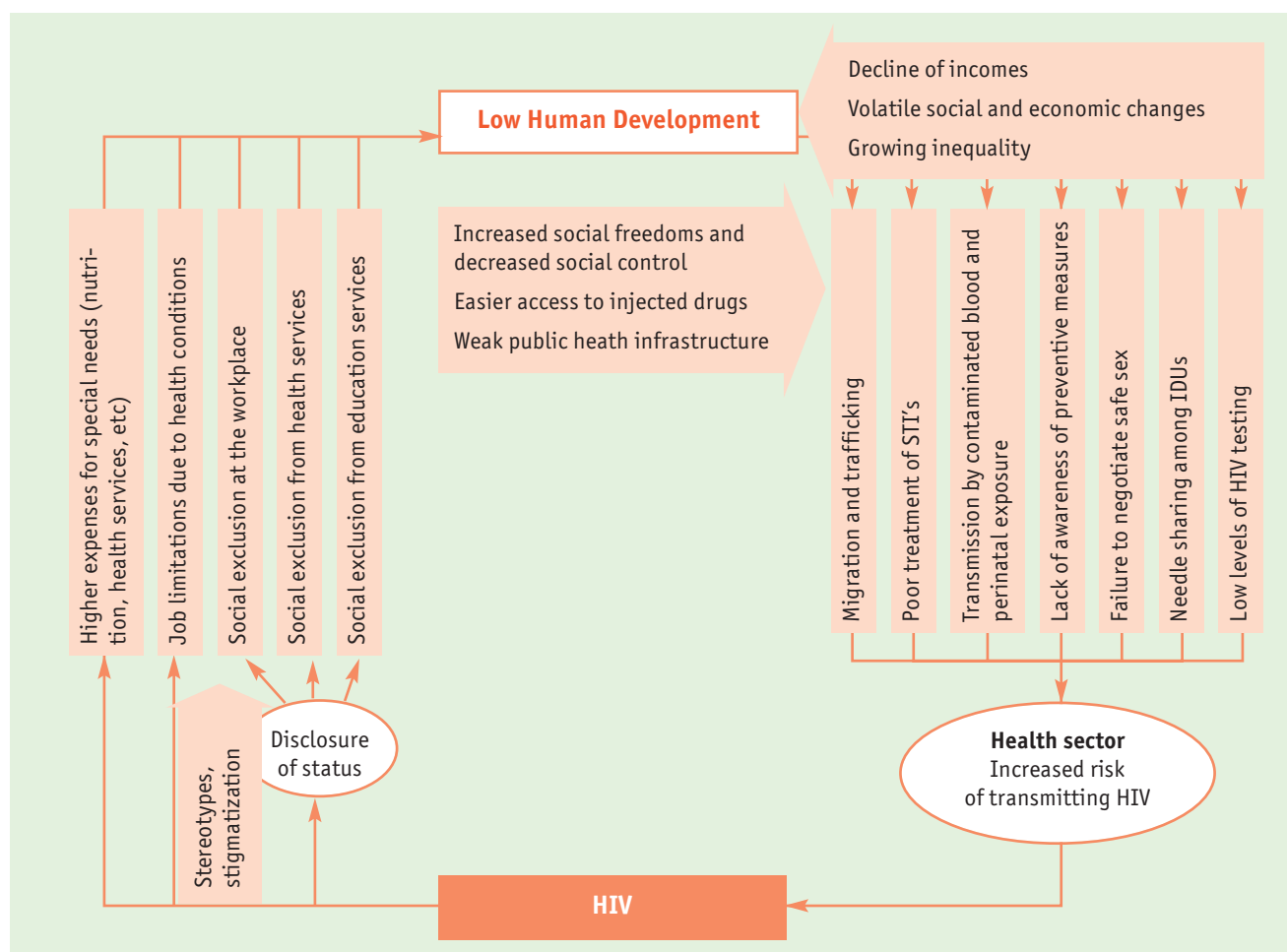
This cycle of mutual reinforcement is outlined in a 'macro model' of factors linking human development and HIV in Eastern Europe and the CIS (Figure 2.1). It visualizes the fact that the determinants of social exclusion are arguably the same determinants of HIV risk. This model underscores the UNDP rationale of treating HIV as a development issue, as opposed to an exclusively public health one. It also suggests that targeting interventions at one level (i.e. human development) may have

an effect on the other (i.e. new HIV infections) and vice-versa. Finally, it means that in order to understand the relationship between human development and HIV prevalence in any given society, a broad cultural matrix must be considered. This framework advances a somewhat optimistic message, that if adequate systems of human development are put in place, which allow people to use their full human capacities, then both the human cost of HIV and the incidence of HIV may decline over time.

### Demographic and economic implications

AIDS affects societies through multiple channels. Increased strain on the public health sector to provide prevention, care, treatment and support services is perhaps the most direct channel, while others include effects on demography, social support spending and ultimately economic production.

**Figure 2.1. Factors linking human development and HIV in Eastern Europe and the CIS**



Major economic and socio-demographic impacts of HIV include a reduced labour force and altered population-age structure. As members of economically productive age groups are lost, the epidemic contributes to increased dependency ratios with fewer workers available to support a relatively greater number of young and elderly/retired persons. Labour force productivity also decreases due to absenteeism.

This effect, and its impact on macroeconomic and socio-demographic indicators, may be especially potent in the European CIS region given the baseline demographic ‘crisis’ broadly unfolding, in which working-age populations are the fastest segment in decline. The combination of very low birth rates and relatively unfavourable mortality trends contribute to overall population decline, in which mortality outpaces birth rates. These problems are particularly serious for low-income CIS countries like Armenia, Georgia, and Moldova, where they are exacerbated by extensive out-migration – particularly of young men, often from rural areas. But the population is decreasing even in the Russian Federation, the recipient of most migration inflows within the CIS.<sup>46</sup> Table 2.1 presents long-term demographic outlooks for the CIS countries, setting the context for AIDS impact.

Several countries in the region have conducted studies to address the question of the socio-economic impact of AIDS. In **Armenia**, a study commissioned in 2006 investigated the potential impact of the epidemic on population growth, employment, social and health services, and the size and growth of GDP over the period 2007–2015. In addition to the opportunity cost of lost labour, tax income and social payment losses, and direct health care costs, the study also calculated potential increases in disability pension, incapacity allowances and orphanage care costs. Assumptions were made based on three scenarios: optimistic, medium and pessimistic. The study demonstrated the potential for human and economic implications even in a low-level epidemic such as that in Armenia. Disability pensions costs “may grow 1.6 to 4-fold” under the optimistic and pessimistic scenarios, respectively. The sum of direct fiscal expenditures, including health and non-health

**Table 2.1. Population in CIS countries in 1989, 1994, 2000, and 2007 (in millions); UN population forecasts (neutral scenario) for 2050**

Country	1989	1994	2000	2007	2050
Armenia	3.3	3.7	3.1	3.0	2.5
Azerbaijan	7.0	7.5	8.2	8.5	9.4
Belarus	10.2	10.2	10.0	9.7	7.0
Georgia	5.4	5.4	5.3	4.4	3.1
Kazakhstan	16.5	16.3	15.6	15.4	17.3
Kyrgyzstan	4.3	4.5	4.9	5.3	6.6
Moldova*	4.3	4.4	4.3	3.8	2.9
Russia	147.4	148	145.6	142.5	107.8
Tajikistan	5.1	5.7	6.1	6.7	10.8
Turkmenistan	3.5	4.3	4.6	5.0	6.8
Ukraine	51.7	51.9	49.7	46.2	30.9
Uzbekistan	19.9	22.1	24.9	27.4	38.4
<i>Total</i>	<i>278.8</i>	<i>284.0</i>	<i>282.4</i>	<i>277.9</i>	<i>243.5</i>
* 2000 – without statistics for the left bank of Dniester and city of Bendery.					

**Sources:** CIS Statistics. Interstate Statistical Committee of the CIS, Statistical Bulletin N17 (272), September 2001, pp. 8–19; Interstate Statistical Committee of the CIS (SNG STAT): Press-release, February 4, 2005; World population Prospects: The 2006 Revision, United Nations, ESA/P/WP.202, 2007.

related costs, and budget revenue losses may reach 2.4 to 13.2 billion drams (\$7.8 to \$42.9 million), depending on the scenario.

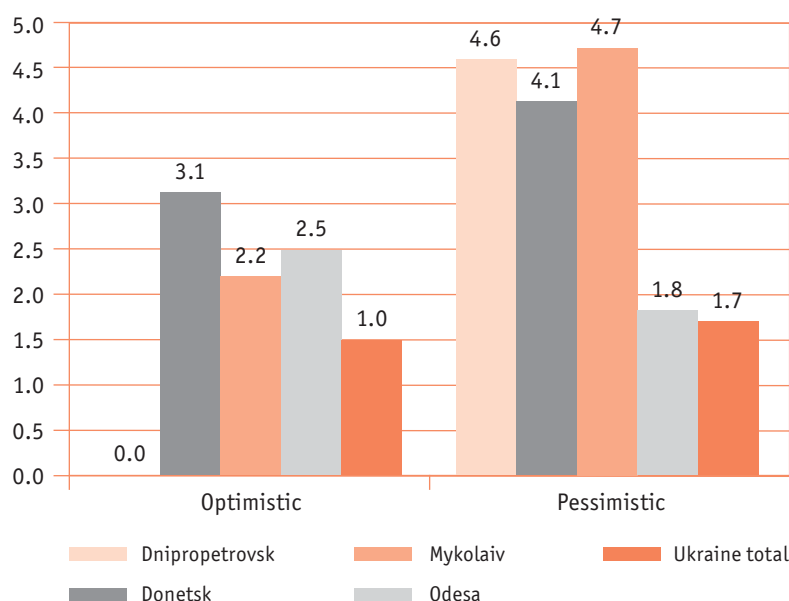
In **Ukraine**, a similar study was carried out in 2006 to assess the demographic and macro-economic implications of HIV under optimistic, medium and pessimistic scenarios, over the period through 2014. The results demonstrate the potential impact on state demographic characteristics through declining population, reduced life expectancy and a dramatically increased proportion of AIDS-related deaths out of the total. The model disaggregated impact by region, demonstrating the considerable variation in relative impact at sub-national levels, an innovation not available in other modelling efforts in the region. Figure 2.2 (on page 16), for example, shows that potential reductions in the labour force may be much more pronounced in regions with relatively higher HIV prevalence.

*Major economic and socio-demographic impacts of HIV include a reduced labour force and altered population-age structure*

<sup>46</sup> Ben Slay, UNDP Bratislava Regional Centre, ‘Demographic trends in CIS countries – How favourable? How irreversible?’ Unpublished draft.



**Figure 2.2. Modelling the impact of HIV on Ukrainian labour force reduction at the regional level; comparison of optimistic versus pessimistic scenarios.**

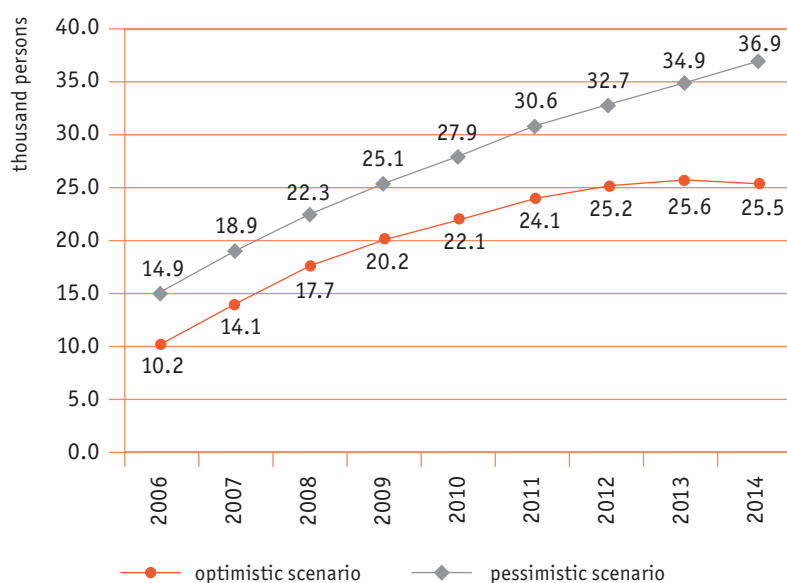


**Source:** "Socioeconomic Impact of HIV/AIDS in Ukraine", the World Bank and International HIV/AIDS Alliance, Kiev, May 2006.

A more recent model developed in 2007 in collaboration between the International Labour Organization, Deutsche Gesellschaft Für Technische Zusammenarbeith (GTZ) and the Ukrainian Ministry of Labour and Social Policy added further innovation, with components addressing sectoral implications in the prison and orphan and vulnerable children (OVC) sectors.<sup>47</sup> As a consequence of the epidemic, a significant increase in the number of children who may lose one or both parents to the disease is anticipated. According to the model, some 25,000-37,000 persons may be orphaned by 2014, leading to additional pressure on the social welfare system, including increased orphanage needs; increased costs for social support and assistance to orphans and the adults that take care of them; and increased demand for trained specialists capable of taking care of these orphans and their families.<sup>48</sup>

In the **Russian Federation**, a handful of mathematical models of the national context have been used to better understand the potential long-term linkages between demographic and economic implications of AIDS. The first two models, from the World Bank and UNDP, were developed at a time when geometric growth in new registered infections had driven much higher expectations for HIV transmission in Russia over time. The pessimistic and medium scenarios proved unrealistically high in their stipulated rate of HIV spread, while even the optimistic scenarios may now serve as more of an instructive hypothetical upper bound for potential macro impact. At the sectoral level, however, understanding the impact that AIDS may have on the economy's dependency ratios requires a more nuanced investigation. As the ratio of pensioners or children to the number of workers in the economy increases, captured as an increase in youth or elderly dependency ratio, national savings decrease and social protection schemes are strained. The third and most recent model, benefiting from more realistic projections, was developed by the International Labour Organization as a policy tool specifically for evaluating the impact of AIDS on social policy. The model demonstrates changes in three key indicators: short-term disability benefit costs, the pension dependency ratio, and the affordable replacement ratio.

**Figure 2.3. Prognosis of the total number of orphans as a consequence of AIDS in Ukraine, ILO model**



47 "The Socio-economic Impact of the HIV/AIDS Epidemic in Ukraine: Prognosis, Modeling, Evaluation" ILO, GTZ, 2007.

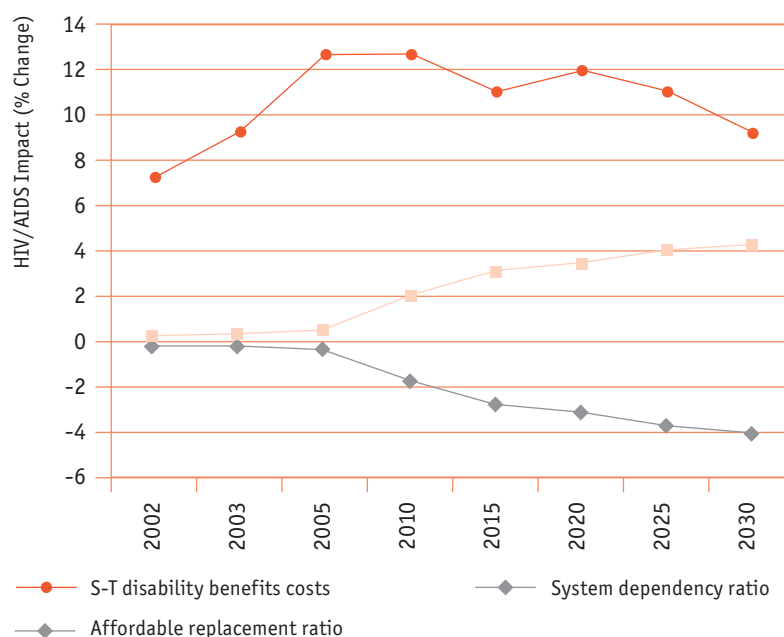
48 "The Socio-economic Impact of the HIV/AIDS Epidemic in Ukraine: Prognosis, Modeling, Evaluation" ILO, GTZ, 2007.

From Figure 2.4, it is possible to discern potentially sustained AIDS-induced strains on Russia's social policy mechanisms. Short-term disability benefit costs rise an additional 13 percent by 2010 due to AIDS and remain over 10 percent higher than baseline for decades. The pension system is equally stressed, with the dependency ratio and affordable replacement ratio moving inversely, reflecting a relative weakening of pension system viability. Even without this effect, Russia may employ only four workers for every three dependents within the next decade.

All three studies bear out the central thesis of the potential impact of the epidemic: by increasing morbidity and mortality among the economy's most productive and reproductive age groups, while at the same time driving up health and social protection costs associated with treatment and care, HIV can exacerbate existing challenges to national health provision and social protection. However, we should reiterate that as the epidemic evolves within countries and the basis for modelling assumptions change, it is important to update models periodically to ensure they remain as relevant and instructive as possible. This is certainly the case for the Russian Federation, where no new modelling effort has been undertaken since 2004.

Another manifestation of the development impact of HIV is the increased financial burden on public health and social protection systems via direct and indirect costs of care and treatment. The scope of these impacts is obviously related to the magnitude of the epidemic, and no country in Eastern Europe and the CIS has yet experienced a generalized epidemic. Due to the nature by which HIV is distributed among populations – overwhelmingly affecting people of reproductive age and incurring large, lifelong costs in order to treat them – even countries without generalized epidemics can be theoretically exposed to substantial economic consequences. However, given the demographic trends in countries in the region that are most affected by the epidemic (outlined in Table 2.1 on page 15), it is clear that investing in HIV care and treatment is not just a humanitarian issue but also an aspect of rational economic choice. From a demographic perspective, then, the additional costs related to the targeted health provision of people living with HIV

**Figure 2.4. Social Policy Implications of HIV in the Russian Federation, ILO model of the magnitude of possible impact of the epidemic under different scenarios on GDP and employment.**



**Source:** Shombi Sharp, UNDP Bratislava Regional Centre, *The Economic Impact of HIV and AIDS in Russia - Current Trends and Perspectives* (constructed from model output) ILO, 2004. Based on S. Miskikhina, V. Pokrovsky, N. Mashkilevson and D. Pomazkin, "A model of social policy costs of HIV/AIDS in the Russian Federation", International Labour Organization, Geneva, 2004, "Risk group saturation scenario".

should be seen as investments in labour force and economic sustainability.

## HIV-related stigma and social exclusion

In addition to their health implications, populations at risk in the region also experience substantial development vulnerabilities due to social exclusion and societal levels of stigma and discrimination. This Human Development Report broadens the scope of what national and regional actors should know about their HIV epidemic. In addition to epidemiologic surveillance data and identification of vulnerable populations, it is vital to identify, acknowledge and understand social and societal processes that determine HIV vulnerability, including HIV-related stigma and discrimination against people living with HIV. From the human development perspective, the broad context of HIV risk and vulnerability is as important as the distribution of cases for formulating appropriate policy, advocacy and prevention measures.

*The additional costs related to the targeted health provision of people living with HIV should be seen as investments in labour force and economic sustainability*

*It is vital to identify, acknowledge and understand social and societal processes that determine HIV vulnerability, including HIV-related stigma and discrimination against people living with HIV*

**Box 2.2. “Living with HIV” – a qualitative research initiative on vulnerability, exclusion and stigma facing people living with HIV in six countries of Eastern Europe and the CIS, commissioned for this report**

The aims of this research were:

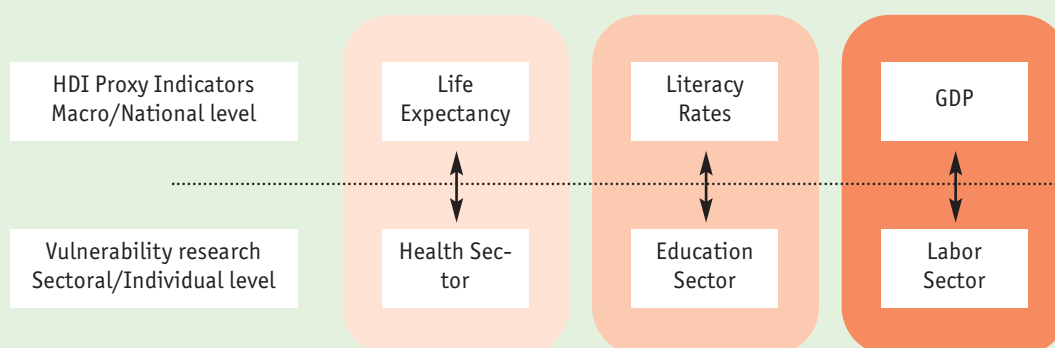
- To elicit detailed and rich descriptions of stigma, discrimination, and exclusion among people living with HIV within selected locations in the region;
- To identify barriers to the full social integration of people living with HIV, structured around three key sectors – the health, education and labour sectors – that form a core of the Human Development concept and provide proxy indicators for the Human Development Index (see below).
- To guide the development of evidence-informed recommendations for advocacy and policy that will improve capacity of local and national governments to reduce discrimination and achieve full integration for people living with HIV in their settings.

This research was carried out in six countries: Estonia, Georgia, the Russian Federation, Turkey, Ukraine and Uzbekistan. Countries were selected to represent regional diversity in development, culture, religion and HIV epidemiology. Research teams in each used a standardized methodology, including training on research aims and objectives, data collection protocols, data management and analysis, and research ethics. Local and regional UNDP staff and international experts provided ongoing consultation and training.

This research used qualitative methods as a technique to understand the ‘lived experiences’ of people living with HIV and to record first-person accounts from key representatives of ‘mirror institutions’ in the health, education, labour and NGO sectors. Unlike quantitative methods, qualitative research (such as interviews and focus groups) does not aim to provide numeric estimates about health outcomes or population-level trends. Rather, qualitative methods allow researchers to elicit information-rich narratives about experiences of stigma, discrimination and exclusion, which cannot be achieved by quantitative methods. Qualitative data are useful counterparts to numeric data provided in epidemiological reports. Using both methodological approaches together offers a more complete depiction of the experiences of people living with HIV.

Even though the research does not claim to be statistically representative, it nevertheless provides important socio-economic characteristics related to the respondents including for example marital status: of the 182 respondents, approximately 30 percent were married, 47 percent were unmarried and 11 percent were divorced. For more information on the study methodology, please see Annex 5.

**Human Development basis for the HIV vulnerability research logical framework**



**Source:** Regional HIV Vulnerability study, UNDP (2006, 2007)

## Stigma and the struggle to develop inclusive societies

As far back as 1987, the late Jonathan Mann, founder and a former head of the World Health Organization's Global Programme on AIDS, identified three stages of the AIDS epidemic. The first stage is the HIV viral infection, which generally may go undetected in the absence of physical symptoms. The second stage is the disease known as AIDS, marked by the illness and death of large numbers of people. The third stage is the social, cultural and political reaction to the epidemic, marked by stigma and exclusion of people living with HIV and people coping with AIDS-related illness.<sup>49</sup>

Twenty years later, these stages seem to have proceeded in reverse order in Eastern Europe and the CIS. Stigma, the epidemic's unfortunate companion, has preceded rather than followed HIV throughout the region. This issue was the focus of a UNDP six-country qualitative study of experiences of stigma among people living with HIV (see Box 2.2 for a description of the study design and methodology). One of the most disturbing findings from this primary research is that many people living with HIV fear social stigma more than the health consequences of the disease. HIV stigma also interacts with pre-existing stigmas, and results in

deepening discrimination towards people who inject drugs, men who have sex with men, sex workers, ethnic minorities and other marginalized populations.<sup>50</sup> The fear of stigma and discrimination is a major cause of the hesitant take-up of essential support services and treatment by people living with HIV, even where these are free.<sup>51</sup>

In its 2001 Declaration of Commitment on AIDS, the United Nations identified stigma, silence, discrimination, denial and the lack of confidentiality as key factors that undermine prevention, care and treatment of HIV and AIDS. The UN hoped to galvanize a response that could eliminate discrimination and marginalization related to AIDS by 2003.<sup>52</sup> This has been shown to be a difficult task. Social scientists Richard Parker and Peter Aggleton have argued that stigma, discrimination and collective denial are "as central to the global AIDS challenge as the disease itself".<sup>53</sup> To fully understand the depth and scope of AIDS-related stigma, Parker and Aggleton stated it is necessary to understand the structural "conditions that produce exclusion from social and economic life".<sup>54</sup> They argued that stigma reflects and reproduces existing inequalities linked to race, class, gender and sexuality, and is inextricably linked to power, inequality and exclusion.<sup>55</sup>

*Many people living with HIV fear social stigma more than the health consequences of the disease*

*The fear of stigma and discrimination is a major cause of the hesitant take-up of essential support services and treatment by people living with HIV, even where these are free*

**Figure 2.5. Social and personal biases against marginalized populations lead to hostility, moral outrage and blame, which contribute to stigmatizing responses to people living with HIV (PLHIV).**



49 Mann, J., *Statement at an Informal Briefing on AIDS to the 42nd Session of the United Nations General Assembly, United Nations, New York, 1987, Vol. 20.*

50 Parker, R, P. Aggleton, 'HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action' in *Social Science and Medicine*, 57, pp. 13-24 (2003).

51 ILO/UNAIDS, *People at Work: Addressing Stigma and Discrimination, ILO/UNAIDS Meeting on AIDS and the World of Work in Latin America and the Caribbean, 2006*, available at [http://www.ilocarib.org.tt/oldwww/infosources/hiv\\_aids/People%20at%20Work.pdf](http://www.ilocarib.org.tt/oldwww/infosources/hiv_aids/People%20at%20Work.pdf)

52 United Nations Declaration of commitment on HIV/AIDS (2001), available at [http://data.unaids.org/publications/irc-pub03/aidsdeclaration\\_en.pdf](http://data.unaids.org/publications/irc-pub03/aidsdeclaration_en.pdf)

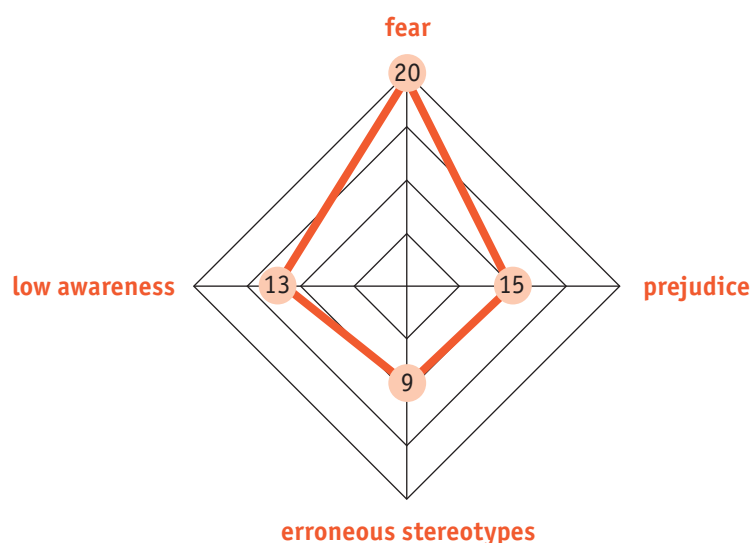
53 This phrase is attributed to Jonathan Mann in Parker and Aggleton, 'HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action' in *Social Science and Medicine*, 57 (2003), p. 13.

54 Ibid, p. 15.

55 Ibid, p. 21.

**Figure 2.6. An illustrative model of stigma – four key factors and their relative weight.**

(Based on qualitative content analysis of answers to the question “How are people living with HIV generally perceived and treated in society?” Ukraine, small sample set)



**Box 2.3.** HIV is often considered an issue for marginalized populations and stigma toward people living with HIV reflect long-standing biases against members of these populations

*“There is a common opinion that a person who has AIDS is either a prostitute, or a drug addict, or a homosexual. They are not considered to be ordinary people. On the contrary, they are perceived as those who went astray and live promiscuous lives. Is there any mercy or compassion? It depends, how the person was infected with the virus. If it will be revealed that the person is a victim of violence, then, yes. However, if it will be revealed that the person was either a drug addict or a prostitute, no compassion remains.”*

– Person living with HIV from Georgia

*“Many people with HIV are not decent people, drug addicts and prostitutes. And they can infect other people knowing of their status. I think so. Therefore we sometimes try to distance ourselves from them. Because there are patients who deliberately want to infect all people.”*

– Doctor from Uzbekistan

*“They are unstable people and it is evident from their way of life – drugs, abundant sex with different partners.”*

– Employer from Russia

*“For me the ways of transmission of the infection are very obvious. Thus, one part is related to drug addiction: they are drug users; they are certainly having sex with one another. There are both homosexual and heterosexual relations. It is one and the same group of people. One and the same social group which is present in Tallinn, Ida-Viru County and elsewhere in Estonia. I as a doctor would draw a line between them and us.”*

– Doctor from Estonia

Source: Regional HIV Vulnerability Study, UNDP (2007)

Aspects of the socialist past have made societies in most countries in the region particularly prone to stigma and exclusion. The history of authoritarian rule, intolerance to diversity and regard for the collective over the individual opens the doors to public support for exclusion of people living with HIV. Intolerance to certain patterns of behaviour and individual choices often transcends to stigmatization of entire populations; these populations subsequently come to share similar patterns of vulnerability and social rejection. HIV status in this regard serves as a ‘common denominator for stigma and discrimination’. For example, men who have sex with men, ethnic minorities and injecting drug users may have little inherently in common with one another besides the fact that they tend to be socially marginalized. However, in the context of the epidemic, these populations also experience heightened risk for HIV infection as well as vulnerability to HIV-related stigma and discrimination.

Thus a broader approach that mobilizes members of most-at-risk populations and reaches out to the general population, advocating for improvements in social justice and inclusion for members of stigmatized populations and people living with HIV, is critical for human development initiatives. Greater social inclusion and improved conditions for members of historically disadvantaged populations are likely to substantially reduce HIV incidence across societies and, in turn, protect against shortfalls in economic, educational, political and health outcomes.

### Foundations of stigma and social exclusion of people living with HIV

HIV is a complicated human development issue due to challenges associated with living with the virus (e.g. compromised health, need for additional resources, impaired productivity) as well as challenges associated with reaching socially excluded populations at risk for HIV. Manifestations of HIV-related stigma exist around the world in a variety of ways, including: ostracism, rejection, discrimination and avoidance; compulsory HIV testing without prior consent or protection of confidentiality; violence against people living with HIV or people who are perceived to be HIV-positive; and the quarantine of people living with HIV. All these factors negatively impact human development, as they crucially limit people’s choices in relation to education, employment, health and many other aspects of life. In many cases stigma is derived



from lack of HIV awareness and knowledge in families, communities, workplaces, educational institutions or health facilities, which hampers access to prevention, treatment and support services for people living with HIV and reduces their opportunities to continue education, employment or social activities. Exclusion from economic, cultural and social services not only leads to isolation but also prevents people living with HIV from speaking openly about HIV, seeking information and accessing support, treatment and legal services.

The results of the qualitative study conducted for the purpose of this report provides some insights into the determinants of HIV-related stigma. For example, Figure 2.6 summarizes data from the Ukraine country report showing the perceived reasons for exclusion as seen by respondents living with HIV. Data shows that the two prevailing components of stigma are people's *fear* and *prejudice*. People living with HIV are often labeled as deviant, immoral and dangerous.<sup>56</sup> This theme, on the basic underpinnings of HIV stigma, was consistent across all sites of the study.

A central consequence of HIV stigma is the fear of a person living with HIV that his or her HIV status will be disclosed. For most people, an HIV-positive diagnosis results in a deep shock. Family members and society could provide essential support, but stigma and exclusion often undermine this possibility at a time of greatest need.<sup>57</sup> Fear of disclosure can adversely affect personal behaviour: people avoid testing because they do not trust the anonymity of services; people avoid taking antiretroviral medication because this could lead to inadvertent disclosure if others see

**Box 2.4. Lack of knowledge about HIV and AIDS leads to misinformation, fear and prejudice**

*Prevention so far has been dominated by shock and fear – fear of syringes, junkies and prostitutes. But we need information to raise awareness of what exactly we need to fear from the syringes ... [we need to know] to what extent we should fear, how not to exaggerate our fears, and how to communicate with those people.*

– Teacher from Estonia

*Because every day people with this problem turn to us because of discrimination, serious stigma; and every day these rights are violated, because in most institutions and organizations it is absolutely dominant, this intolerant attitude, unwillingness to treat such people as equals at all. It is just blind fear, instinctive estrangement from things one knows nothing about.*

– Social worker from Ukraine

*I am talking about such simple information. It is not technical information: HIV does not pass to other people by means of working together, eating together, or hugging and kissing each other. We need such a simple sensitivity. We do not need a long time to understand this.*

– Employer from Turkey

**Source:** Regional HIV Vulnerability study, UNDP (2006, 2007)

them taking medications; people avoid accessing regular healthcare because this might raise suspicion among others. As a result, stigma can have a direct impact on the life expectancy of people living with HIV and create conditions for further spread of the epidemic. Stigma operates at different levels – among individuals, families, institutions and societies – and can impact differently on individual and family processes (see Table 2.2 on page 22).

**Figure 2.7 Mechanics of Stigma: Inadequate HIV information and knowledge lead to fear, avoidance and blaming responses to people living with HIV (PLHIV)**



<sup>56</sup> 'Evaluating the vulnerability of people living with HIV in Ukraine,' UNDP: Kiev, 2008.

<sup>57</sup> Laryea, M., L. Gien, 'The impact of HIV-positive diagnosis on the individual, Part 1: Stigma, rejection, and loneliness' in *Clinical Nursing Research*, 2, 245-63 (1993).

**Table 2.2. “Influence Matrix”: Levels of stigma influence human development processes of individuals and families**

Level of Stigma	Effect on	
	Individuals	Families
<b>Individual</b>	<ul style="list-style-type: none"> <li>Self-perceived stigma restricting choices regarding work/school</li> <li>Depression, anxiety; potential for disease progression/decline</li> </ul>	<ul style="list-style-type: none"> <li>Early entry of children and youth into the workforce, restricting educational opportunities</li> <li>Reluctance to seek care in formal sector drains family resources for home care</li> </ul>
<b>Family (affected individual)</b>	<ul style="list-style-type: none"> <li>Loss of primary income</li> <li>Push deeper into poverty</li> <li>Lack of resources</li> <li>Orphans and vulnerable children</li> </ul>	<ul style="list-style-type: none"> <li>Withdrawal from economic activity for caretaking or secondary stigma</li> <li>Differential treatment of orphans by family – forced into economic activity, internal migration rather than education</li> </ul>
<b>Institution</b>	<ul style="list-style-type: none"> <li>Prohibited access to schools, jobs, health care, insurance through compulsory testing/notification</li> <li>Absenteeism due to illness</li> <li>Health care costs, if provided by the institution</li> <li>Interpersonal relationships (trust, morale)</li> </ul>	<ul style="list-style-type: none"> <li>No/limited access to micro-credit or market-level resources (e.g., farmers unable to sell food products at the market due to stigma)</li> <li>Religious institutions denying socioeconomic support/ educational opportunities to affected families</li> <li>Absenteeism due to caretaking, with further implications for stigma</li> </ul>
<b>Structure/society</b>	<ul style="list-style-type: none"> <li>Individual consequences of laws: privacy, access to health care thus affecting economic opportunities</li> <li>Driving people into informal/ illegal/ unregulated economies (sex work, drugs)</li> <li>Loss of savings/pension revenue</li> </ul>	<ul style="list-style-type: none"> <li>Migration restrictions leading to reduced remittances to families</li> <li>Restricted marriage for people living with HIV, thereby limiting access to pensions/land</li> <li>Driving people into informal/ illegal/ unregulated economies (sex work, drugs)</li> <li>Loss of savings/pension revenue</li> </ul>

**Source:** HIV-related stigma and discrimination in Asia: a review of human development consequences. UNDP Regional Centre in Colombo, July 2007.

Adopted from [http://www.undprcc.lk/Publications/Publications/HIV/HIV\\_Related\\_Stigma.pdf](http://www.undprcc.lk/Publications/Publications/HIV/HIV_Related_Stigma.pdf)

### The collective benefits of including the excluded

Social exclusion is a process through which people experience marginalization in economic, social and cultural life.<sup>58</sup> It is a process whereby certain individuals or social groups

are pushed to the edge of society and prevented from participating fully by virtue of their poverty, or lack of basic competencies and lifelong learning opportunities, or as a result of discrimination. This distances them from job, income and education opportunities as well as social and community networks and activities. They have little access to power and decision-making bodies and thus often feel powerless and unable to have control over the decisions that affect their daily lives. Social inclusion places emphasis on the individual's right “to enjoy a standard of living and well-being that is considered normal in the society in which they live”, as well as on the government's “duty to care,” ensuring all necessary means for every person to be part of mainstream society with equal social, economic and political opportunities, and to address all forms of domestic inequalities.

The concept of social inclusion has explicit implications for people living with HIV. Social inclusion also aims explicitly to undermine forces (agents, institutions and processes) of social exclusion as a central part of the human development process. A social inclusion perspective can thus help sharpen the strategies for achieving human development by addressing discrimination, exclusion, powerlessness and accountability failures that lie at the root of poverty and other development problems. The two concepts are complementary with regard to policy, with human development placing a stronger focus on ‘what’ needs to be achieved and social inclusion on ‘how’ it should be achieved.

Social exclusion of people living with HIV brings negative outcomes not only for affected individuals, but for whole societies at large. Inadequate health services and lack of life-saving medications contribute directly to higher mortality, and consequently contribute to lower overall life expectancies, greater health expenditures and disrupted families and communities. Exclusion of people living with HIV from the education system reduces a country's average education levels and deprives sections of society from developing intellectually and professionally. Workplace discrimination leads to reduced incomes and weakened economies. Each of these factors further contributes to

<sup>58</sup> Parker, R, P. Aggleton, ‘HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action’ in *Social Science and Medicine*, 57 (2003).

lower overall national human development indicators. Addressing these manifestations of social exclusion of people living with HIV – and most of all, their determinants – can have significant implications for opportunities and levels of human development.

Recent studies showed that life-saving antiretroviral therapy significantly increases the life span following HIV infection from eight years prior to the advent of antiretroviral medication to over 30 years in the case of full-scale therapy. Social exclusion, leading to the unavailability of antiretroviral treatment, or, even worse, preventing the uptake of antiretroviral treatment due to fear of status disclosure, can significantly and unnecessarily shorten the life span of people living with HIV, and consequently impact Human Development Indices.

Table 2.3 (on page 24) summarizes differences in current Human Development Indices for countries within the region and shows simulated HDI values for people living with HIV in two scenarios – one in which states ensure access to antiretroviral medications and another in which states do not provide access to medications. It is clear that in the latter scenario, Human Development Indices deteriorate significantly below the ‘medium development’ threshold of 0.700 and enter levels of ‘low human development’.

This is, to be sure, a relatively crude illustration of complex and multidimensional linkages. The benefits of social inclusion go well beyond Human Development Indices and increased life expectancy.

### Living openly with HIV

The previous sections have outlined the harsh and powerful effects of stigma and discrimination. However, for those courageous enough to disclose their status in the face of likely stigma and discrimination, anecdotal evidence indicates that doing so can result in a significant easing of the psychological burden and potential health gains. According to one study involving 373 respondents, people living with HIV who disclosed their HIV sta-

tus experienced relative increases in CD4 cell counts.<sup>59</sup> Moreover, as more people living with HIV disclose their status to those around them, HIV becomes less impersonal and foreign in society. Increased numbers of people who are open about their HIV status can facilitate social capital and community-building among people living with HIV, which can undermine general social stigma.

#### Box 2.5. National Study on stigmatization and the forms of discrimination against people living with HIV in Tajikistan

A recent study conducted by the Strategic Research Centre under the President of Tajikistan and the NGO Guli Surkh, with support from UNDP Tajikistan, provided a detailed look at stigma and discrimination of people living with HIV in the country. This study used a quantitative survey to assess attitudes towards people living with HIV, and respondents included medical workers, teachers, law enforcement officials, lawyers and judges, service sector representatives, Muslim and Christian religious leaders, mass media staff and members of local administration bodies (Hukumat). Interviews were also conducted with people living with HIV to elaborate on their experiences of stigma and discrimination.

The results show that many respondents believed that people living with HIV do not have the right to work (42 percent of law enforcement officials, 29 percent of teachers, 23 percent of judges and lawyers, 20 percent of Hukumat). As many as 77 percent of respondents believed that people living with HIV do not have the right to work in the service sector. One-third of respondents believed a person could be dismissed from employment based on their HIV status.

The study also reveals a huge ‘discrimination potential’ in the education sector as well. Forty-two percent of respondents overall believed that children living with HIV should not be allowed to attend classes with other children who are not living with HIV. Many respondents believed that children living with HIV should not be allowed to attend regular secondary school (57 percent of law enforcement officials, 46 percent of teachers, 61 percent of service sector employees and 50 percent of mass media employees).

Discrimination in the health sector appears to be slightly less prominent – but still substantial. Thirty-eight percent of medical workers indicated they were not ready to give the same medical assistance to people living with HIV. Forty-one percent of people living with HIV indicated that the confidentiality of their HIV test results had been violated and 38 percent of them indicated they had been refused treatment in medical facilities (women reported this more frequently than men).

**Source:** ‘National Study on the stigmatization of and forms of discrimination against people living with HIV’

<sup>59</sup> Disclosure might boost CD4 cell count, Reuters Health, Will Boggs, [http://www.aidsmeds.com/articles/1667\\_11327.shtml](http://www.aidsmeds.com/articles/1667_11327.shtml)



**Table 2.3. Impact of social exclusion of people living with HIV (PLHIV) on Human Development (reflected in Human Development Index)**

	National HDI, 2006	HDI for PLHIV receiving antiretroviral treatment	HDI for PLHIV not receiving antiretroviral treatment
Albania	0.807	0.704	0.565
Armenia	0.777	0.674	0.536
Azerbaijan	0.759	0.656	0.524
Belarus	0.817	0.714	0.576
Bosnia and Herzegovina	0.890	0.787	0.648
Bulgaria	0.834	0.731	0.592
Croatia	0.862	0.758	0.620
Cyprus	0.912	0.809	0.670
Czech Republic	0.897	0.794	0.656
Estonia	0.870	0.767	0.629
Georgia	0.763	0.659	0.521
Hungary	0.877	0.774	0.635
Kazakhstan	0.807	0.704	0.577
Kyrgyzstan	0.694	0.590	0.468
Latvia	0.863	0.760	0.621
Lithuania	0.869	0.766	0.627
Macedonia (FYR)	0.808	0.705	0.566
Moldova	0.719	0.615	0.477
Montenegro	0.821	0.718	0.579
Poland	0.875	0.771	0.633
Romania	0.826	0.722	0.584
Russian Federation	0.806	0.702	0.582
Serbia	0.821	0.718	0.579
Slovakia	0.871	0.768	0.629
Slovenia	0.921	0.818	0.680
Tajikistan	0.684	0.581	0.453
Turkey	0.780	0.677	0.539
Turkmenistan	0.723	0.620	0.513
Ukraine	0.786	0.682	0.548
Uzbekistan	0.701	0.598	0.468

Note: Calculations based on figures from Human Development Indices, statistical update 2008 and life expectancy data from N. Lohse and H.T. SNrensen, "Survival of Persons with and without HIV Infection in Denmark, 1995–2005", *Ann Intern Med.* 2007; 146: 87–95.

Here we present in brief the experience of three people living openly with HIV whose photos can be found on the front cover of this report. All three have managed to overcome challenges associated with being open about their status and are empowered to serve as role models for others. It should be noted, of course, that the vast majority of people living with HIV and are aware of their status carry on leading 'secret lives' for fear of the consequences of disclosing their status to those around them.

**Timur Abdulaev, 29 years old,  
Tashkent, Uzbekistan**

In early 2006, I underwent an HIV test as part of a requirement to get an Egyptian visa. The test came back positive. Do I need to explain my feelings? I think not. I was young, had never had blood transfusions or used drugs, and was very mindful about condoms. I did not have the perception that HIV is a problem only for some 'marginalized groups' or that I couldn't contract HIV. But the diagnosis still came to me as a very unpleasant surprise.

I have to say that I am not a 'typical' case of a person living with HIV for my country and probably for the entire region, where intravenous drug use is clichéd as the main driver of the epidemic, and a 'regular' HIV-positive person is usually thought to be using drugs. Does this affect public attitudes towards people living with HIV? Of course! Just like in the West, where at earlier stages of the epidemic an HIV-positive man would be taken as gay, the first question that I hear (or read in the eyes) is "Do you, a person with a Master's from a British university and a good job, use drugs?"

This is not the only aspect of my being a non-typical case. I speak openly about my status. I have done so almost from the very moment I learnt that I'm positive. I know people who have lost their jobs because of HIV. I spoke openly about my being positive at my workplace. Did I lose my job? No. I think when you *know* your rights and how to protect them, you won't lose your job. Knowledge and persistence are great powers, believe me. But did I feel stigmatized? Again, no. I don't really know why. Maybe it was because my colleagues knew me well before they heard about my HIV status, or maybe it was because I wasn't a typical case. Or maybe it was because I did not stigmatize myself?

My wife is not HIV-positive, and I hope she will never be. We met before I found out about the diagnosis. But even after that she was the first one to learn about it. The news struck her probably even more than me, but she accepted it, as I did. Finally, after several years of being together, on the 8<sup>th</sup> of August, 2008 (08.08.08!) we got married, which made me the happiest man in the world.

Shortly after marriage, I started taking ARVs. Even though my CD 4 count was pretty high, I needed ARVs to bring down the viral load, so that we could have a child without risking my wife's health. I love being a husband, and I'm dreaming about becoming a loving parent.

I had health problems a while ago, but – thanks to free treatment available from the AIDS Center and the support of my wife – I got better. At the moment I'm pretty good, and I recently started working as an employment specialist for a joint project of UNDP and the Uzbek Ministry of Labor. By the way, my colleagues knew about my status from the beginning and, as you see, I got the job!

What can I say about social exclusion? It exists everywhere, probably. But it is my belief that it pretty much depends on the person, rather than on the environment. Certainly, there are places where it doesn't matter how courageous you are; when people learn about your diagnosis they make their conclusions and there is hardly a force that would be able to make them change their minds. But I saw so many people from so called "marginalized groups", who were able to change their lives after they discovered their positive serostatus: HIV literally made them stronger, smarter and healthier! Their lives became *positive* in many senses, you see!

When people ask me what I think about HIV, I say that to me it is *a curse, a test, and a gift* – all in one. Because of the virus, there are many new things which don't seem so nice, such as regular medical checks, treatment, or even a need to get a special waiver in order to be allowed into the US. But, just like any other serious trouble, HIV made me re-think my life, review values, maybe even become wiser. To me, my diagnosis was a kind of rebirth. I started appreciating every moment of my life as if it was the last one.

We, people living with HIV, are not different from those without the virus. You can't say that

every HIV-negative person is good, just like it would be wrong to say that every HIV-positive person is bad. What is important is what we are and how we see ourselves. If we waste our lives, why should others respect us? If we consider ourselves victims or disabled – mercy will be the attitude we will get. I believe – and this is actually what psychologists say – that people take us in the way we take ourselves, and it absolutely does not matter if you have a virus or not!

**Svetlana Izambaeva,  
Kazan, Russian Federation,  
winner of the "Miss Positive Russia"  
contest**

When I found out I had HIV the first thing that came into my mind was that's it, my life is over. There's no future. I don't want to study; I don't want to work; I don't want anything. The respect that I have gained over 22 years in my village, in my town, was all of a sudden gone. I thought people would fling apples, or stones, at me. It was a shock to me.

I have acknowledged my status. I realized that I can live with it. Being HIV-positive is not a shame. This is just a new chapter in your life.

I feel perfectly well at the moment, I love life. I'm loved, I'm happy, I have a wonderful, healthy child who loves her mom. Her name is Eva-Maria. My husband is also HIV-positive.

This is a new chapter for me – I help people. Initially, I was at a stage where I had to get enough information in order to overcome my inward stigma. Now, I'm at a stage where I share my experience, talk to other women, other HIV-positive people.

I hold support group meetings for women who are living with the HIV. Right now we are planning on developing several projects to propose to state and foreign organizations. We registered our fund and I, Svetlana Izambayeva, am the chair. I have my own programme on helping people who are diagnosed HIV-positive. I want to help, coming from a woman's standpoint. If we invest in women, if women invest in other women, we'll see better, healthier and happier families. And I have certain programs developed that I would like to implement. We have to become more open; we have to speak about this issue. We should reach the stage where we are able to tell society, "Yes, I'm HIV-positive!"

So what? I can live with this.” Society should also be more tolerant towards this. This is also a problem we have to work on.

**Marina Britvenko, 36 years old,  
Saint Petersburg**

*Inferior treatment for people living with HIV provided at general polyclinics is an important area of health care vulnerability*

I was addicted to drugs when I was young. As a result I contracted HIV, hepatitis B and C and tuberculosis, all of which caused me a lot of problems in my family and society and brought pain and disappointment. When I look back on my past I feel shame and fear, but when I think about the present, I feel happiness and my heart is full of forgiveness and gratitude.

I have been living a healthy life, free from drugs for over ten years now. I married a great person and my son was born absolutely healthy. Marrying an HIV-negative man made me understand that love can overcome and break through all barriers, giving you the power to move forward and stand up when life seems to not make any sense. Such love gives you the chance to start your life with a clean slate despite previous mistakes. Anybody can make a mistake, and everyone has the chance to start a new life.

I am happy because people close to me love me. They help me and do not judge me. I have a very interesting job and I work with people who have problems similar to mine. And I want to say that the face of the HIV epidemic is the face of millions of people on earth. Life is beautiful and very interesting, even if you have HIV or TB. You just need to make the effort to change the situation and be happy.

Movies about the Second World War often show wounded and disabled soldiers coming back from the war and being accepted as they are because their families love them. Today we have HIV and a lot of people with HIV live healthy, productive lives full of interest because they are accepted by society and family. Ignorance should not be a result of HIV-related problems.

## HIV-related vulnerabilities

Social exclusion and diminished human development opportunities related to HIV are shown in the daily challenges reported by people living with HIV. The qualitative research conducted for this report investigated how HIV

status translates into vulnerability in three major areas of human development – health, education and employment.

## Vulnerabilities in the health sector

Participants in the qualitative research described access to high quality health care as the issue of primary importance for people living with HIV. Due to their health status, disruptions and compromises in the quality of health care, particularly HIV-related health services, can worsen their illness, reduce their opportunities for engaging in society and possibly increase their chance of transmitting HIV to others. Stigma and discrimination against people living with HIV was reflected in substandard health services provided at polyclinics, hidden health care expenses and sometimes even denial of service provision. Stigma and discrimination among health professionals appeared to be rooted in inadequate education, training and hospital resources for providing services to people living with HIV and, importantly, adequate Universal Precaution protocols and materials to ensure the safety of health workers.

Four main issues related to health care barriers were observed from the data: (a) inferior HIV-related health treatment at polyclinics compared with specialized AIDS centres; (b) hidden additional costs for HIV and AIDS services; (c) inadequate staff training and resources; and (d) explicit health care professional biases against HIV and AIDS patients.

The first area of health care vulnerability described by respondents was inferior treatment provided at general polyclinics. Health provision for people living with HIV in the six countries generally follows a model of segregated services for HIV- and AIDS-related needs. Specialized AIDS centres provide services such as antiretroviral medications, diagnosis and treatment of opportunistic infections, and assessment of viral load and t-cell count. General health services are provided at polyclinics which treat basic health matters or at other specialized centres, such as dentistry or gynaecological clinics. This system of bifurcated (general versus specialized) care allows people living with HIV to receive support for their HIV-related needs in one environment, where they might feel more comfortable being open about their health concerns.

Participants consistently reported that attitudes and professional skills of medical staff varied according to the site of health provision. Medical staff who worked at specialized AIDS centres and who, by definition, regularly interacted with people living with HIV were described as having more humane and understanding attitudes to their patients, less fear of HIV infection and stronger skills at providing symptom diagnosis, treatment and counselling. By contrast, medical staff at non-HIV specialized clinics were less adept at working with people living with HIV and more likely to express stigmatizing attitudes and discriminatory treatment.

A second area of health care vulnerability for people living with HIV was the hidden extra costs for HIV and AIDS services. Although national policies stipulate affordable or free HIV- and AIDS-related services in countries throughout the region, participants noted financial burdens incurred when seeking health care.

The need to travel long distances to access health services was a major challenge. In most countries, specialized AIDS clinics are located in urban areas, such as Istanbul or Ankara, Moscow or Kiev. Rural inhabitants described spending entire days travelling to and from AIDS clinics. In addition to transport costs, patients lost daily wages for themselves and accompanying family members.

Participants described having to provide or to pay for medical supplies used in their treatment, such as in Uzbekistan where certain drugs and syringes must be purchased by the patient, and in Chelyabinsk and Irkutsk in the Russian Federation, where patients had to buy medical examination materials such as gloves, cotton pads and bandages. In some countries, it was reported that medical staff expected bribes to deliver treatment to people living with HIV. In Ukraine, in two cases 'informal payments' were demanded. One respondent recalled a health facility not admitting an HIV-positive pregnant woman into a maternity house until they received an additional payment, and another Ukrainian man reported being refused hospital services because of his HIV status, but later being admitted after his mother paid an additional fee.

### Box 2.6. Experiences of prejudice in contacts with health services

*One of my acquaintances had a partner and she didn't know he was HIV-positive. When she was in her 6th month of pregnancy, she went to an antenatal clinic to get registered and she was told she was positive – then she heard many negative words about her. Later, when she came to another hospital, the contractions started but she was simply refused to be accepted. She was told they were not going to soil themselves with her, although she had brought the whole set – even nappies in order to lie on her own things to deliver the child. She was humiliated, insulted and she said she just left in tears and decided to bear her child right in the city garden.*

– Person living with HIV from Ukraine

*I went to a physician some time ago. He wanted me to take off my T-shirt. But when he saw my diagnosis on the paper, he did not even touch or examine me.*

– Person living with HIV from Turkey

*I had problems during deliveries. In our ward we had drug addicts with lice, prostitutes, all sorts of beggars ... I was paying for a good ward, but [was assigned to a ward] for all sorts of street beggars. [The ward personnel] refused to do Cesarean deliveries for HIV-positive mothers, but this increases the risk of infection for a child ... They said, "Maybe you should deliver the child yourself."*

– Person living with HIV from Russia

*The first and the only wish of doctors – if they have suspicions that a patient is HIV infected – is to get rid of him/her as soon as possible and to send him/her to a specialized medical establishment, AIDS centres, in particular. This is even though, according to the legislation, sick people have the right to get specialized medical care at regular polyclinics and hospitals, while AIDS centres specialize in opportunistic infections, therapeutic assistance and so on.*

– Health professional from Ukraine

Source: Regional HIV Vulnerability study, UNDP (2007)

Respondents in a study of people living with HIV in Macedonia also pointed out the financial difficulties brought about by both the burden of the high cost of medical care and of their reduced earning capacities due to stigmatization. Due to high prices and the reduced earnings, only 27 percent of respondents reported that they can afford the medications they need. The lack of access to medicines undermines health, further reducing earning power and the self-esteem that comes with productive work.<sup>60</sup>

*Hidden extra costs for HIV and AIDS services is another important area of health care vulnerability*

<sup>60</sup> Viewpoints of the HIV/AIDS infected in The Republic of Macedonia, UNDP Macedonia, 2005.



### Box 2.7. Insufficient knowledge and resources in the health sector

*We do not know much about the illness. It would be good if the State finances a program and invites a lecturer, who will discuss with medical specialists.*

– Health professional from Georgia

*During our training visits to the periphery, when you tell a nurse to use gloves while having lessons, she laughs. I asked one why she laughed, and she said they have no gloves. They were never given gloves, they say.*

– Doctor from Turkey

*Yes we do have protective equipment. But they are not always in sufficient quantities. For example, the doctor sees 25-30 patients per day 25-30, which makes 25-30 gloves! And they are not always available in such number.*

– Doctor from Uzbekistan

*Perhaps it is lack of tailored specialists because doctor-infectiologists know something about HIV. Highly tailored specialists are needed here that can treat with background knowledge of HIV infection. We don't have enough of such specialists.*

– Person living with HIV from Ukraine

*Generally speaking, the best method of curing the disease is isolation. And do you remember leprosy? A terrible disease that could not be cured, only by isolation... So perhaps for those [PLHIV]... if the prison is already a place for such hopeless people, perhaps these prisons already exist.*

– Doctor from Estonia

**Source:** Regional HIV Vulnerability study, UNDP (2007)

*Outside of specialized AIDS centres, health providers often lack basic training on HIV epidemiology, transmission, prevention, counselling, rights issues and treatment*

A third area of vulnerability in the health sector for people living with HIV was related to inadequate staff training, professional capacity and resources. Respondents described health service clinics as understaffed and underfunded, especially in rural areas serving poorer populations. Outside of specialized AIDS centres, health providers lacked basic training on HIV epidemiology, transmission, prevention and treatment. Universal precautions were not consistently known or practiced, and physicians perceived themselves at high risk for infection, as stated by one Estonian physician: "We [the medical profession] are actually a risk group. I belong to the risk group". In Turkey, health professionals commented on the lack of protective tools and technologies – such as latex gloves, needle dispensaries and post-exposure prophylaxis –

and described reluctance among medical personnel to treat HIV-positive patients. In Georgia, health care professionals discussed inadequate resources and protocols for treating HIV-positive patients. Similarly, an Uzbek physician explained that doctors cannot protect themselves or their patients properly and that, despite the policy of treating all patients as people living with HIV, doctors acknowledge that often this does not or cannot realistically happen due to limited time, training and material resources.

The fourth area of health sector vulnerability relates to accounts of explicit and blatant discrimination against people living with HIV seeking health services. One scenario that occurred across countries was the refusal of physicians to treat people living with HIV, for fear of their clinic being associated with socially stigmatized patients. Another common attitude described by physicians was a preference to isolate people living with HIV in hospital settings as a way to minimize potential transmission.

Some health professionals questioned the appropriateness of allocating increased attention and health services specifically to HIV in contexts where prevalence remains low and where other health problems are under-resourced. For these physicians and administrators, 'special' services for people living with HIV were a source of frustration and disagreement.

### Vulnerabilities in the education sector

In contrast to the detailed narratives about health sector vulnerabilities, accounts of stigma and discrimination against people living with HIV in the education sector were less detailed and appeared to be based predominantly on hypothesis and conjecture. This may be because few adult participants living with HIV had recently pursued education, and because parents might not disclose their own or their children's HIV status to schools. However, this analysis indicated that schools are generally unprepared for the enrolment of HIV-affected students, despite the fact that the issue becomes more urgent as the number of school aged children living with HIV increases rapidly in some countries of the region.

One issue that participants did speak of is the need to respond better to HIV-positive school children and to children whose parents are living with HIV. Few known HIV-positive students are currently enrolled in primary or secondary schools or in universities in the region, which might reflect low rates of disclosure. Parents living with HIV and parents of HIV-positive children described anxiety regarding school-based stigma, discrimination and bullying towards their children. Teachers and school officials showed disturbing trends favouring segregated classrooms for HIV-positive children. Teachers and school officials also described a lack of policy guidelines for enrolling and working with HIV-positive children in their classrooms, and were concerned that other parents would remove their HIV-negative children from school if an HIV-positive student were to be enrolled. Notably, the narratives from this study focused on education for school-aged children rather than university education for adults, which did not appear to be a salient issue in this sample of participants. Additional research is necessary to examine barriers to university education for people living with HIV.

Three specific issues emerged across countries regarding HIV-related vulnerabilities in the education sector: (a) mandatory disclosure of students' HIV status; (b) negative responses from other school children to HIV positive students; and (c) separation and segregation of children.

#### **Forced disclosure of students' HIV status.**

Participants described that in many countries of the region, health certificates are required upon enrolment, thereby effectively coercing disclosure of HIV-status. For example, Russian and Ukrainian participants described having to present a child's full medical history to new schools, which contain both the child's and the parents' health information. Disclosure was also reported to be an issue for adults seeking education, due to restrictions barring HIV-positive individuals from working in certain professions (e.g. health care) and requirements to disclose their status when entering these fields. According to participants, disclosure of the child's or parent's HIV status leaves them vulnerable to stigma and discrimination by teachers, other students or families in the school community.

There were mixed attitudes toward mandatory school disclosure policies. Some participants

favoured these policies as protective of HIV-positive schoolchildren – so that teachers and nurses could respond to students' health emergencies – and potentially protective of other children and staff, in avoiding potential con-

#### **Box 2.8. Kyrgyzstan: Stigma translated into personal vulnerability**

In Osh, Kyrgyzstan, nosocomial transmission in hospital settings has left at least 76 children HIV positive in recent months. UNICEF and partners, under the programme '*Social Support for Families Suffering from HIV*,' is working to ensure a continuity of medical and social services to enable children and their parents to resume healthy and productive lives.

But stigma and discrimination, at health facility and community levels, have posed the most severe challenges to affected families. Two mothers, Nurjan and Farida, describe the challenges experienced.

"When your child is unwell, you become aggressive, embittered towards the whole world." Until he was three, Nurjan's son was a very active, clever boy and a fast developer. Then he contracted meningitis at kindergarten. "For those three months, when we lay with him in intensive care, I had to pay for everything – for the room, for the medicine, pay the nurse for injections, pay the doctor to make sure he was well looked after, and pay the auxiliary for cleaning the room," cries Nurjan. "And what did I buy? I bought HIV for my son!" she says in despair.

Her son will soon be four and a half. He cannot eat by himself, dress himself or look after himself, and he has stopped developing. The child needs constant care and so his mother, who has two university degrees, cannot work and experiences financial strain. Her husband abandoned her and left for Russia. His relatives blame Nurjan for the child's illness and have practically disowned the boy, though neither they, nor Nurjan's own parents, yet know that the child has HIV. "They've had enough hardship in their lives as it is," cries Nurjan. "Why kill them with this?"

"We've been in a state of shock for a year and a half already," says Farida, the mother of another HIV infected child. "We don't even know now who needs help more – our sick children or us ourselves. It's like a vicious circle. A child with HIV needs better food, constantly needs to be given expensive medicines, and we are so poor, and have other children. What will happen to them?" the unfortunate woman asks. "When my husband found out what trouble we had got into he threw me out of the house and told me to 'go and live where you found AIDS!' Besides, everyone in the village – from 7 to 70, knows that we have AIDS in our family, and everyone makes gestures with fingers, and jumps away from us in the street," cries Farida, a young woman whose life has been divided into 'before' and 'after' HIV.

*Representatives of the education sector agreed that other parents would remove their children if an HIV-positive student was enrolled in their school*

tact with blood. Parents generally acknowledged the need to report their children's HIV-status to school principals and nursing staff, but did not feel this information should be shared with other teachers and parents. However, many parents were cautious of potential discrimination and rejection from biased principals, teachers and other parents.

**Negative responses from other schoolchildren to HIV-positive students.** Teachers and school officials expressed concern that HIV-positive students would be targets of stigma by their peers. For example, Uzbek educators cautioned that disclosure of a student's HIV status would result in school bullying by other students. This observation suggests that schools can be potentially unsafe spaces for young stu-

dents living with HIV, who might be victimized by their peers. A Ukrainian representative commented that students living with HIV might be vulnerable to internalized stigma, which can contribute to educational challenges and a feeling of social isolation.

Many parents living with HIV felt anxiety around stigma directed toward their HIV-negative children in the classroom and schoolyard. Some parents chose not to disclose their HIV status to protect their children from discrimination or mistreatment.

**Separation and segregation of children.** Teachers and school officials expressed concern that enrolment of HIV-positive children would lead other parents to remove HIV-negative children due to fear of potential transmission. For example, in Georgia, all representatives of the education sector agreed that parents would voluntarily remove their HIV-negative children if an HIV-positive student was enrolled in their school.

School administrators discussed financial implications due to the voluntary removal of large numbers of HIV-negative students, and spoke of a potential financial pressure to refuse entry of HIV-positive children. School officials in Ukraine described an instance in which "other children's parents got to know about it [admission of an HIV-positive student] and immediately wrote a letter asking to expel this child from the kindergarten" and that "not a single headmaster will act against parents' will." Uzbek respondents also reported parent-induced pressures on school administrators to exclude HIV-positive children from schools.

Consequently, general community stigmas and fears towards HIV and their children among school children could impact on school attendance, enrolment rates and the financial viability of schools. School officials feared the hypothetical economic implications of reduced classroom sizes that would result from large-scale student withdrawals.

## Vulnerabilities in the employment sector

Employment sector vulnerabilities for people living with HIV are linked to the overall economic state of the country. Although most

### Box 2.9. Stigma against children living with HIV and conflicting attitudes toward school segregation

*When asked "Would you like your child to be in the same class as HIV-infected kids?" parents answer, "No, it would be better to create a boarding-school for them, so that they are schooled separately." And it is parents that say this more often, they are more scared than students and children. There are even health care workers who have no understanding of this issue and similarly to parents say, "And why should they be together?" Senior people also talk about isolating the infected ones.*

– Teacher from Ukraine

*Yes, they are really dangerous. I think that such children [living with HIV] should not attend neither schools nor kindergartens as the other children will not be safe.*

– Teacher from Georgia

*In my opinion, [segregation] is absolutely wrong, as it will bring up a young man with anger against the society that was discriminating against him. This fury may force him to stab someone in the bus with an infected syringe. Where is the guarantee that we will not be infected? And simply because he is angry, and this bad feeling has been inside him since his childhood.*

– Teacher from Russia

*I don't think that HIV-infected kids should be isolated from other children in any way or limited in something. They are not impaired... We can't create certain conditions for them in some boarding school and collect them there, as some suggest. What will they see there? They're already growing up feeling confined and uptight. They should study among other children, communicate the same way as others, get the same education.*

– Teacher from Ukraine

**Source:** Regional HIV Vulnerability study, UNDP (2007)

areas in the region are marked by general employment difficulties, people living with HIV described particular challenges in obtaining and maintaining employment. In addition, employers and managers participating in focus groups described hesitations in hiring HIV-positive job applicants, though were more likely to be sympathetic towards existing employees who had been recently diagnosed. The results suggest that improving the clarity of anti-discrimination policies and workplace guidelines for protecting employees living with HIV is essential.

**Barriers for people living with HIV seeking and obtaining employment.** Participants living with HIV showed a high sensitivity to the potential for employment-related stigma. Almost all of the respondents said that obtaining a job would be impossible if they disclosed their HIV status during the application process. Respondents living with HIV from Estonia, Georgia, Russia, Ukraine and Uzbekistan shared similar accounts, fearing rejection due to disclosure of HIV-status.

Perhaps owing to the challenges in finding work whilst also dealing with their HIV status, many non-working respondents lacked motivation to seek work and resigned themselves to unemployment or participation in the informal work sector. For example, a well-educated Georgian woman living with HIV said that her HIV status would keep her from being hired or relegate her to low-level or manual labour.

Many employers participating in focus groups remarked that, given the choice between hiring an applicant living with HIV versus one without HIV, their inclination would be to hire the candidate who posed fewer perceived problems to the work environment. One representative of Georgia's employment sector declared, "Why should I employ someone with HIV and spend more on an infected person when I can employ someone else".

Because of the potential for discrimination against job applicants living with HIV, many participants who had sought jobs did not disclose their HIV status. When asked to provide certification of their HIV status, some participants provided falsified documents or paid bribes to keep their status secret.

**Challenges in the work environment for people living with HIV.** Respondents who held

steady jobs described a range of challenges in their day-to-day work life due to their HIV status. Some spoke with fear that their status would be discovered and, consequently, that

### **Box 2.10. Albania: Overcoming rejection by peers – 'mission possible'**

In Albania, a mother living with HIV has used her professional experience as a lawyer to fight for the rights of her twin boys to education, challenging institutional and community stigma and discrimination.

When she first discovered that she was HIV positive, Teuta was devastated. "The first effects are shocking. It is not easy at all to have a positive HIV result. And for a parent, the first thing that comes to your mind is your children. Who was going to take care of my children? Who...?" Teuta's fears were confirmed when her children were denied access to educational support. "I had been waiting for an answer from the Ministry of Education for two years, but I received only silence. My children are considered as belonging to one of the groups in need, but the state does not give them any financial support. I pay taxes like the rest of the citizens, but I do not receive basic public services back, such as the education of my children," Teuta says. Other parents protested over the school enrolment of Teuta's children: "Take your children with you and kill yourselves, all of you, and leave us and our children alone."

But rather than acquiesce, Teuta fought back. She organized meetings between physicians, educators and parents in the community to dispel myths that her children could infect their children. Teuta received support from the school, and teachers communicated with other parents the law, which assures children access to education. Teuta's struggles prevailed, and her sons were admitted to school. She reflects, "The entire neighbourhood was alarmed by my children starting school. They all talked about that only, seeming to have forgotten that we had been living there for years and had not caused trouble to anyone. How can people be so selfish?"

Now, Teuta has established the Albanian Association of People Living with HIV/AIDS and feels that she has gained the support of others like her. She encourages others to fight against stigma and discrimination, for the sake of oneself and one's children: "It is not easy to fight against the mentality of an entire society. Now I understand and I know that one has to work hard in life and never give up. Giving up is the simplest action in life. I chose to fight... I have fought for making my life longer, because first of all I am a mother and while fighting for my life I fight for that of my children."

She is optimistic about the future of her family: "My biggest dream is reaching the moments when HIV is not a 'permanent guest' in my family and see my children growing healthy...We even today have a lot of beautiful and happy moments together. I see joy and happiness in my children's eyes."

(UNICEF story credit: Valbona Sulçe, author and Ilir Baçi, translator)



### Box 2.11. Barriers for people living with HIV seeking and obtaining employment

*I know beforehand my status will certainly hinder the chance to get job or to be promoted... I do not search for a job as I think they will have a negative attitude towards me.*

– Person living with HIV from Georgia

*When I was choosing the job, I tried to see that it was not physically tough. Because I always bear illnesses with problems – when I had a flu, I spent two weeks in bed with 40-degree fever, and it did not go down. I am always taking medicine.*

– Person living with HIV from Russia

*A friend of mine faced it, in food industry she could earn good money, but she didn't go there, because she had to disclose her status, and she was forced to go do work that didn't correspond to her education – and with a lower salary.*

– Person living with HIV from Ukraine

*You may interpret it as you wish, but I would not receive an infected person even for office work. I have such presentiment. They say the disease does not spread by respiratory means, but who knows. Why should I take the risk?*

– Employer from Georgia

*It seems to me that our society is not yet ready to work with somebody with HIV. Just imagine – an HIV-positive primary school teacher comes to a school and says, "Employ me." I'm 100 percent sure that nobody will hire him.*

– Person living with HIV from Ukraine

*There is an HIV-positive employee in a firm, whose management are very attentive to him because he's a good expert. And this person receives ART in Kiev. His managers understand his visits to the capital for the treatment, and they even help him financially to cover such trips. It depends a lot on the personal element – how the management will take it.*

– Person living with HIV from Ukraine

**Source:** Regional HIV Vulnerability study, UNDP (2007)

they would be mistreated by colleagues or fired. One Russian professional stated that disclosing his HIV status would invite comparisons with socially marginalized people, and could be grounds for dismissal.

Respondents who were employed also spoke of the delicate intersection of HIV status and work performance, and of the challenges

each posed for the other. For example, respondents with compromised health states described lacking stamina and strength to perform physical forms of work, including lifting objects, standing or walking long distances, and working extended hours. Respondents also described that demanding and high-pressure jobs could worsen their health. Many needed extra time to rest, eat and attend to their health needs during the work day, although some jobs did not permit these time allowances. One Ukrainian respondent reflected, "I know, for example, that I have to eat regularly. And I understand at once that if I work in a bank, with a computer, I'll be able to go out only during lunch." This issue was compounded by a fear of disclosure and negative consequences: participants feared that requesting flexible time to attend to their needs or taking HIV medications while at work would risk involuntary disclosure of their HIV status.

Not all accounts of being a person living with HIV in the workplace were negative. Some participants described colleagues who were aware of their HIV status and who expressed genuine compassion. Several employers spoke with concern about ensuring the job security and protecting the health of existing staff members who had disclosed their HIV status. Narratives were suggestive that, after disclosing their status to valued colleagues or trusted supervisors, some workplaces can potentially be supportive of the health and employment needs of HIV-positive individuals.

**Gaps in employment policy for the protection of people living with HIV.** Throughout individual interviews with people living with HIV and focus groups with employers, respondents described a weak policy environment for protecting employees with HIV. A critical and consistent issue was the lack of awareness of, and mechanisms to enforce, legal protections against mandatory pre-employment HIV testing in most workplace settings. For example, Georgian law stipulates that only specific occupations can exclude people living with HIV for safety issues; however, Georgian individuals and employers alike were unaware of an official list of occupations from which those with HIV are excluded. In Ukraine and Russia, people living with HIV described that pre-employment HIV tests are not required for low-skill jobs, such as cleaners, but are required for more desir-

able or professionally skilled jobs. Participants also described socioeconomic differences that underlie employment discrimination for people living with HIV: supervisors and colleagues were generally more supportive of professional and affluent individuals living with HIV, but those in low-skilled jobs were generally considered ‘replaceable’ and more vulnerable to discrimination and inappropriate firing.

Notably, people living with HIV from across country sites described a lack of confidential legal recourse in the case of unfair job dismissal or workplace mistreatment. By bringing forward allegations of job discrimination or wrong-doing, people living with HIV would risk greater disclosure of their status and could find their names reported in the media.

Employers expressed confusion over safety concerns and lack of guidelines about work-site considerations for employees living with HIV, such as providing additional time off for medical appointments, on-site equipment such as latex gloves and bandages, and protocols for addressing health emergencies.

Although most countries included in the study have legal policies prohibiting discrimination in the workplace, individuals and employers alike described their legal frameworks as being underdeveloped and un-monitored. For example, in Turkey employers reported that they can “usually dismiss HIV-positive employees under pretexts that are legally acceptable.” In other cases, such as Ukraine, the process of prosecuting an employer would not be sufficient to set new legal precedent due to variability and laxity of legal institutions.

## Gender dimensions of the epidemic

Since the early registered HIV cases in Eastern Europe and the CIS in 1996, the face of HIV has largely been thought of as young men. However, as the epidemic spreads and HIV is increasingly transmitted through heterosexual contact, new infections among women and

### Box 2.12. Challenges for people living with HIV in the work environment

*A sewing factory learned that a female employee was HIV-infected. So [the employer] forced all employees to pass HIV test and fired her. Naturally he could not give HIV as the reason, but they found other ways to fire her.*

– Person living with HIV from Russia

*We have a friend living in [name deleted] city. He is a worker and he can’t carry his medication with him since he has an unlocked shared locker. He can’t use his medication because he fears his friends will learn about his situation.*

– Person living with HIV from Turkey

*There was a case in Poltavaska oblast when a man was forced to resign because he was HIV-infected; the staff didn’t want to work with him, so the director fired him. Unfortunately, information about his HIV-status leaked and he was forced to resign.*

– NGO representative from Ukraine

*People cannot seek for their legal rights in order not to be disclosed. If you bring this case to court, you can never be sure that your name will not be mentioned in the newspapers, that you will not be disclosed with your pictures in the newspapers. Therefore, people do not bring these cases to court.*

– Person living with HIV from Turkey

*If an employer finds out that one of his employees is HIV-infected, he will not take any legal measures, or illegal steps. He will make sure that all of the other workers know about [the HIV status] and the person will leave, as he/she will not be able to work anymore in this company. Everyone will treat him differently, even without saying anything. He will quit.*

– Person living with HIV from Russia

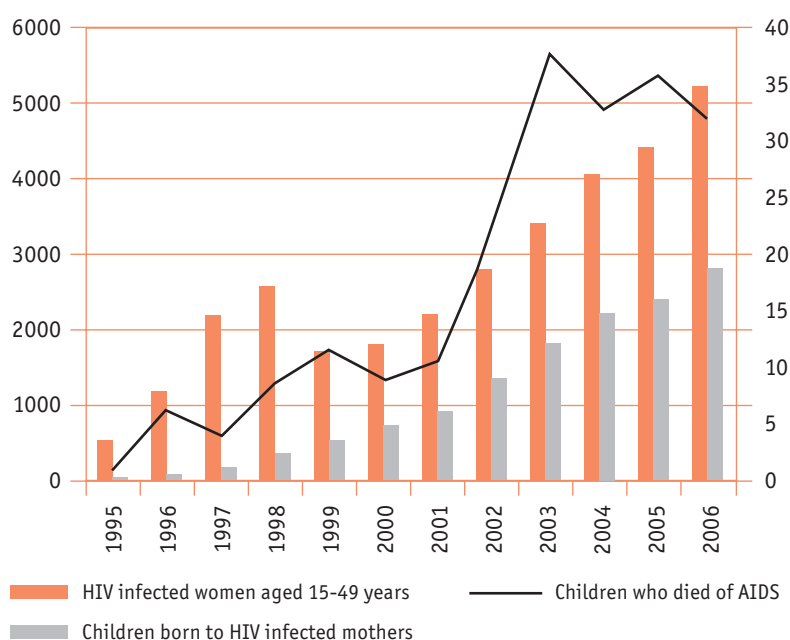
Source: Regional HIV Vulnerability study, UNDP (2007)

children born to women living with HIV have grown, indicating a shift in the nature and trajectory of the epidemic. In 2006, about 40 percent of newly registered HIV cases in the region were among women.<sup>61</sup> It is estimated that approximately 50 percent of women in the region living with HIV were infected by their male partners and that 35 percent were infected through injecting drug use. The following graphs below depicts a marked rise in women living with HIV and children with HIV-infected

<sup>61</sup> EuroHIV 2007, Eastern Europe and Central Asia, AIDS Epidemic update, Regional Summary, UNAIDS/WHO, 2007, p. 2.

**Figure 2.8. Dynamics of the number of HIV-positive women in reproductive age and children born to HIV-positive mothers in Ukraine in the period of 1995–2006 (absolute number).**

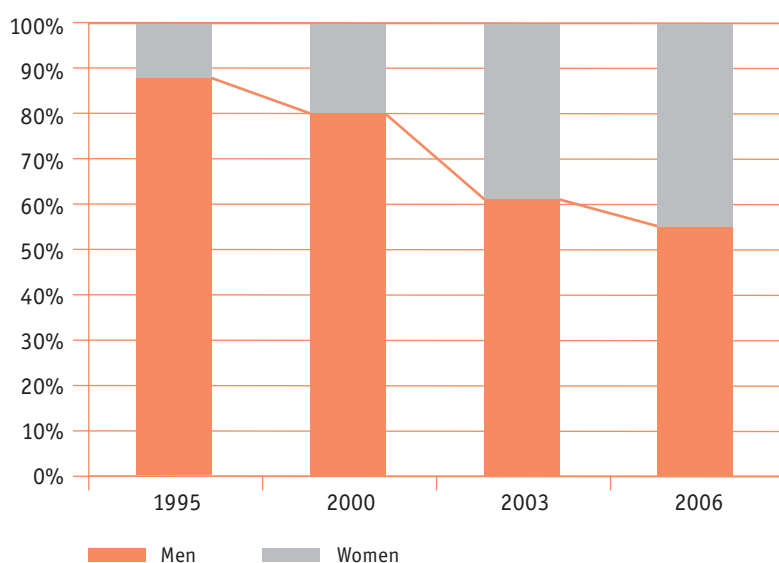
Gender dimensions of the epidemic's impact



**Note:** The decrease in the number of people living with HIV in 1999–2001 was connected with a decreased number of tests, which in turn was caused by introducing the legal principle of voluntary testing. Based on HIV Infection in Ukraine. Informational Bulletin No. 27, Kyiv–2007

**Figure 2.9. Share of newly registered HIV infections by sex, 1995–2006, Russian Federation.**

Share of newly registered HIV infections among women and men, Russian Federation 1995–2006



Based on Vadim Pokrovsky (2006). The HIV/AIDS Epidemic in Russia: trends, lessons, and key challenges and opportunities for scaling up response

mothers in Ukraine during the previous decade and a growing proportion of women living with HIV in Russia:

In 1991, the United Nations Commission on the Status of Women adopted the landmark Resolution 35/5 which addressed women's vulnerabilities for HIV infection: "Women and the prevention and control of acquired immunodeficiency syndrome (AIDS)", followed by a more nuanced statement in 2008, Resolution 25/4 on "Women, the Girl Child and HIV,"<sup>62</sup> which focused on gender-related HIV vulnerabilities throughout the life cycle. Gender relations – particularly disparities in accessing information, assets, generating livelihood opportunities, negotiating safer sex and protecting themselves from HIV – play a crucial role in the vulnerabilities to HIV for both women and men.<sup>63</sup> A gender analysis of HIV and AIDS ensures meaningful insights into strategies for improving the health and well-being of women and men in families, communities and societies in the region.

Box 2.13 presents a summary from this report, entitled 'Monitoring the Rights of Women in the Russian Federation: A Thousand Women's Stories,' which highlights experiences of discrimination, stigma and violation of basic rights for pregnant women living with HIV.

The types of HIV-related vulnerabilities, as determined by socially defined gender roles, evolve over different stages of life. Vulnerabilities begin at the earliest stages of life, stemming from early exposure to cultural beliefs and stereotypes associated with male dominance and privilege, and with female submission and inferiority. These belief systems are likely to be internalized by girl and boy children alike, shaping the ways they see the world and the expectations they have of themselves as females or males. In each subsequent phase of the life cycle, these gender-related beliefs are manifested in the ways that females and males are prone to entering high-risk contexts or engaging in high-risk behaviours associated with HIV transmission. For example, deriving from cultural beliefs,

<sup>62</sup> UN Commission on the Status of Women, E/CN.6/2008/11, Resolution 52/4 on Women, the Girl Child and HIV/AIDS, 2008.

<sup>63</sup> UNDP corporate HIV Strategy, available at [http://www.undp.org/hiv/docs/alldocs/HIV%20Corporate%20Strategy%20\(2006\).pdf](http://www.undp.org/hiv/docs/alldocs/HIV%20Corporate%20Strategy%20(2006).pdf)

girls generally experience lower educational expectations and are encouraged to leave school early in order to marry, work, reproduce and care for the family. This may leave them unskilled and undereducated for adult life challenges, and renders them economically dependent on male family members (husbands or fathers). Boys too are exposed to early gender-role expectations that restrict their beliefs and behaviours. For example, cultural standards of masculinity and power may be associated with men's sexual risk behaviours, drug use, violence and aggression towards women. Following from this analysis, HIV policies and programmes need to address the specificities of gender-based vulnerabilities associated with each period within women and men's life cycles.

Examples described in Table 2.4 (on page 36) are based on research conducted in Kazakhstan, Kyrgyzstan, Tajikistan and Uzbekistan from 2007 to 2008 as part of a study of gender and HIV vulnerability in Central Asia.<sup>64</sup> Specific examples were selected to illustrate gender-based challenges and the need for transformative empowerment to address HIV. Notably, this analysis indicates processes by which males as well as females may experience vulnerabilities that contribute to HIV risk.

## Chapter conclusion

This chapter has outlined the major linkages between human development and HIV, with summary evidence arguing that the epidemic should be viewed through a development framework, addressing the underlying factors that contribute to and derive from HIV in society. Findings from a six-country qualitative research study identified vulnerabilities to stigma and discrimination for people living with HIV in the specific domains of health, education and employment. Addressing the challenges of the epidemic also has clear social dimensions. 'Including the excluded' (e.g. people living with HIV, or members of disadvantaged populations at risk for HIV) can substantially benefit societies in the region due to the public health, development and economic impacts associated with greater

### Box 2.13. Excerpt from "Monitoring the Rights of Women in the Russian Federation: A Thousand Women's Stories": On the challenges experienced by pregnant women living with HIV

The majority of Russian women living with HIV are in their reproductive years. In 2007 alone, 8,000 Russian women living with HIV gave birth to a child. Challenges in Russia associated with the epidemic have shifted due to improvements in access to antiretroviral treatment. People living with HIV are now surviving longer, but their long-term social vulnerabilities warrant attention. Pregnant women and mothers might be particularly vulnerable to stigmatizing consequences of HIV status due to interactions of gender and illness. This project involved 40 interviews with pregnant women or mothers living with HIV in St. Petersburg between 2005–2006. The aim was to examine and analyse violations of rights and discrimination against pregnant women and HIV-positive mothers.

Among the most striking issues identified were unacceptable forms of **abuse and neglect by doctors and health providers against women living with HIV.**

*The attitude is very bad, especially if one enters the hospital as a matter of urgency ... As soon as you are in the corridor they know about your positive status. That was in the [Name deleted] Hospital. I was brought there pregnant. [I] gave birth in the corridor by the window. I said that I was cold. "We can't do anything to help; we can't put you in on a bed. It's only for paid patients. We can't put you in a double, as they're for healthy people there. Only a single." We had to pay 700 rubles for only one day.*

– Nadezhda, 27 years old, mother of a 6 month old

Women expressed concerns about **stigma and disclosure of their HIV status in the community, workplace and at school.** Women's concerns ranged from the psychosocial consequences of isolation and alienation to the economic consequences of discrimination. They were particularly anxious about the impacts of stigma on their children.

*I went with my child to a normal polyclinic ... I didn't say anything to anyone, just that I lost my child's card. We wouldn't be accepted at school otherwise. The only thing that is problematic is vaccinations. It is very difficult to avoid showing the card. It is difficult to fool the kindergarten. The lines are enormous. If they find out that the child is from a family with someone with HIV – all is lost. It's better to deny under any pretext. You should forget and never think about having a good kindergarten for your child.*

– Natalia, 26 years old, mother of a 4 year old

The study documented cases of **unlawful disclosure of information** about HIV-positive status of women and their children in general hospitals, regional polyclinics and social institutions.

*We should have been observed at the polyclinic near my place of residence ... but I had to move. Medical secrecy is not preserved, I am convinced of that, because I have friends and acquaintances whose doctors told their relatives everything. I have been seen in the polyclinic. I had the card in my hands, but wouldn't leave it in the clinic as it would reveal everything about me to anyone who sees it. Anyone could come to registration, give my name, and be given the card...*

– Lilya, 22

These examples demonstrate some of the striking and unique challenges faced by women living with HIV in the Russian Federation. For the full report (in Russian only) "Monitoring the rights of women in the Russian Federation: a thousand women's stories" UNDP Russia 2008, see [www.undp.ru](http://www.undp.ru)

<sup>64</sup> UNIFEM fact sheet series in Central Asia, unpublished master's thesis of OECD College and ADB transport and HIV vulnerability project.



**Table 2.4. Examples of gender-related processes operating at different phases of the life cycle associated with HIV risk.**

Age group	Female	Male
0-4	Girl children may experience discrimination in nutrition and care compared to male siblings.	Boy children exposed to cultural standards of acceptable versus unacceptable male/female behaviour.
	<p>Low education expectations; pressures to leave school early, especially in rural communities, which might not prioritize resources to support female students' needs.<sup>65</sup></p> <p>Limited and inadequate sexual health education for girls, including information about pregnancy and reproduction, hygiene and sexually transmitted infections.<sup>66</sup></p> <p>Expectations to assume role of family caregiver.</p> <p>Cultural taboos pertaining to discussion of sexual relations; contributes to misunderstandings and silence about HIV, STIs.<sup>67</sup></p>	<p>Boys exposed to gender stereotypes of culturally acceptable sexual behaviours.<sup>68</sup> Emphasis on virility and dominance for males, virginity and submission for females</p> <p>In some undeveloped or rural areas, boys pressured to exit school early to work to support family.</p> <p>Cultural taboos pertaining to discussion of sexual relations; contributes to misunderstandings and silence about HIV, STIs.<sup>69</sup></p>
15-24	<p>Sexual and reproductive rights for women are not upheld. Females internalize the idea of subjecting themselves to males' sexual interests.<sup>70</sup></p> <p>Unwanted or forced marriage and bride kidnapping without consent are still practiced in some areas.<sup>71</sup></p> <p>Targets for human trafficking: Female trafficking has increased in the past decade throughout the region.<sup>72</sup></p> <p>Girls are expected to abstain from premarital sexual intercourse.<sup>73</sup></p>	<p>Normative social pressures to uphold masculine gender-role expectations pertaining to sex, drug use, other risk behaviours.</p> <p>Work migration patterns. Time away from home and family facilitates exposure to high-risk sexual situations, drug use.<sup>74</sup></p>
Adults	<p>Domestic violence.</p> <p>Economic dependency.</p> <p>Subordination of own needs relative to those of family members.</p> <p>Lack of autonomous access to resources, markets, training, services, information or assets.<sup>75</sup></p> <p>Low efficacy to use condoms, especially with husbands.<sup>76</sup></p> <p>Pressure to reproduce and raise children.</p> <p>Poor implementation of laws to protect the rights of women.<sup>77</sup></p>	<p>Pressure to economically support family<sup>78</sup> encourages seasonal migration.</p> <p>Gender norms restrict support seeking and encouraging unhealthy strategies to cope with stress, including use of alcohol and drugs as well as violence.<sup>79</sup></p> <p>Social norms that promote men's use of violence in the domestic setting.<sup>80</sup></p>
Aged	<p>Expectation to assume caring role for extended family, especially when adult males move away.</p> <p>Expectation to care for orphaned children.</p>	

social inclusion. Efforts to address the unequal status of women and girls and sexual minorities may be particularly relevant, as the HIV epidemic takes on a gendered dimension. Human development initiatives that aim to improve the well-being and opportunities of people living with HIV and people at risk for HIV in these societies must confront and address explicitly the challenges posed by HIV – an epidemic that will continue to persist, and quite possibly expand in scope and consequence.

65 Hsu, L-N, *Outcome evaluation of HIV programme of UNDP Tajikistan*, 14 January 2007, p. 9.

66 UNIFEM fact sheet, Kazakhstan, 2006.

67 UNIFEM Tajikistan and Uzbekistan fact sheets, 2005.

68 Ibid, 2006.

69 UNIFEM Tajikistan and Uzbekistan fact sheets, 2005.

70 UNIFEM funded research carried out by Panorama Public Foundation, Tajikistan, 2005.

71 *Gender dimensions of HIV/AIDS in Kyrgyzstan*, UNIFEM, 2005.

72 *Living in Violence*, FPH/SIDA/Counselling Against Family Violence, March 2008, p 16-17.

73 *Gender Dimension of HIV/AIDS in Kazakhstan*, UNIFEM fact sheet, 2006.

74 *Tajikistan GFATM HIV grant evaluation report*, UNDP GFATM PIU, 2006.

75 Asian Development Bank, 'Promoting rural women's entrepreneurship in transition economies,' ADB Technical Assistance Report, December 2007, p. 1.

76 *Statements for International Women's Day*, 8th March 2008, UNAIDS and The Global Coalition on Women and AIDS

77 *Promoting rural women's entrepreneurship in transition economies*, ADB Technical Assistance Report, December 2007, p. 1; and *Living in Violence*, FPH/SIDA/ Counselling Against Family Violence Joint publication, April, 2008, p. 5.

78 *Gender dimensions of HIV/AIDS in Kazakhstan*, UNIFEM fact sheet, 2006

79 *Knowing your epidemic in gender terms*, Ukraine gender and HIV assessment, UNAIDS/PCB(20)/07.11/CRP1, pp. 29-30.

80 *Living with Violence*, 2008, pp. 5-6.



# Chapter 3: Pillars of an effective regional response

## Globalized frameworks and national policies

HIV emerged on a significant scale in Eastern Europe and the CIS a decade or more after epidemics became visible in Africa, the West and South-East Asia. Consequently, Eastern European and CIS countries have the benefit of learning from experiences elsewhere and the challenge of adapting those lessons to their own epidemiology as well as to their own local social, political, and cultural contexts.<sup>81</sup> There is no exact analogy elsewhere in the world for the HIV epidemic in Eastern Europe and the CIS. There are similarities to parts of South-East Asia, with HIV initially spread through injecting drug use and then crossing over more into commercial sex, but important differences exist, including in the structure of the commercial sex industry. Eastern Europe and the CIS has a formal health care infrastructure that is closer to that of Western Europe than to Africa or South Asia, but much less of a tradition of civil society mobilization around health issues. The region can learn from others but must find its own answers.

## AIDS 'exceptionalism' in the regional context

Debates about AIDS 'exceptionalism' have abounded in policy discussions. This debate refers to whether HIV should be viewed as an exceptional epidemic – one that is unlike other global health problems – and be tackled with exceptional health and social policies. Early views about AIDS exceptionalism were based on concerns over the abuses of the civil rights of people living with HIV and argued that HIV responses should be governed by different policies from those that govern the approach to other infec-

tious diseases.<sup>82</sup> This early position of AIDS exceptionalism was supported by the notions that (a) the potentially dire consequences of HIV status disclosure are such that people with HIV require enhanced legal protection, and (b) the health, social and economic impacts on affected communities are unlike most other infectious diseases, in particular because AIDS most often affects young adults who would otherwise be economically productive and raising families. A later argument was added to the exceptionalism position based on the belief that AIDS represents a substantial development and security threat for heavily affected developing countries. It claimed that exceptional resources are required to contain it, particularly regarding provision of antiretroviral medications for all people living with HIV. The global mobilization to respond to AIDS has in turn generated increased attention and commitment to other grave pandemics like tuberculosis and malaria and to strengthening health systems more broadly; nevertheless, HIV continues to attract more development assistance funding than other diseases.

But counterarguments to AIDS exceptionalism have emerged. One such position<sup>83</sup> has proposed that special funding for AIDS treatment is unjust because people living with HIV have no greater claim on society's resources than people living with any other disease, and that people living with other diseases (here they cite cancer, mental illness and disability) also face stigma and discrimination. It is argued that the absence of benefits for people living with other pandemic-level diseases leaves AIDS exceptionalism open to accusations of injustice.

While acknowledging the constructive nature of this debate and the clear need to adapt policy packages appropriately as the epidemic evolves, this report argues that much of this criticism misses the point in pitting one disease against

*HIV emerged on a significant scale in Eastern Europe and the CIS a decade or more after epidemics became visible in Africa, the West, and South-east Asia*

*There is no exact analogy elsewhere in the world for the HIV epidemic in Eastern Europe and the CIS*

81 Buve, A, S. Kalibala, J. McIntyre, 'Stronger health systems for more effective prevention and care' in *International Journal of Health Planning and Management*, 18, S41-S51 (2003).

82 De Cock, K, A. M. Johnson, 'From exceptionalism to normalisation: a reappraisal of attitudes and practice around HIV testing' in *BMJ*; 316:290-293 (1998).

83 Casarett, D. J, J. D. Lantos, 'Have We Treated AIDS Too Well? Rationing and the Future of AIDS Exceptionalism' in *Annals of Internal Medicine*, 128, 756-759 (1998).

*More and more people will be able to live with HIV as a manageable chronic disease, allowing them to enjoy long and healthy lives*

another. The AIDS epidemic remains an exceptional confluence of factors discussed in the referenced debates, where the whole is more destructive than the sum of the parts in a way not found with other diseases. HIV is an epidemic observed on a large and growing scale in Eastern Europe and the Commonwealth of Independent States. HIV is transmitted through highly intimate social behaviours; it is infectious and thus both a serious public health concern and inherently preventable, with high rewards to preventive interventions. And HIV brings devastating social consequences of stigma and discrimination across all ages and walks of life, with an especially heavy burden among youth in the region, as witnessed in this report. Prevention must remain at the centre of responses to HIV, and it has been clearly demonstrated that effective prevention requires action not just by health ministries and health service providers, but by a much wider range of actors, including those active in education, prisons, law enforcement, gender equality and drug treatment. Finally, AIDS without treatment is fatal. Yet with treatment, people living with HIV can lead long, healthy lives. Indeed, other illnesses are epidemic as well, and some cause more deaths or may be more costly; some may also be infectious, treatable or preventable and some may even be associated with severe stigma and discrimination – but no other disease combines all of these qualities in one compelling claim for an exceptional and multisectoral response more than AIDS.

At the same time, as access to antiretroviral therapy is scaled up in the region, and appropriate care and treatment for people living with HIV made available beyond specialized institutions, more and more people will be able to live with HIV as a manageable chronic disease, allowing them to enjoy long and healthy lives. In this way, through an exceptional response, we can seek to make living with HIV less exceptional. Support for an exceptional response also implies that rather than view health policies with an ‘either-or’ lens, increasing attention should be paid to ensuring that AIDS programming enhances the capacity of broader health systems. As Dr. Peter Piot, Executive Director of UNAIDS recently noted, AIDS programming has both led the way in identifying health system shortcomings in many countries and has marshaled largely additional resources that are increasingly used to

strengthen the broader health sector as part of the response to HIV.<sup>84</sup> This has certainly been the case in Eastern Europe and the CIS, especially in terms of other infectious diseases including sexually transmitted infections, tuberculosis and even malaria in Central Asia. General capacities for procurement, service delivery and monitoring and evaluation within national ministries have also been strengthened. In many countries of the region, the HIV response has led the way in forming working public-private partnerships between state and non-state entities to deliver services where this concept was unknown just over a decade ago, yielding clear systemic benefits even beyond the health sector.

### Guiding principles of the response in a rights-based framework

Universal access to HIV prevention, treatment, care and support will never be achieved without greater attention to human rights. A rights-based approach is universal in the sense that the whole society – and not just ‘privileged’ groups or individuals – benefit from it. For full list of rights relevant to people living with or affected by HIV see Annex 1.

One of the major challenges with regard to mainstreaming human rights-based approaches into policy and practice is a persistent misunderstanding of the issue. Human rights are not a ‘burden’ on governments. Greater attention to human rights has practical and pragmatic results because it makes the response to the HIV epidemic more effective and efficient. The argument can be also reversed: better inclusion of people living with HIV means *de facto* advance in respect to their human rights. Improving the conditions for meeting human rights obligations is not a ‘zero-sum game’ as it is often perceived: it opens a virtuous circle of mutual benefits for both affected individual and their societies.

Some countries in this region might face specific challenges in translating human rights-based standards into policy and practice. Policies that focus on the rights of individuals who belong to historically vulnerable populations may be especially difficult to pursue in some settings.<sup>85</sup> Another major challenge with regard to ‘mainstreaming’ rights-based approaches is the perception of human rights as an imposed agenda,

*Improving the conditions for meeting human rights obligations opens a virtuous circle of mutual benefits for both affected individuals and broader society*

<sup>84</sup> Lecture given by Dr. Peter Piot at the “AIDS Exceptionalism Revisited” seminar, London School of Economics, 15 May 2008.

<sup>85</sup> Piot, P, R. Greener, S. Russell, ‘Squaring the circle: AIDS, poverty, and human development’ in *PLoS Medicine*, 4(10): e314, 1571-1575 (2007).

something that governments should only follow because international conventions oblige them to do so. However, countries may also benefit from rights-based efforts to improve the status of historically marginalised populations, which can lead to lower rates of HIV transmission (and fewer health disparities in general) and to improvements in economic and development outcomes.<sup>86</sup>

By contrast, evidence suggests that rights limitations can fuel the spread of the epidemic and exacerbate the impact of HIV on individuals and communities around the world.<sup>87</sup> This is a major argument in favour of rights-based approaches in the response to the HIV epidemic in the region. Respect for human rights makes national responses to HIV more effective. For example, discrimination against and stigmatization of key populations at higher risk – such as people who inject drugs, sex workers and men who have sex with men – drives these communities underground inhibiting the ability of social and public health programs to reach these populations with prevention efforts. An elaborated and consistently implemented human rights framework makes it possible to involve those populations, respond to their specific prevention and support needs and reduce the risk of spreading the epidemic. In the long run effective promotion of human rights is necessary to achieve Universal Access and Millennium Development Goal commitments in the region.

As part of the UN General Assembly Special Session on AIDS in 2001, states made the commitment to report regularly on a range of standardized indicators. One of the indicators, which is considered to be objective because it is scored by non-governmental and international organization representatives in the country, measures the degree to which respondents feel the country has put “policies, laws and regulations in place to promote/protect human rights in relation to HIV and AIDS”. It is more appropriate to evaluate trends within a country over time than compare scores across countries, given the variety in data collection methods in each (see Figure 3.1). It is worth noting, however, that countries in the region have improved their ratings in recent years. Of course, there is still room to improve.

### Box 3.1. Kyrgyzstan court affirms the right to confidentiality of HIV status

In 2007, Kyrgyzstan for the first time upheld the right to privacy of a person living with HIV who was filmed against his will for a television documentary. The court won a conviction against a doctor who intentionally exposed the man’s identity, in the first case of its kind in Central Asia. The case was brought to court by the legal aid NGO Adilet, a UNDP partner and one of the few organizations in Central Asia offering legal aid to people living with HIV. In 2005 the chief physician of the AIDS centre in Jalal-Abad was approached by reporters looking to document the work done by the centre for a documentary to air on World AIDS Day. After his interview the physician suggested that the reporters film patients receiving care in the centre. The plaintiff, who was in the centre awaiting transfer to an acute care ward, flatly refused to be interviewed. The physician then suggested the photographer film him sitting in a courtyard without his consent through a window in the physician’s office. The plaintiff was clearly identified as a person living with HIV. Immediately upon broadcast of the report, the plaintiff and his immediate and extended families experienced such severe discrimination and social exclusion that they were forced to move from their native village. Although the plaintiff died before the complaint was brought to court, the doctor was charged with a grave breach of the man’s right to confidentiality. Despite the difficulty in engaging expert witnesses from the medical community, the prosecution case brought about a guilty plea from the physician.

*HIV/AIDS Policy and Law Review, Canadian HIV/AIDS Legal Network, December 2007*

### National HIV legislation and its implementation

Despite the extensive scope of global declarations and commitments on HIV, national legislation remains the most important means of protecting the specific rights of people living with HIV within the national context. Aside from preventing existing laws from violating the rights of people living with HIV, national legislation can be a powerful tool for addressing acts of discrimination against people affected by HIV. Some countries in the region have taken steps to ensure their legislative framework adequately provides this protection. However, recent years have also seen the beginning of a subtle shift in the types of HIV legislation being adopted in the region. Whereas previously many countries had promoted laws aimed squarely at preventing the spread of the virus and introducing protection for

*Rights limitations can fuel the spread of the epidemic*

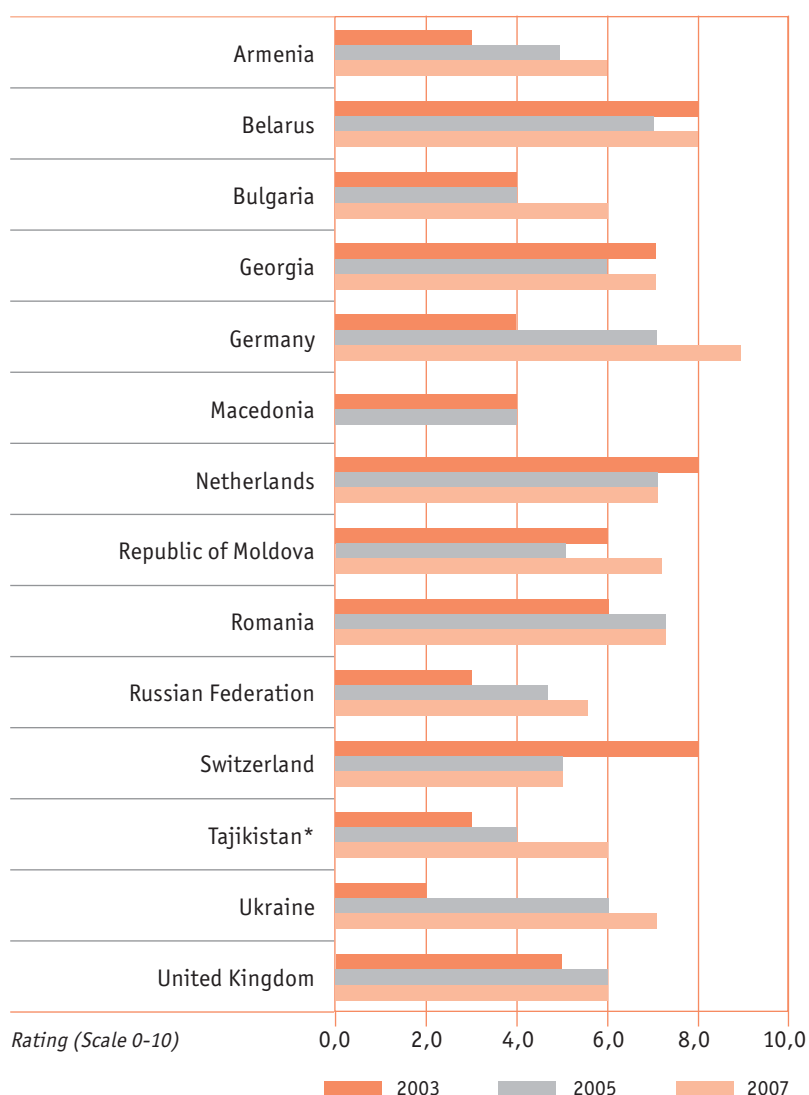
*Respect for human rights makes national responses to HIV more effective*

<sup>86</sup> Chopra, M, N. Ford, ‘Scaling up health promotion interventions in the era of HIV/AIDS: challenges for a rights based approach’ in *Health Promotion International*, 20, 383-90 (2005).

<sup>87</sup> Moszynski, P, ‘Human rights abuses are fuelling HIV epidemic, charities say’ in *BMJ*, 337:a900 (2008). See also K. Krauss, ‘Botswana and Swaziland: report links violations of women’s rights to HIV’ in *HIV/AIDS Policy and Law Review*, 12, 38-9 (2007).

**Figure 3.1. UNGASS NCPI Part B, I.R (Human Rights): Overall score – Policies, laws and regulations in place to promote/protect human rights in relation to HIV and AIDS (scale 0/low – 10/high).**

UNGASS 2, NCPI, Part B, I.R (Human Rights)



**Source:** Adapted from Sharp, S. „Political Leadership” Chapter in „Progress on implementing the Dublin Declaration on partnerships to fight HIV/AIDS in Europe and Central Asia”, WHO 2008, p. 34/UNGASS National Reports

people living with HIV, in recent years some countries have begun taking steps to introduce measures that have little public health benefit while effectively criminalizing people living with or at risk of HIV. A notable exception, Georgia recently reformed its national legislation to decriminalize HIV and reduce stigma and discrimination as part of a project supported by UNDP and others.

Yet there remain gaps in the region that need extensive amendment. For example, sex among men is still criminalized in two countries in the region, Uzbekistan and Turkmenistan, which serves only to drive these populations underground, to say nothing of human rights infringement. And of the 12 countries in the world that still place some restrictions on the entry and stay of people living with HIV, three come from this region.<sup>88</sup> In Moldova and Russia, certification of HIV status is required to apply for visas and work permits for stays of longer than 3 months, while in both, and Armenia as well, foreigners discovered to be HIV positive are required to leave the country.<sup>89</sup> The issue is currently a major topic of international advocacy. The United States, for example, initiated action just this year to repeal its own 15-year-old law banning entry to people living with HIV in acknowledgement that it has failed to serve a public health purpose.

Criminal prosecution for HIV transmission is still an issue as well. One survey of Europe, which did not include Central Asia, found that nine countries in Eastern Europe criminalize transmission of the virus, while another eight allow for prosecutions for simple exposure of a person to the risk of transmission. The same study found that legislation in some countries would allow a child (or some competent authority) to enter a criminal complaint against its mother for infection.<sup>90</sup> Laws criminalizing HIV transmission have come under scrutiny recently for several reasons. In many countries, such laws do not discriminate between intentional HIV transmission and negligence. Yet the likelihood of a reduction in people seeking HIV testing due to fear of potential prosecution poses public health dangers that outweigh potential reductions in transmissions as a result of the law.<sup>91</sup> Furthermore, the scientific methods necessary to prove transmission from one person to another are beyond the means of most justice systems in the region. Existing laws are usually more than sufficient to prosecute the rare case of intentional transmission of the virus without need for additional specific legislation that further stigmatizes HIV and can be easily abused.

With few exceptions, countries in the region feature legislative contexts that are largely in line with international norms. Effective monitoring

<sup>88</sup> International AIDS Society Policy Paper, *Banning Entry of People living with HIV/AIDS*, December 2007.

<sup>89</sup> European AIDS Treatment Group which can be accessed at <http://www.hivtravel.org>

<sup>90</sup> GNP+ Europe/Terrence Higgins Trust, *Criminalisation of HIV Transmission in Europe*, 2005.

<sup>91</sup> Bird, S. M., A. Brown, 'Criminalisation of HIV Transmission' in *British Medical Journal*, 323:1174-1177 (2001).



and enforcing application of the law, however, remains a serious challenge in most countries of Eastern Europe and the CIS. The research undertaken for this report uncovered many first-hand instances of unlawful discrimination, but legal redress was exceedingly rare. Mechanisms to monitor acts of legal violations are still weak, and in many cases people are unwilling to press for their rights for exactly this reason. Nonetheless, there are a number of successful efforts in the region aiming to make legal aid services and hot-lines available to people affected by HIV, demonstrating that rights can be translated into action in Eastern Europe and the CIS. The following box describes a rights monitoring and legal support network in Ukraine.

## Areas of priority attention

A comprehensive response to the epidemic requires a set of population-specific and targeted interventions implemented in the framework of general approaches in terms of harm reduction, reducing risk behaviour and limiting the probability of spreading the infection. These areas are mutually complementary and reinforcing. This section outlines the parameters of the general context and measures that are necessary for successful and effective response to the epidemic.

### Harm reduction programmes for people dependent on drugs

Two harm reduction measures have proven especially effective at reducing HIV transmission and improving the health of people dependent on drugs: needle and syringe exchange programmes and opioid substitution therapies (with methadone or buprenorphine). However, despite the fact that the epidemic in most of the region is primarily driven by injecting drug use, these harm reduction measures are not available to most of those who need them. While all countries in Eastern Europe and the CIS reported having at least one dedicated needle and syringe exchange programme by the end of 2005, coverage is inadequate in terms of the number of sites available and the number of injecting drug users reached.<sup>92</sup>

<sup>92</sup> Donoghoe, M, 'Injecting drug use, harm reduction and HIV/AIDS' in Matic, Lazarus and Donoghoe, *HIV/AIDS in Europe. Moving from Death Sentence to Chronic Disease Management*, WHO Europe, 2006.

### Box 3.2. Legislative review in Croatia

In 2006, a team of legal experts in Croatia undertook an analysis of legislation in order to observe the solutions that already existed regarding HIV, to find out if there were regulations of discriminatory or stigmatizing character, and to determine what kinds of regulations were missing when it came to protecting persons living with HIV. The experts, brought together at the behest of the UN Theme Group on HIV in Croatia, analysed regulations regarding testing, privacy, health and medical assistance, criminal liability for transmission, social welfare, indemnity, education, work, the status of children living with HIV, asylum seekers and prisoners and recommended new or different legal solutions that were considered necessary.

The resulting publication found that there remain certain discriminatory legal provisions in relation to people living with HIV in Croatia. The following acts and ordinances have been adopted or modified since:

- The Act on Protection of the Population from Infectious Diseases eliminated the possibility of HIV testing prior to employment or during employment
- The person examined should give consent to HIV testing by signing a form containing, among other things, a statement that he/she was in a stable mental state when giving consent to the exam.
- Foster parents who take care of HIV positive children or youth are entitled to a higher remuneration per foster child.
- The new ordinance on blood and blood components no longer prescribes that persons engaged in homosexual behaviour are permanently excluded as blood donors. Before refusal, the ordinance now requires asking a donor whether their sexual behaviour would put them at high risk of contracting infectious diseases.
- HIV infection is no longer considered a permanent obstacle to work on maritime vessels, crafts and yacht crews.
- The government's national human rights programme aims to monitor legislation so as to prevent discrimination against people living with HIV.

Although most of the mentioned legal documents were improved, since May 2006 HIV testing for police officers is not a part of regular health protection, but represents a health capability assessment for employment.

The Croatian Association for HIV and the UN Theme Group on HIV in Croatia are collaborating to bring about further changes recommended in the review, such as eliminating provisions that even healthy persons living with HIV are barred from employment in the police and private security sectors. For more information, see:

*HIV/AIDS in the Legislation of the Republic of Croatia*, 2007, available at [http://www.undp.hr/upload/file/109/54735/FILENAME/UNAIDS\\_brosura\\_2006\\_engl\\_zadnje.pdf](http://www.undp.hr/upload/file/109/54735/FILENAME/UNAIDS_brosura_2006_engl_zadnje.pdf)



*Needle and syringe exchange programmes reduce HIV transmission among people who inject drugs and opioid substitution therapy reduces drug use behaviours that contribute to HIV transmission*

Currently the majority of drug treatment services in the region are highly medicalized and centralized, a legacy of the Soviet narcological treatment system. They are based mainly on the provision of government controlled short-term, in-patient detoxification with little psychological or follow-up care.<sup>93</sup> Drug treatment is also often accompanied by registration of names of people who use drugs, as well as HIV testing without

consent. People who use drugs might not trust the treatment system and may associate treatment with high failure rates, short remissions and continuing drug use.<sup>94</sup>

Harm reduction measures are not supported in some settings in the region, and are sometimes actively undermined. This public health restriction runs counter to scientific evidence, which demonstrates that needle and syringe exchange programmes reduce HIV transmission among people who inject drugs<sup>95</sup> and opioid substitution therapy reduces drug use behaviours that contribute to HIV transmission.<sup>96</sup> The three major United Nations drug control conventions further support approaches that treat drug use as a health concern.<sup>97</sup> In particular, the conventions can be correctly interpreted to support the implementation of measures such as substitution therapy and needle and syringe programmes.<sup>98</sup>

Viewing these services as evidence-based public health programmes justifies their inclusion in states' rights-based HIV prevention policies. The UNAIDS 2007 AIDS Epidemic Update notes some progress in the region in harm reduction measures, while outlining the need for further scale up and introduction of pilot comprehensive harm reduction programmes where lacking.<sup>99</sup>

### Access to voluntary HIV testing and counselling

An increasing number of non-governmental organizations in the region offer voluntary HIV testing and counselling in conjunction with harm reduction services such as needle exchange programmes. However, HIV diagnosis and treatment in government AIDS centres has emphasized testing and social scrutiny of patients in virtually all former Soviet countries.<sup>100</sup> Recently, an international consensus has emerged that in addition

### Box 3.3. Ukrainian example of human rights monitoring and legal support provision

In 2007 together with NGO partners, UNDP Ukraine helped support the launch of AIDS Watch Ukraine, a human rights monitoring and legal support initiative, in six regions. The project achievements include the establishment of the legal remedial centre in Kiev to provide qualified legal assistance to people affected by HIV; the establishment of HIV-related rights monitoring outlets in five regions; the launch of a specialized website devoted to HIV-related rights monitoring and analysis – [www.tabo.com.ua](http://www.tabo.com.ua); and the setting up of an all-Ukrainian HIV rights protection organization 'Gidnist' (Dignity).

As a result of the project activities 295 consultations have been provided to the clients of remedial centre; 64 HIV-related human-rights violations registered, including 39 in the public health sector, four in education and three in the employment sector; 88 people received legal aid with regard to violation of their rights related to HIV; 11 statements of claim were submitted in court; five complaints were sent to appropriate state institutions; and four cases were successfully won in courts.

To take one example, in June 2006 in the regional hospital of Kirovograd a mother was deprived of the right care for her newborn daughter on the grounds that she (the mother) had HIV. The child was forcefully separated from her mother by medical workers and the mother was discharged from the hospital and forbidden to attend to her daughter. As a result of active intervention of AIDS Watch Ukraine (revealing the case, filing an claim in court etc.) the Kirovograd court ruled the actions of the medical workers unlawful, and ordered moral compensation in favour of the plaintiff.

93 Mendelevich, V, 'Narcology: Drug treatment in Russia', in 'Open Society Institute briefing on drug treatment, HIV, and the challenge of reform', Open Society Institute, New York, 2006.

94 Bobrova, N. et al., 'Barriers to accessing drug treatment in Russia: a qualitative study among injecting drug users in two cities', *Drug and Alcohol Dependence*, 2006, 82:557.

95 Wodak, A, A. Coonery, 'Do needle syringe programs reduce HIV infection among injection drug users: a comprehensive review of the international evidence' in *Substance use and Misuse*, 41, 777-813 (2006).

96 Gowing, L, M. Farrell, R. Bornemann, L. Sullivan, R. Ali, 'Substitution treatment of injecting opioid users for prevention of HIV infection' in *Cochrane Database of Systematic Reviews*, Apr 16; (2):CD004145 (2008).

97 *The 1961 Single Convention on Narcotic Drugs; the 1971 Convention on Psychotropic Substances; and the 1988 United Nations Convention Against Illicit Traffic in Narcotic Drugs and Psychotropic Substances.*

98 UNDCP (Legal Affairs Section), 'Flexibility of treaty provisions as regards harm reduction approaches', Decision 74/10, UN Doc. E/INCB/2002/W.13/SS.5, 30 September 2002.

99 UNAIDS 'AIDS Epidemic Update Regional Summary – Eastern Europe and Central Asia' March 2008, Geneva, p.8

100 Sarang, A, R. Stuijke, R. Bykov, 'Implementation of harm reduction in Central and Eastern Europe and Central Asia' in *International Journal of Drug Policy*, 18:129 (2007); D. Wolfe, 'Paradoxes in antiretroviral treatment for injecting drug users: Access, adherence and structural barriers in Asia and the former Soviet Union' in *International Journal of Drug Policy*, 18:246 (2007).

to the traditional model of client-initiated voluntary counselling and testing (VCT) in health care settings, new approaches to HIV testing and counselling must be implemented in more settings, and on a much larger scale than has so far been the case.<sup>101</sup> Expansion of HIV testing and counselling is one of the conditions for achieving the aim of universal access to prevention, care, treatment and support for all who need such services.

The availability and accessibility of voluntary, confidential HIV testing and counselling remains low in some countries in the region. Even where HIV testing is available, people are discouraged from learning their HIV status due to a number of factors: the climate of stigma and discrimination, and barriers to HIV care, treatment and support. For example, in Montenegro, the government has recognized that little incentive for an individual to be tested for HIV exists, given the high AIDS stigma and low confidentiality of the testing process.<sup>102</sup> Where testing is available, people living with HIV frequently report having been tested without pre- or post-test counselling, which can lead to unnecessary psychological trauma.<sup>103</sup>

In some countries, members of vulnerable populations are subjected to HIV testing without consent.<sup>104</sup> In Armenia, compulsory testing of populations considered at risk is legal under Article 11 of the Armenian Law on HIV/AIDS. Furthermore, the 2005 Standards of Treatment of Narcological Diseases also require HIV testing for every injecting drug user who is admitted to a narcological centre, either voluntarily or involuntarily.<sup>105</sup> Testing without informed consent raises human rights concerns, especially when it is done without the existence of relevant safeguards or access to basic HIV prevention and care services.

## Access to antiretrovirals

The right to health of people living with HIV in the region is compromised by inadequate access to HIV antiretroviral medications. At the 2006 United Nations High-Level Meeting on HIV/AIDS, all governments in the region made a commitment to work towards “universal access to comprehensive ... treatment, care and support” by 2010.

There has been significant progress towards these aims in Eastern Europe and the CIS in the last few years: 39,000 more people received antiretroviral treatment at the end of 2007 than at the end of 2003.<sup>106</sup> However, it was estimated that as of the end of 2007 only 17 percent of those in the region needing antiretrovirals received them. In some countries, interruptions in the supply of antiretroviral medications and intermittent availability of tests have a negative impact on medication adherence and undermine confidence in health systems.<sup>107</sup>

The lack of access to antiretrovirals is acute for marginalized populations. In Eastern Europe and the CIS, where more than 70 percent of HIV cases are attributed to injecting drug use, people who inject drugs represented only 39 percent of the total number of people on antiretroviral treatment at the end of 2006.<sup>108</sup> This situation may be significant in the Russian Federation,<sup>109</sup> though efforts to provide ARV access to people who inject drugs have improved since 2006. In some countries in the region, people who inject drugs may be denied treatment if they are known to be actively using drugs, because they cannot combine treatment for addiction, tuberculosis or hepatitis with HIV treatment due to a lack of appropriate protocols and coordination across vertical service providers, or because they cannot

*Even where HIV testing is available, people are discouraged from learning their HIV status due to a number of factors: the climate of stigma and discrimination, and barriers to HIV care, treatment and support*

*There has been significant recent progress in scaling up ARV access in the region, yet it was estimated that as of the end of 2007 only 17 percent of those in need received them*

101 'HIV/AIDS policy in the Ukraine: A civil society perspective', New York, Public Health Program of the Open Society Institute, 2007; UNAIDS Reference Group on Human Rights, 'Report of the Meeting', 7th Meeting, Geneva, 12-14 February 2007.

102 Montenegro, "UNGASS Country Report 2007". Available at [www.unaids.org](http://www.unaids.org)

103 Balabanova, Y. et al., 'Stigma and HIV infection in Russia' in *AIDS Care*, 18(7):846 (2006).

104 This may be in compliance with national laws, but remains contrary to international human rights law. 'Sex work, HIV/AIDS, and human rights in Central and Eastern Europe and Central Asia', Vilnius, Lithuania, Central and Eastern European Harm Reduction Network, 2005.

105 Markosyan, K, A. Kocharyan, A. Potosyan, 'Meeting the challenge of injection drug use and HIV in Armenia' in *Health and Human Rights*, 9(1):128 (2006).

106 'Towards universal access: scaling up priority HIV/AIDS interventions in the health sector: progress report, June 2008', Geneva, WHO/UNAIDS/UNICEF, 2008. Available at [www.who.int/hiv/mediacentre/2008progressreport/en/index.html](http://www.who.int/hiv/mediacentre/2008progressreport/en/index.html)

107 Bernays, S, T. Rhodes, A. Prodanovic, 'HIV treatment access, delivery and uncertainty: A qualitative study in Serbia and Montenegro,' Belgrade, UNDP, 2007; 'Harm reduction developments 2008', New York, International Harm Reduction Development Program of the Open Society Institute, 2008.

108 'Towards universal access: scaling up priority HIV/AIDS interventions in the health sector: progress report, June 2008', Geneva, WHO/UNAIDS/UNICEF, 2008.

109 Aceijas, C. et al, 'Antiretroviral treatment for injecting drug users in developing and transitional countries one year before the end of the 'Treating 3 million by 2005. Making it happen. The WHO strategy' ('3 by 5')' in *Addiction* 101(9):1246 (2006); M. Donoghoe et al, 'Access to highly active antiretroviral therapy (HAART) for injecting drug users in the European Region 2002-2004' in *International Journal of Drug Policy*, 18(4):271 (2007).

afford the informal payments for medical tests related to treatment.<sup>110</sup>

### HIV prevention, treatment, care and support for prisoners

Under international human rights law, prisoners retain all rights and privileges not necessarily suspended due to their incarceration. Living conditions in prisons in many countries fall far short of international standards. The medical care in many prison systems is inadequate and does not approach that available in the community, as is required under international treaties and standards.<sup>111</sup>

Recent guidance has recommended that states provide prisoners with “no-cost access to appropriate and professional HIV care, treatment and support equivalent to that available in the outside community, including access to diagnostics and antiretroviral treatment”.<sup>112</sup> Progress in that regard is still limited, however. Needle and syringe programmes exist only in some prisons in Armenia, Belarus, Kyrgyzstan and Moldova.<sup>113</sup> As of 2007, only Moldova and Poland provided substitution therapy, to a very small number of prisoners in each country, and mostly as pilot programmes in select prisons.<sup>114</sup> Access to voluntary HIV testing and counselling remains limited in prison and tests are often undertaken without consent and with little or no benefit to prisoners. Few prisoners who need antiretroviral medications get them, even where countries have enacted legal and policy frameworks mandating antiretroviral therapy for prisoners.<sup>115</sup> For example, in Ukraine, as of April 2008, only around 100 prisoners were on antiretroviral therapy and the target by the end of 2008 is 300 – while studies have shown that between 15 and 30 percent of the total 160,000 prisoners may be living with HIV.<sup>116</sup>

### Privacy and confidentiality in health care

Ensuring the privacy of personal information supports the right to health and is an important legal obligation in and of itself. In post-socialist (and post-collectivist) environments, however, respect for the privacy and integrity of personal data has yet to be achieved. Stigma and discrimination reinforce the problem. Together, insufficient respect for personal data privacy and the climate of stigma further the exclusion of people living with HIV.

Exclusion resulting from disclosure can lead to economic harm, including loss of employment, insurance or housing, as well as medical harm due to compromised medical care and interrupted treatment. The International Guidelines on HIV/AIDS and Human Rights<sup>117</sup> call on states to ensure that governments and the private sector develop codes of conduct regarding HIV issues that translate human rights principles into codes of professional responsibility and practice, with accompanying mechanisms to implement and enforce these codes. Unauthorized disclosure of confidential patient information continues to happen despite national laws that protect the privacy and confidentiality of people living with HIV. The tendency on the part of medical staff to circumvent established laws out of fear of HIV transmission should be allayed through appropriate implementation of internationally adopted Universal Precaution protocols, elaborated later in this report.

### Education and information

The right to education, as set out in Article 13 of the International Covenant on Economic, Social and Cultural Rights, guarantees that

*In some countries of the region, people who inject drugs may be denied treatment if they are known to be actively using drugs*

*Ensuring the privacy of personal information supports the right to health and is an important legal obligation in and of itself*

110 Wolfe, D, ‘Paradoxes in antiretroviral treatment for injecting drug users: Access, adherence and structural barriers in Asia and the former Soviet Union’, 2007, *International Journal of Drug Policy*, 18:246; ‘Harm reduction developments 2008’, New York, International Harm Reduction Development Program of the Open Society Institute, 2008.

111 Bobrik, A, K. Danishevski, K. Eroshina, M. McKee, ‘Prison health in Russia: the larger pictures’ in *Journal of Public Health Policy*, 26, 30-59 (2005).

112 ‘HIV/AIDS prevention, care, treatment and support in prison settings: A framework for an effective national response’, New York, UNODC, WHO, UNAIDS, 2006.

113 ‘Needle and syringe programs and bleach in prisons: Reviewing the evidence’, Canadian HIV/AIDS Legal Network: Toronto, 2008.

114 International Harm Reduction Development Program of the Open Society Institute, ‘Harm reduction developments 2008’, OSI: New York, 2008.

115 Wolfe, D, ‘Paradoxes in antiretroviral treatment for injecting drug users: Access, adherence and structural barriers in Asia and the former Soviet Union’, *International Journal of Drug Policy*, 18:246 (2007).

116 Zhivago, S, ‘HIV/AIDS epidemic situation in penitentiary system of Ukraine’. Presentation at “HIV/AIDS in Prisons in Ukraine – From evidence to action: Prevention and care, treatment and support.” Kiev, 1-2 November 2005.

117 Available at [http://data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines\\_en.pdf](http://data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines_en.pdf)

those living with HIV should not be denied access to education on the basis of their HIV status. The right to education is especially important to children and young people living with HIV. The United Nations Convention on the Rights of the Child reaffirms the right of children to non-discrimination, education and health. The Committee on the Rights of the Child has affirmed that states must “ensure that primary education is available to all children, whether HIV-positive, orphaned or otherwise affected by AIDS.”<sup>118</sup>

In Romania, over 7000 children and youth are living with HIV. Fewer than 60 percent of children living with HIV attend any form of schooling, despite legislation providing for free and compulsory education through 10th grade or until age 18.<sup>119</sup> And many other Romanian children living with HIV are inappropriately relegated to special schools with inferior resources. The refusal to admit to school or denial of educational opportunities to people living with or presumed to be living with HIV is an infringement of their right to education and has no public health justification. Again, any concerns on the part of education administrators, teachers, health care staff and others about the possibility of HIV transmission in the event of medical emergencies in the school education setting should be allayed through appropriate implementation of the Universal Precaution protocols elaborated below.

### Prevention of mother-to-child transmission (PMTCT)

As the number of children born to women living with HIV increases in the region, interventions to prevent mother-to-child transmission take on greater importance. PMTCT has been shown to be a highly effective and relatively straightforward methods of preventing HIV infection if implemented according to internationally adopted guidelines. With appropriate intervention, the rate of vertical HIV transmission from mother to child can be reduced dramatically.

Implementation of antiretroviral treatment for HIV-positive pregnant women in Russia and Ukraine show promising results (84 percent and 90 percent, respectively). Prophylaxis measures for pregnant women in Russia contributed to a decline in mother-to-child transmission from 19.3 percent<sup>120</sup> to 6.2 percent<sup>121</sup> of children born to women living with HIV in 2004. In Ukraine, measures to prevent mother-to-child-transmission have been targeting all pregnant women who have agreed to undertake voluntary HIV testing since 2000. In 2003, 15.9 percent of infants born in Ukraine to HIV-positive mothers tested positive, a 43 percent reduction compared to 2001.

The case in Box 3.4 illustrates the difference working with health care settings can make in the lives of pregnant women living with HIV and their children.

### Meaningful participation of people living with HIV

The involvement of civil society is of crucial importance in dealing with HIV. An effective response to the HIV epidemic requires a partnership approach in which governmental agencies, communities, non-governmental organizations and populations affected by HIV – especially people living with HIV – are involved.

Challenges faced by people living with HIV are related largely to dominant attitudes. For example, the dominant approach to people living with HIV or other ‘invalids’ in post-socialist environments is one of neglect, denial or stigmatization. Measures must counteract these long-held tendencies.

Governments have made explicit commitments to promote the role of civil society for greater involvement of people living with HIV in the fight against AIDS. At the 1994 Paris AIDS Summit, 42 heads of state – including the heads of state of the Russian Federation and of Romania – declared that greater involvement of people living with or affected by HIV (i.e. the GIPA Principle) is critical to ethical and effective national re-

*Exclusion resulting from disclosure also can lead to economic harm, including loss of employment, insurance or housing, as well as health problems due to compromised medical care and interrupted treatment*

*The refusal to admit to school or denial of educational opportunities for people living with HIV is an infringement of their right to education and has no public health justification*

118 Committee on the Rights of the Child, ‘General Comment 3: HIV/AIDS and the Rights of the Child’, 2003, paragraph 9 (CRC/GC/2003/3).

119 Human Rights Watch, “‘Life doesn’t wait’: Romania’s failure to protect and support children and youth living with HIV”, New York, August 2006, Vol. 18, No. 6(D).

120 Resource Centre for HIV/AIDS Policy Research, Russia. <http://www.hivpolicy.ru/publications/index.php?section=50&id=66>, accessed 1 October 2008.

121 Resource Centre for HIV/AIDS Policy Research, Russia. <http://www.hivpolicy.ru/topics/?id=48>, accessed 1 October 2008.



sponses. They expressed determination to fully involve “people living with HIV/AIDS in the formulation and implementation of public policies [and] ensure equal protection under the law for persons living with HIV.”<sup>122</sup> The GIPA Principle has since been adapted to ‘the meaningful involvement of people living with HIV’ (MIPA) to acknowledge that greater does not necessarily mean better. Its implementation depends upon states respecting, protecting and fulfilling essential democratic and political rights, especially for those who belong to historically disadvantaged populations.

### Box 3.4. Ukraine: A story of positive experience with health care providers

Olga was diagnosed as HIV-positive during pregnancy. She was worried and frightened about her delivery in a local maternity hospital. She thought that she would be treated as a mentally challenged person infected with the plague, and that this would apply also to her newborn baby.

But all her concerns turned out to be wrong. From the first minute of her admission to the hospital she found only warm attitudes and kindness from the staff. Health care providers gave her support and talked with her about her situation, trying to find solutions. She had the impression that she received the best attention in the whole hospital. And perhaps most importantly, she was taught how to live with HIV and how to ensure a normal life for her child. She even wrote a letter to the hospital staff expressing her gratitude for all they had done and telling them that she now has hope in her life and confidence in her future.

It should be mentioned that two months prior to admission the staff received training on prevention of mother to child transmission (organized by UNICEF), including information on stigma and discrimination against PLHIV in communities and health institutions. The training involved the participation of people living with HIV, who shared their experience of facing negative attitudes when accessing health care services.

Olga’s story proves that the attitudes of health care workers can be effectively changed with sensitization and training about the importance of tackling stigma and discrimination in healthcare institutions.

(UNICEF story credit)

## Populations of priority attention

The general policy context outlined above provides the basis for targeted population-centred interventions. Calibrating responses to meet the specific needs and terms of populations at risk is a practical necessity for effectiveness and efficiency. This approach, however, often does not emerge naturally within the cultural and historical context of the region, requiring deliberate communication efforts to build policy support. In many countries of the region, the legacy of authoritarian governance is reflected in intolerance of diversity, which has fed discrimination against social groups that do not meet a national ideal.<sup>123</sup> At times, HIV has been seen as a matter of jeopardy for the collective society, which made repression and persecution of populations associated with HIV publicly acceptable. Countries in the region have made progress in this regard, although a lot still needs to be done to build a critical mass of public support for implementing governments’ commitments to effectively provide key populations at higher risk with all the services they are entitled to. For that purpose, thematic (sector-specific) commitments and actions need to be complemented by group-focused actions targeting individual key populations at higher risk.

**People who inject drugs.** This population is often not recognized by law or society as being entitled to enjoy full human rights, and as a result faces discrimination both in state institutions and in society as a whole. Drug use is often treated principally as a criminal law issue rather than an individual and public health issue. Punitive laws making possession of relatively small amounts of illicit drugs a punishable offense in countries such as Georgia, Poland, the Russian Federation, and Ukraine, for example, typify a more criminal law approach and can present obstacles to harm reduction efforts.<sup>124</sup> Such approaches may have un-

122 ‘From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)’, Geneva, UNAIDS, 1999 (UNAIDS/99.43E). Available at [www.unaids.org](http://www.unaids.org)

123 Rhodes, T. M. Simic, ‘Transition and the HIV risk environment’ in *British Medical Journal*, 331:220 (2005). See also Rhodes, T. and M. Simic, ‘Transition and the HIV risk environment’ in *BMJ*, 331:220 (2005); Rhodes, T. et al., ‘The social structural production of HIV risk among injection drug users’ in *Social Science & Medicine*, 61:1026 (2005); Brown, H., ‘Russia’s blossoming civil society holds the key to HIV’ in *Lancet*, 368:437 (2006); Rechel, B. and M. McKee, ‘The effects of dictatorship on health: the case of Turkmenistan’ in *BMC Medicine*, 5:21 (2007).

124 Malinowska-Sempruch, K., ‘IHRD director criticizes Polish antidrug policies’, New York, International Harm Reduction Development Program of the Open Society Institute, 15 January 2004. Available via [www.soros.org](http://www.soros.org); Neier, A., ‘Abuses in the name of law and order’, in *Protecting the human rights of injection drug users: The impact of HIV and AIDS*, International Harm Reduction Development Program of the Open Society Institute: New York, 2005; ‘Rhetoric and risk: Human rights abuses impeding Ukraine’s fight against HIV/AIDS’, Human Rights Watch, New York, March 2006, Vol. 18, No. 2(D); Sarang, A., R. Stuijke, R. Bykov, ‘Implementation of harm reduction in Central and Eastern Europe and Central Asia’ in *International Journal of Drug Policy*, 18:129 (2007); ‘Harm reduction developments 2008’, International Harm Reduction Development Program of the Open Society Institute: New York, 2008; Barrett, D., ‘Recalibrating the regime: The need for a human-rights based approach to international drug policy’, The Beckley Foundation Drug Policy Program, 2008, Report No. 13.



intended adverse consequences. Incarceration exacerbates the risk of HIV infection among people who inject drugs. Lack of harm reduction measures in prison helps the epidemic spread among prisoners. Lack of access to evidence-based HIV prevention measures such as needle and syringe programmes and opioid substitution therapy, as well as lack of access to HIV treatment and care and other health care services, is a disturbing reality for many people who inject drugs.

**Sex workers.** Although sex work in the region is not criminalized to the same extent as drug possession, sex workers are subject to discrimination and other human rights abuses. Public opinion about sex workers tend to ignore why individuals (mostly women) enter sex work – largely due to limited income opportunities, social marginalization or coercion/trafficking. Unless the systemic determinants are dealt with, individuals who engage in sex work may continue to experience higher rates of HIV, sexually transmitted diseases, forced sex, violence, unlawful detention and other rights violations.<sup>125</sup>

**Men who have sex with men.** In the Soviet Union, homosexuality was regarded as a crime and a serious mental disorder. During the transition most former Soviet countries have repealed laws criminalizing consensual sex between men, and in fact today the region scores relatively well against other low and middle income regions in terms of the legislative framework in place for the rights of lesbian, gay, bi-sexual and transgender/transsexual people (LGBT). A recent study categorized 25 out of 27 countries in the region as having either ‘neutral’ or ‘protective’ legal frameworks while, by comparison, only 11 out of 24 countries in East Asia and the Pacific scored accordingly.<sup>126</sup>

But levels of social tolerance have not changed as noticeably. Due to stigma against same-sex sexual relations, many homosexual relationships

and communities in the region remain largely underground. Moreover, gay men in parts of the region report abuse by police, and discrimination when attempting to access medical and social services.<sup>127</sup> Many governments in the region have largely ignored the HIV prevention needs of men who have sex with men and, at times, have contributed to the stigma and discrimination that can make them vulnerable to HIV.

The message here is clear: promoting the tolerance of sexual diversity, even though challenging within the context of traditional values in the region, can underpin a practical and effective response to the HIV epidemic. The fact that civil society’s efforts to bring public attention to the rights of sexual minorities have been met with stigma, discrimination and even violence<sup>128</sup> is discouraging. It is even more worrying when public leaders direct prejudiced remarks at gay men and lesbians, thereby undermining national efforts to respond to HIV.

**Ethnic minorities.** Denial of human rights for ethnic minority populations can minimize the effectiveness of public health interventions to prevent HIV. For example, Roma people are caught in a vicious circle of poverty, stigma and marginalization, reduced access to health and social services, and high rates of preventable illness.<sup>129</sup> Social exclusion, geographic isolation and low educational attainment, when combined with a failure on the part of governments to fund targeted prevention programmes, leave many Roma uninformed about the risk factors associated with HIV infection. Roma women are particularly disadvantaged given traditional social norms and gender expectations in Roma communities, which limit their individual capacity to seek health information and services.

Other minority groups in the region also face heightened HIV risk. In Estonia, for example, Russian-speakers often find themselves *de facto*

*Promoting the tolerance of sexual diversity, even though challenging within the context of traditional values in the region, can underpin a practical and effective response to the HIV epidemic*

125 ‘Rhetoric and risk: Human rights abuses impeding Ukraine’s fight against HIV/AIDS’, New York, Human Rights Watch, March 2006, Vol. 18, No. 2(D).

126 Caceres, C. et al, ‘Review of legal frameworks and the situation of human rights related to sexual diversity in low and middle income countries’, study commissioned by UNAIDS, April 2008.

127 ‘Report by the Commissioner for Human Rights, Mr. Thomas Hammarberg, on his visit to Ukraine, 10-17 December 2006’, Strasbourg, Council of Europe, 26 September 2007, CommDH(2007)15; ‘Access to health care for LGBT people in Kyrgyzstan’, Public Health Program of the Open Society Institute: New York, 2007.

128 Human Rights Watch, ‘Poland: Official homophobia threatens basic human freedoms’, HRW Letter to Polish Prime Minister Kazimierz Marcinkiewicz, 5 June 2006; Human Rights Watch, ‘Poland: Official homophobia threatens human rights’, HRW Letter to Polish President Lech Kaczynski, 15 February 2006; Human Rights Watch, ‘Russia: Investigate anti-gay violence’, HRW Letter to Mayor Lushkov, 8 May 2006; Human Rights Watch, ‘Reverse ban on lesbian and gay rights demonstration, end discrimination’, HRW Letter to Interim General Mayor Ursa, 19 May 2006; Human Rights Watch, ‘Latvia: Reverse ban on gay rights demonstration’, Media release, New York, 22 July 2006.; Human Rights Watch, ‘Russia: Gay rights under attack’, Media release, Moscow, 14 June 2007.

129 Kelly, J. A, Y. A. Amirhanian, E. Kabachieva et al, ‘Gender roles and HIV sexual risk vulnerability of Roma (Gypsies) men and women in Bulgaria and Hungary: an ethnographic study’ in AIDS Care, 16, 231-45 (2004).

*Increasing development opportunities for ethnic minorities is a critical element for dismantling the vicious circle of poverty, exclusion and HIV*

*A growing number of children born to women living with HIV are abandoned and often sent to separate orphanages or segregated from other children within regular orphanages*

excluded from the labour market and educational system, further contributing to their social exclusion and vulnerability to HIV.<sup>130</sup> Thus the chain between 'reduced opportunities' and 'marginalization' and 'higher levels of risk' is affirmed. This also suggests that in some countries increasing development opportunities for ethnic minorities is a critical element for dismantling the vicious circle of poverty, exclusion and HIV.

**Children.** The stigmatization of people living with HIV has especially harsh consequences for pregnant women living with HIV and their children. In the Russian Federation, a growing number of children born to women living with HIV are abandoned.<sup>131</sup> The issue is aggravated by the dominating approach of institutionalized care for abandoned and disabled children in post-socialist countries. These children are often sent to separate orphanages for HIV-positive children, or segregated from other children within regular orphanages.

Romania has the largest number of children and youth living with HIV in the region, a legacy of poor medical practices that spread HIV among children in state orphanages in the late 1980s and early 1990s.<sup>132</sup> Pervasive ignorance, stigma and discrimination are barriers to education, medical care, government services and employment for these young people.

Recognizing the needs of orphans and vulnerable children in Eastern Europe and the CIS is crucial to promoting the health of the region. Access to education, age-appropriate health, and stimulating and nurturing social environments can minimize the chances that these severely disadvantaged youth will experience social and health disadvantages as adults.

**Mobile Populations.** As outlined earlier, population mobility is a defining factor of this region. Yet the needs and rights of mobile populations often do not receive much attention. As the region scales up universal access, migrants and other mobile populations are at risk of being left

behind. Risks might be particularly high for undocumented migrants. The number of undocumented migrants in the Commonwealth of Independent States region is estimated at between five and 15 million. Undocumented migrants face discrimination, exploitation and abuse. The region is an important transit route between Asia and Europe, and many migrants in transit become stranded in Russia and Ukraine for long periods of time due to the tight border controls to enter the European Union. Because migrants may lack social networks and linguistic or cultural capacity to assimilate into host countries, they are likely to have little access to either health services or education about prevention, even when legally entitled.<sup>133</sup>

The health risks of migrants can be exacerbated due to trafficking and forced movements. UNIFEM has estimated that between 500,000 and four million people are trafficked every year,<sup>134</sup> with most trafficking emerging from Central and South-Eastern Europe, the Commonwealth of Independent States and Asia. Trafficked people face great health risks and have little access to services. Some trafficked women and children are particularly vulnerable to HIV and sexually transmitted infections, due to their forced involvement in the sex industry.

**Health care workers and universal precautions.** People who come into contact with blood on a regular basis as part of their profession are also susceptible to HIV infection and have the right to protect themselves in their workplace. This sometimes gives rise to the mistaken believe that the right of patients living with HIV to keep their status confidential conflicts with the rights of health care workers to protect themselves. Not only would abrogation of the right to confidentiality lead in many cases to simple denial of medical services to people living with HIV, it is well established that the risk of such transmission is exceedingly low with up to only 500 such infections estimated worldwide each year, mostly in developing countries.<sup>135</sup> Moreover, by

130 'Estonia: Linguistic Minorities in Estonia: Discrimination must end', Amnesty International, 2006, EUR 51/002/2006; 'Memorandum to the Estonia Government: Assessment of the progress made in implementing the 2004 recommendations of the Commissioner for Human Rights of the Council of Europe', Strasbourg, Council of Europe, 11 July 2007, CommDH(2007)12; Downes, P, 'Intravenous drug use and HIV in Estonia: socio-economic integration and development of indicators regarding the right to health of its Russian-speaking population', *Liverpool Law Review*, 28:271 (2007).

131 'Positively abandoned: Stigma and discrimination against HIV-positive mothers and their children in Russia', New York, Human Rights Watch, June 2005, Vol. 17, No. 4(D).

132 "'Life doesn't wait': Romania's failure to protect and support children and youth living with HIV', New York, Human Rights Watch, August 2006, Vol. 18, No. 6(D).

133 Ivakhnyuk, *Ibid.*, p. 4.

134 Facts & figures on violence against women, UNIFEM,

[http://www.unifem.org/gender\\_issues/violence\\_against\\_women/facts\\_figures.php](http://www.unifem.org/gender_issues/violence_against_women/facts_figures.php)

135 Prevention of health care-associated HIV infection, WHO, available at: <http://www.who.int/eh/en/HealthCareHIV.pdf>

following internationally adopted Universal Precaution protocols, health care institutions and workers can and should employ simple and effective means of protecting themselves from a range of bloodborne infections, including HIV. This is further supported by the consideration that the majority of people living with HIV are unaware of their status. Universal precautions should therefore be “followed in the care of every patient, regardless of their diagnosis and should be applied universally.”<sup>136</sup> Consistent application of universal precautions allows the individual rights of people living with HIV and health care workers to be equally observed without contradiction, while providing the most effective means of avoiding HIV transmission in the health care setting.

## Integrating gender in HIV programmes and policies

In line with the 2001 UNGASS Declaration of Commitment by Member States, a priority of HIV policy should be to transform the status of women in society, address issues such as economic insecurity, access to education and legal protections. By emphasizing gender-related economic and social barriers as determinants of HIV risk, this Declaration engages the non-health sectors to support transformative and empowering HIV interventions for women. Multisectoral collaborations are needed to complement health or medical intervention programmes in this regard. National AIDS programmes must cooperate and coordinate with development sectors responsible for the status of women in order to meet the UNGASS objectives.

A report by the World Health Organization suggested four essential principles for integrating gender in HIV programmes and policies:<sup>137</sup>

1. Do no harm
2. Gender sensitive programmes
3. Transformative interventions
4. Empowering interventions

This framework begins from the most basic principle of social interventions – the mandate to avoid harm – which aims to ensure that HIV policies and programmes do not adversely affect females. A ‘gender sensitive’ approach ensures HIV policies and programmes consider specific factors that underlie the unique HIV vulnerabilities of females and males; gender sensitivity is considered vital to ensuring that policies and programmes will be acceptable to women and effective in local contexts. In order to truly impact on women’s specific HIV vulnerabilities, the

*Consistent application of universal precautions allows the individual rights of people living with HIV and health care workers to be equally observed without contradiction*

### Box. 3.5. Achieving gender-sensitive AIDS responses

As HIV is most often transmitted sexually, it has long been recognized that unequal relationships between men and women, and the social norms that perpetuate them, have important impacts on HIV epidemics. In 2008 UNDP, in collaboration with the UNAIDS Secretariat, UNIFEM and a broad range of stakeholders, presented a guidance paper for promoting gender-sensitive national AIDS responses. The gender guidance aims to promote increased and improved action on the intersecting issues of AIDS and gender inequality at country level, emphasizing three cross-cutting principles: (1) know your epidemic; (2) ensure that responses are evidence-informed; and (3) root strategies, policies and programmes in human rights.

The guidance emphasizes that setting gender and AIDS programme priorities will vary according to a country’s epidemic situation and local contexts, and recommends collecting data that fully capture information about the gender dimensions of the HIV epidemic. Identifying and supporting discordant couples is important in both contexts, as is paying attention to the differential impact of HIV on women and men, either as people living with HIV or as care-givers or family members.

Integrating gender into strategic planning is also crucial. Multisectoral AIDS programmes should ensure that specific actions to advance gender equality are planned, implemented and evaluated. It is essential however that national AIDS authorities provide the central vision, leadership and actions on gender that are required for effective and sustainable responses to AIDS.

The final objective of the guidance is to use the gender AIDS responses to promote wider gender-equality goals. One way to work towards this is by promoting the AIDS capacities of those working on gender equality, while also developing the gender capacities of those working on AIDS issues. In 2009, UNDP and civil society partners in the region plan to adapt the gender guidance to the specificities of the Eastern European and CIS context.

<sup>136</sup> Ibid.

<sup>137</sup> WHO Integrating gender into HIV Programmes – A review paper, Department of Gender and Women’s Health, Family and Community Health, 2003, pp. 27–41.

*In order to truly impact on women's specific HIV vulnerabilities, HIV interventions should seek to mitigate the overarching social dynamics that place women at a lower status than men at various points across the lifespan*

WHO calls for HIV interventions to bring about transformations in social and cultural processes that contribute to gender disparities. This goes beyond addressing 'women's needs' exclusively, but rather aims to address and alter the overarching social dynamics that place women at a lower status than men throughout the lifespan. In order for gender-related HIV interventions to be sustained over time, policies and programmes must also aim to empower women – to have the capacity, liberty and resources to advocate for themselves, hold positions of authority and determine their own outcomes. Over the past five years, many countries in the region such as Albania, Bosnia and Herzegovina, Croatia, Serbia, Ukraine, Kyrgyzstan and Tajikistan, to name just a few, have witnessed successful efforts in programmes adopting a multisectoral approach to address gender-related HIV vulnerabilities.

## Chapter conclusions

States in Eastern Europe and the CIS have committed to achieve Universal Access by 2010. Achieving this goal is intrinsically linked to respect for the rights of people living with HIV and populations at risk of infection. Explicit efforts for protecting and fulfilling human rights are both a means and an objective in that regard: Universal Access means eliminating discrimination against vulnerable populations and taking specific measures to ensure the full enjoyment of basic rights and freedoms by people living with HIV as the most effective means of responding to the epidemic.

Meeting these Universal Access obligations is not simply a matter of states agreeing to international treaties and declarations, but a matter of overcoming inherited prejudices and social exclusion of vulnerable populations. Implementing the laws on the books, where they exist, and advocating for legislative change where they do not, require both a critical mass of support from mainstream societies and institutional partnerships on the ground that offer legal services and empower people to claim their rights. Deliberate communication and advocacy campaigns are necessary to rally support and encourage social change.

As far as gender aspects of the response are concerned, this chapter has highlighted that actions in multiple sectors – health, education, welfare, economic – are needed to improve the status of women, which will help to reduce HIV throughout society. Raising the status of women means changing gender roles, which are deeply entrenched within societies.<sup>138</sup> Even where gender equality has been supported by law, socially prescribed expectations and interactions still impact the HIV vulnerabilities of men and women. Thus, stated legal policies need to be accompanied by social transformation actions to ensure gender equality in order to reduce HIV vulnerabilities.<sup>139</sup> This includes improving access to education for girls; programmes to improve understandings of sexual health and reproduction among both females and males; measures to better understand and address the vulnerabilities of sexual minorities, including men who have sex with men; measures to protect women's choices regarding marriage and fertility; measures to protect women from violence, coercion and trafficking; and measures to improve women's economic opportunities and empowerment.

<sup>138</sup> du Guerny, J. E. Sjöberg, 'Interrelationship between gender relations and the HIV/AIDS epidemic,' in Mann, J. M., S. Gruskin, M. A. Grodin, G. J. Annas, *Health and human rights*, Routledge: New York, 1999, p. 209.  
<sup>139</sup> *Gender guidance for national AIDS responses*, UNAIDS/PCB(22)/08.3, pp. 1-2.

# Conclusions: Looking forward – building blocks for national advocacy and policy

This Chapter concludes the report with four synthesized themes, drawn from the epidemiologic research and policy reviews in Chapters 1-3 and from research findings from the six-country study conducted for the purpose of this report. The thematic synthesis is followed by sector specific recommendations from that study.

## General parameters of the national response frameworks

Conclusions presented here can serve as the bases for region-specific policy and advocacy recommendations to achieve the dual, complementary goals of protecting individual rights and mounting effective national responses. The four themes are as follows: i) Need for measures to enhance policy leadership and improve national capacity for 'Knowing Your Epidemic' and ensuring 'Universal Access'; ii) Building robust state/non-state partnerships to overcome stigma and deliver services; iii) Improving mechanisms to operationalize rights and counter discrimination; and iv) Applying a gender-sensitive response.

### Enhanced policy leadership, Knowing Your Epidemic and Universal Access

A rigorous and accurate evidence base is fundamental to effective policy and advocacy strategies for people living with HIV. The 'Know Your Epidemic' agenda, advocated by UNAIDS, encourages states to use surveillance and research to define the epidemiological and behavioural situation and context and the populations, geographic locations and risk settings most in need of HIV services.<sup>140</sup> Whenever possible, analysis should focus not just on HIV overall, but the most recent infections, to ensure that prevention responses evolve as epidemics evolve. Based on this information, states and local actors can adapt strategies that best fit their circumstances – achieving the right mix of efforts working with key populations, addressing cross-over infections from key populations to their partners, and working with other vulnerable populations. Whatever the combination of populations and behaviours being targeted, states must also develop strategies that respond to immediate service and information needs (such as condom promotion and distribution to key populations) as well efforts to influence the context within which HIV risk and vulnerability is generated and sustained (such as initiatives to de-stigmatize sexual minorities so that they are more likely to seek and benefit from services). Moreover, context-specific information allows for policies to build on local strengths and sub-national capacities, while also acknowledging limitations that might undermine well intentioned programmes that lack feasibility and acceptability.

High quality surveillance and ongoing social research is needed for key actors to achieve a comprehensive knowledge of their epidemic. This includes standard sentinel surveillance and case reporting, but must also involve 'second generation surveillance' measures. As defined by the World Health Organization, second generation surveillance<sup>141</sup> involves the following features: (a) being appropriate to the epidemic typology, where concentrated, generalized or mixed; (b) being dynamic and adapting to shifts in the epidemic; (c) using resources where they will generate the most useful information; (d) combining biological and behavioural information with other types of research, such as data on drug use and drug treatment, sexually transmitted in-

*A rigorous and accurate evidence base is fundamental to effective policy making*

*High quality surveillance and ongoing social research is needed for key actors to achieve a comprehensive knowledge of their epidemics*

<sup>140</sup> UNAIDS. *Practical guidelines for intensifying HIV prevention: towards universal access*, 2007.

<sup>141</sup> UNAIDS/WHO working group on global HIV/AIDS and STI surveillance, 2000.



fections and other forms of morbidity and mortality; and (e) using data to inform local and national policy responses. UNAIDS/WHO have produced technical guidelines<sup>142</sup> to assist the conducting of population-based surveys. The guidelines also provide information on how to combine these results with data obtained from sentinel surveys to produce a 'best' estimate of HIV prevalence in a country.

*Qualitative studies can provide in-depth understandings of the experiences of people living with HIV and those vulnerable to infection*

In addition to accurate HIV-prevalence data, other types of information are needed for advocacy and policy. Qualitative studies can provide in-depth understandings of the experiences of people living with HIV and those vulnerable to infection. Quantitative surveys often do not capture other social issues that co-exist with HIV, such as poverty, rights violations, gender dynamics and legal and health infrastructures for supporting the well-being of people living with HIV and members of most-at-risk populations. Strategies for gathering qualitative information concurrently with biological and behavioural risk data may identify strategic channels for focusing prevention and treatment resources, which can yield more effective outcomes.

Researchers and policy makers have agreed that an integrated and targeted approach to prevention, treatment and care is essential for responding to HIV. In 2001, world leaders came together at the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) and committed to a broad range of indicators and targets, including enhanced political leadership. In 2004, leaders from the region signed the Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia, setting out region-specific means of achieving and even going beyond these commitments. In addition, the Global Fund has required that all recipient countries have a coordinated and integrated national strategy for HIV prevention, treatment and care, in line with the UNAIDS-promoted Three Ones requirement for effective responses, including one agreed national action framework, one inclusive, multi-sectoral coordination authority and one country-level monitoring and evaluation system.<sup>143</sup> However, although many countries in the region can produce on paper a coordinated and integrated national HIV strategy, many fall short of realizing those goals in practice.

*An integrated and targeted approach to prevention, treatment and care is essential for responding to HIV*

In order to be truly effective, an integrated and nationally owned HIV policy response must be based on an astute awareness of the local epidemic, including shifting trends in new infections, risk behaviours and HIV-related norms and attitudes. Information from research and surveillance systems must be interpreted with regards to achieving the aims of Universal Access to prevention, education, testing and treatment, as well as making informed resource allocation decisions.<sup>144</sup> In light of the ambitious aims of the Universal Access agenda, multi-sectoral cooperation and collaboration is crucial; no single-intervention programme or single-sector response can provide sustained success.<sup>145</sup>

### **Specific recommendations in this area**

- *All countries should submit timely, comprehensive UNGASS reports, uphold Dublin Declaration commitments, and set ambitious Universal Access targets that will meet critical coverage necessary to achieve impact. Regional bodies such as the CIS Coordination Council on AIDS should continue to play a role in enhancing coordination and experience-sharing across countries.*
- *National responses should be based on accurate and updated evidence to 'know your epidemic' and inform HIV policy and resource allocation, with close attention to service-coverage of populations at risk. Introducing or scaling up second generation surveillance systems to compliment sentinel and case reporting is a key condition.*

<sup>142</sup> Ibid.

<sup>143</sup> UNAIDS, "Three ones" key principles: Coordination of national responses to HIV/AIDS: Guiding principles for national authorities and their partners, 2004.

<sup>144</sup> UNAIDS, 'Towards Universal Access: Scaling up priority HIV/AIDS interventions in the health sector: Progress report,' April 2007.

<sup>145</sup> For more information on a well-balanced and consistent approach to tackling the epidemic see G. Hernes, 'UNESCO and HIV/AIDS: Ten Lessons,' pp. 253-261, in C. Coombe, *The HIV Challenge to Education: A Collection of Essays*, IIEP, UNESCO: Paris, 2004.

- *In addition to strengthening the 'Three Ones' at the national level, governments should ensure that HIV programming is integrated into national development planning instruments, including Poverty Reduction Strategies to ensure long-term uninterrupted funding to meet the exceedingly long-term nature of the epidemic. Integration into the country's plans will provide a strong 'enabling environment' for implementing HIV programming. However, it is also necessary to understand the capacity gaps at sector, organizational and individual levels that may impede implementation. Such an understanding can be gained through a comprehensive capacity assessment (see Annex 4).*
- *Increase the visibility of political leadership and solidarity in support of the fair treatment of people living with HIV and other key populations at risk, including (but not limited to) people who inject drugs, sex workers, men who have sex with men, ethnic minorities, women and migrants.*
- *Uphold the greater and meaningful involvement of people living with HIV (GIPA/MIPA) principle by ensuring that people living with HIV are empowered to participate in national decision-making processes. Special effort can be made to actively encourage employment of people living with HIV in official positions within government organizations responsible for aspects of the government response.*
- *Given the paramount role of injecting drug use in spreading HIV across the region, harm reduction should feature in any national response where injecting drug users comprise a core population at risk. This includes scaling up needle exchange and substitution therapy programmes where such programmes are available, or assessing the feasibility of introducing them and pilot testing where they are not.*
- *Adopt approaches that address HIV risk behaviours as a public health concern, rather than criminalizing and persecuting these behaviours.*

*The challenge for Eastern European and CIS countries is to mobilize and build social support networks for an effective response where HIV remains in the collective conscience a 'minority issue'*

### Building robust state/non-state partnerships to overcome stigma and implement services

Addressing stigma must remain central in advocacy and policy efforts, as stigma lies at the root of the obstacles faced by people living with HIV. International experience has shown that stigma can be tackled where civil society and state priorities combine in a joint effort.

Among the key findings of the Dublin Declaration, on partnership to fight HIV/AIDS in Europe and Central Asia, is the need for political leadership to assertively and decisively speak out on HIV alongside the need for increased civil society involvement in the response to HIV.<sup>146</sup> In this respect, the low level of civil society political engagement and activism that have characterized some countries in the region is a significant barrier to developing grass-roots programmes. Another barrier is the capacity of civil society organizations to manage development projects and administration, to expand and diversify networks and to guide and effect change both within organizations and in their environments. The challenge for Eastern European and CIS countries is to mobilize and build social support networks for an effective response where HIV remains in the collective conscience a 'minority issue'. A strategic objective, in this case, would be to build a broad social alliance against all forms of stigma, concentrating on common goals among different populations.<sup>147</sup> Understanding the cultural, social and political nature of these links will point to effective strategies in each country.

Although leadership might not always emerge at the grassroots of any struggle, the work of leaders can powerfully turn the tide of policy at local and national levels. Thus, local leadership should be encouraged through programmes which empower people living with HIV in the region. Inter-

<sup>146</sup> WHO Europe/UNAIDS, *Progress on implementing the Dublin Declaration: on partnership to fight HIV/AIDS in Europe and Central Asia: Policy Brief*. UNAIDS: Geneva, 2008.

<sup>147</sup> For a helpful discussion on the differences between conversion, convergence and the strategic engagement needed for establishing complementarities between different constituencies see T. O'Neil, *Human Rights and Poverty Reduction: Realities, Controversies and Strategies*, 2006, available at [http://www.odi.org.uk/rights/Publications/Rights%20Meeting%20Series%20Publication%202006/intro\\_screen.pdf](http://www.odi.org.uk/rights/Publications/Rights%20Meeting%20Series%20Publication%202006/intro_screen.pdf) (accessed December 2007).

*Local leadership should be encouraged through programmes which empower people living with HIV in the region*

national organizations have the potential to help build broad alliances among communities and states, bridging the public and private sectors, which are needed to shift policy. But this work cannot and should not substitute for ground-level advocacy and initiatives by citizens themselves. Instead, the work of international organizations should seek to reinforce and support locally generated initiatives and promote public-private partnerships. This goes beyond the funding of initiatives, towards using existing systems and structures rather than stand-alone project implementation units.

### **Specific recommendations in this area**

- *Governments should increasingly seek and facilitate public-private partnerships (PPP), ease tax burdens on non-profit organizations and improve direct public funding of non-governmental organizations to carry out service provision for key populations. PPPs are not simple to develop: capacity development at the enabling environment and organizational levels may be necessary (based upon the findings of a capacity assessment targeting this area – see Annex 4). This can include creating the necessary legislative and policy framework to facilitate these partnerships, as well as developing the capacities of organizations to engage in PPP (including contracting and procurement systems, oversight and monitoring mechanisms and other elements).*<sup>148</sup>
- *Fund and implement social educational programmes aimed at the general public, in partnership with non-state and private sector media organizations, to heighten basic understandings about HIV transmission and reduce lingering myths that drive fear and avoidance.*
- *Partner with organizations of people living with HIV and other NGOs to provide required educational training on HIV for civil servants, policymakers, reporters and other professional bodies that disseminate information to the public*
- *Encourage and support more responsible reporting on HIV by the media, with special emphasis on efforts to humanize people living with HIV.*
- *Promote the active engagement of faith based communities and religious leaders in the response to HIV, especially in reducing stigma and discrimination and providing care and support to people living with HIV.*
- *Prioritize support and technical assistance to NGOs that work with populations at risk, including injecting drug users, men who have sex with men, sex workers, ethnic minorities and migrant populations. In addition to technical assistance focusing on the individuals in the NGOs, it may be necessary to strengthen functional capacities at the organizational level, which include the NGOs' abilities to engage in multi-stakeholder dialogue, analyse a situation and create a vision for change, and formulate programmes and strategies; budget, manage and implement projects, and monitor and evaluate them. In addition, issues such as leadership and the core business processes (human resources, financial management) may also need to be strengthened.*
- *Seek to relax legal barriers on the freedom of association and expression of non-governmental organizations and populations at risk, in order to facilitate their partnership in the national response.*

*The challenge often has less to do with introducing legislative changes and more to do with strengthening mechanisms to monitor and enforce existing legal frameworks.*

### **Operationalizing rights**

As underscored in the preceding chapters, the challenge of upholding rights for an effective response in Eastern Europe and the CIS often has less to do with introducing legislative changes and more to do with strengthening mechanisms to monitor and enforce existing legal frameworks.

<sup>148</sup> For more information on capacity development for public private partnerships, please see [http://www.capacity.undp.org/index.cfm?module=ActiveWeb&page=WebPage&s=public\\_private\\_partn](http://www.capacity.undp.org/index.cfm?module=ActiveWeb&page=WebPage&s=public_private_partn)

Indeed, each chapter of this report provides evidence (both primary data from respondents as well as secondary data from published sources) on the role that a general lack of awareness and resource limitations play in hindering support for the implementation of rights for people living with HIV that already exist in the region. People living with HIV spoke directly of the lack of infrastructure to monitor and support their legal rights, and members of mirror institutions commented on the need for training and capacity building to ensure that legal provisions practically benefit those suffering rights violations.

### **Specific recommendations in this area**

- *In partnership with civil society, governments should publicly assess and periodically review national legislation compliance with international commitments. This can include a capacity assessment of the enabling environment looking at whether there are overlaps or duplications (or gaps) in national legislation that impede compliance with international commitments. Such an assessment can also examine the process through which legislation is developed and whether government and civil society organizations have the capacity to engage meaningfully in such processes.*
- *Promote the active engagement of parliamentarians, as outlined in the joint handbook for parliamentarians “Taking action against HIV and AIDS” produced by the International Parliamentary Union, UNDP and the UNAIDS secretariat.*
- *Ensure that people living with HIV are consulted in the design and implementation of such laws and related enforcement mechanisms.*
- *Establish, strengthen and scale-up accessible legal aid, support and counselling services<sup>149</sup> including crisis helplines for people living with HIV and populations at risk.*
- *Ensure that enforcement mechanisms for anti-discrimination legislation are adequately funded, and have adequate independence and powers to investigate and resolve complaints and enforce remedial action. Partner with ombudsman and other national rights monitoring institutions in this regard.*
- *Actively prosecute parties, within the means provided by law, that violate anti-discrimination policies.*
- *Promote legal education campaigns and publicize legal remedies for instances of discrimination.*
- *Provide human rights training to those in the justice and criminal justice systems (police, judges, correctional authorities) as well as to professionals in the health, education and employment sectors. This training should focus on the application of both international human rights law and standards and relevant national legislation in the context of the local HIV epidemic.*
- *Ensure that training programmes are based on comprehensive organizational capacity assessments and viewed as one component of broader capacity development of the justice and criminal justice systems. Adequate incentives within organizations, such as increases in remuneration, or linking training to career growth, can be important to ensure that trainees apply learned skills and effect change.*

*Gender plays a fundamental role in determining both biological susceptibility and vulnerability to the social consequences of HIV*

### **Applying a gender-sensitive response**

While often overlooked, gender plays a fundamental role in determining both biological and social susceptibility to HIV infection and vulnerability to the consequences. Because HIV is increasingly affecting women in the region, policies and programmes should aim to address underlying factors in gender inequality and empower women to advocate for improved health, education, legal protection and economic independence. Greater efforts to understand and ad-

<sup>149</sup> See the website of the AIDS Law Project for more information: <http://www.alp.org.za/>

dress HIV transmission among sexual minorities, including men who have sex with men, is another important dimension of gender in the region. At the same time, it is important to engage men both to reduce their own vulnerability linked with male gender roles as well as to address their key role in determining the vulnerability of women.

*Coordinated, multi-level national responses to address stigma are warranted throughout the region*

### **Specific recommendations in this area**

- *Ensure that national monitoring, evaluation and surveillance systems collect gender-disaggregated data to inform gender-sensitive responses.*
- *Ensure public awareness campaigns are accessible to at-risk women and men by targeting media campaigns appropriately, and by designing health education messages that consider interactions between gender and age/developmental stage.*
- *Acknowledge the multi-faceted roles of women in society—e.g., as independent and autonomous individuals, carers, wives, mothers and professionals—when designing HIV prevention and educational campaigns.*
- *Enhance data collection and response efforts at regional and national levels targeting ‘hidden epidemics’ among men who have sex with men and other sexual minority populations.*
- *Implement frameworks to support women suffering from domestic violence, coercive sex within marriage and economic disempowerment to achieve improved control over their lives.*
- *Scale up awareness and prevention programmes targeting partners/spouses and families of populations at risk, including those of injection drug users and migrants.*
- *Improve access to sexual and reproductive health education and services so that women can make informed decisions about sexual behaviour, pregnancy and family planning.*
- *Women living with HIV need access to the full range of reproductive/gynaecological health services without discrimination. Governments should redouble efforts to address the widespread discrimination evidenced through this report.*
- *Ensure that appropriate counselling and support services for pregnant women diagnosed with HIV during provider-initiated (e.g. routine opt-out) voluntary testing are in place and enforced.*
- *Implement provider-initiated, routine opt-out voluntary HIV testing for pregnant women during antenatal visits and/or at delivery only with appropriate counselling and full access to medication to prevent mother-to-child transmission.*

## **Sector-specific recommendations on decreasing vulnerability**

Drivers of stigma towards people living with HIV and specific manifestations of stigma in the health, education and employment sectors indicate that a coordinated, multi-level national response is warranted throughout the region. Although the six countries identified for the primary research clearly differ according to HIV prevalence, infrastructural capabilities and social and cultural processes, the study has identified common weaknesses that reinforce stigma and perpetuate the unfair and illegal treatment of people living with HIV in the region. Here we summarize the major recommendations for policy and advocacy, grouped according to sector.

### **Recommendations for the health sector**

Strengthened policies for treating people living with HIV in the health sector are needed to protect and improve the well-being of HIV-positive patients as well as health professionals who provide care. Specific strategies include:



- Where possible, ensure that HIV programming prioritizes capacity development and the potential of HIV-focused work to strengthen the broader health sector.
- Provide mandatory comprehensive HIV education for all health professionals at polyclinics.
- Integrate basic HIV education (epidemiology, symptom diagnosis, prevention, counselling, treatment, care, universal precautions) into both the training of all medical students and re-training programmes for medical professionals. In addition, contextualize this training in the broader capacity development of the organizations in which the trainees will work, to ensure that the training meets organizational needs and will be able to impact the effectiveness of the organization.
- Prioritize Universal Precautions for all staff in all health care settings. Provide materials to protect health care staff from accidental exposure to HIV (e.g. latex gloves, post-exposure prophylaxis), and ensure sufficient supplies. Monitor compliance with universal precautions at regional health facilities.
- Monitor health settings for discriminatory treatment of people living with HIV or populations at risk.
- Respect the rights of patients living with HIV, including the right to informed consent to treatment, access to scientifically and medically appropriate treatment, and respect for the right to privacy. Make information on rights publicly available in health care settings.
- Conduct provider-initiated voluntary HIV testing only under conditions of the three Cs: counselling, informed consent and confidentiality.
- Ensure uninterrupted supply of antiretroviral medications by removing barriers in pricing, tariffs and trade agreements, improving legislation and strengthening procurement and delivery systems.
- Consider policies to improve continuity of healthcare for migrants living with HIV. Regional bodies, such as the CIS Coordination Council on HIV/AIDS can play a role in coordinating healthcare continuity for migrants across countries.
- Improve psychological and mental health support services for people living with HIV as part of an integrated health services package.
- Improve quality and access to substance use treatment services, including harm reduction programmes, for people living with HIV and members of most-at-risk populations.

### **Recommendations for the education sector**

Research presented in this report indicates a growing need for the educational sector to develop explicit and unambiguous policies to prepare for growing numbers of students affected by or living with HIV. Specific strategies can include the following:

- Ensure that HIV-status disclosure and confidentiality policies for the education sector are broadly known and enforced, with policies clearly explained on student enrolment forms and in educational settings.
- Provide mandatory HIV education for all school principals, administrators, teaching and nursing staff, including training targeting the reduction of stigma. Age-appropriate HIV education for students is also fundamental.
- Ensure Universal Precaution protocols are in place for in-school medical facilities to support confidentiality of student HIV status, with basic safety training for all teachers and school staff.
- Monitor school settings for discriminatory treatment of children living with HIV or other children affected by HIV. Involve educational governing bodies in monitoring and enforcement activities to promote equal and unbiased education for children affected by HIV.
- Support schools (principals and teachers) where children living with HIV are enrolled, especially with regards to addressing community-level stigma towards children affected by HIV.
- Anticipate supporting children of parents living with HIV to ensure their access to education, including legal aid services. It will be important to look not only at the demand side for these services, but also the capacity of the organizations to deliver them.

*There is a growing need for the education sector to develop explicit and unambiguous policies to prepare for the growing number of students affected by or living with HIV*

### **Recommendations for the employment sector**

People living with HIV may experience unique challenges in gaining and maintaining employment. Policies to protect their right to work and assure a safe workplace are needed. Managers and supervisors warrant additional support to ensure their awareness and compliance with legal policies. Specific strategies to improve access to fair and appropriate employment for people living with HIV include:

- *Provide guidelines to employers and trade unions and promote programmes to support the health and well-being of HIV-positive employees and reduce stigma and intolerance in the workplace.*
- *Ensure universal precautions to reduce incentives for confidentiality breaches in relevant workplace medical settings.*
- *Offer confidential job counselling and placement services for people living with HIV seeking employment.*
- *Monitor and address discriminatory treatment of people living with HIV in the workplace, including legal counselling programmes to address cases of employment discrimination.*
- *Publicize HIV-status disclosure and confidentiality policies for job applicants, and have all policies clearly labelled on application forms.*
- *Collaborate with employers and trade unions to make the rights of employees known to them and to monitor discrimination.*
- *Establish and implement personnel policies on HIV/AIDS in the workplace, with major a focus on education, prevention and communication activities.*

*People living with HIV come from all walks of life, representing the full spectrum and diversity of the region*

### **In summary**

As demonstrated in the preceding pages through data and first-person narratives, HIV is a critical issue in the daily lives of many hundreds of thousands, if not millions of people across Eastern Europe and the CIS. With tens of thousands of people infected with HIV in the region each year, there is no simple profile of a person living with HIV. People living with HIV come from all walks of life, representing the full spectrum and diversity of the region. Despite this, all face the physical challenges associated with HIV and the social vulnerability wrought by stigma, discrimination and exclusion. At the same time, 'living with HIV' can also be used to describe the states of the region in their quest for effective responses to a challenge that is best considered in terms of decades, or even generations, rather than years. No longer can the region hope to avoid an epidemic outright. Rather, efforts are now focused at reducing the long-term impact of AIDS and adjusting health, social and other systems to accommodate the needs of the growing ranks of people living with HIV and populations at risk in a way that strengthens health systems.

In over 25 years of global experience responding to AIDS, we have learned that it is possible to make dramatic improvements in the lives of people living with HIV to lead long, healthy and productive lives, while in turn fostering effective public health responses that reduce the spread of new infections. The measures recommended in the preceding pages to improve the rights and standard of living of individuals can and must happen simultaneously with measures to protect public health; these are not incompatible goals but are mutually reinforcing. A greater regard for individual social inclusion will advance both the public good of collective human capital and build conditions for the most effective response to HIV in the countries of Eastern Europe and the CIS. In summary, what is good for people living with HIV and populations at risk is good for society as a whole.

*A greater regard for individual social inclusion in the countries of the region will both advance the public good and build the conditions for the most effective regional response to HIV*

# ANNEXES

## Annex 1: Rights relevant to people living with HIV

Provisions from international human rights treaties have significant implications for the effectiveness of the response to the HIV epidemic

*The right to the highest attainable standard of health.* Access to humane, non-discriminatory and high-quality health services and essential medications is the *sine qua non* of society's health obligations to PLHIV. In practical terms it means that health systems should be responsive to specific needs associated with HIV – both of people infected as well as of the general population so that the risk of infection is diminished.

*The right to life.* The United Nations International Covenant on Civil and Political Rights (ICCPR) recognizes that “every human being has the inherent right to life”. In practical terms PLHIV warrant every effort to protect and prolong their lives.

*Non-discrimination and equality before the law.* ICCPR Articles 14 and 26 together guarantee the rights to equal protection before the law and to be free from discrimination on many grounds. The United Nations Commission on Human Rights has confirmed that ‘other status’ in non-discrimination provisions in international human rights treaties is to be interpreted to include health status, including HIV status<sup>150</sup>.

*Human rights of women.* The United Nations Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) obliges states parties to address all aspects of gender-based discrimination in law, policy and practice. Equal protection of the rights of women and girls is critical to preventing HIV transmission and to lessening the impact of the epidemic on women.

*Human rights of children.* Under the United Nations Convention on the Rights of the Child (CRC), children are confirmed to have many of the rights of adults, in addition to specific rights for children. Children have the right to freedom from trafficking, prostitution, sexual exploitation and sexual abuse; the right to seek, receive and impart HIV information; and the right to special protection and assistance, if deprived of their family environment. They also have the right to education, the right to health and the right to inherit property. The right to special protection and assistance, if deprived of his or her family environment, protects children if they are orphaned by the death of parents from AIDS. Children also have the right to be actors in their own development, to express their opinions and to be involved in the design and implementation of child-focused HIV-related programs.

*Right to marriage and family.* ICCPR Article 23 recognizes the right to marry and found a family. Mandatory pre-marital HIV testing as a precondition for marriage, or forced abortions or sterilization of women living with HIV, violate these (and other) rights.

*Right to privacy.* This right, set out in the ICCPR Article 17, encompasses obligations to respect physical privacy (e.g. the obligation to seek informed consent to HIV testing) and the need to respect confidentiality of personal information (e.g. information relating to a person's HIV status).

*Right to education and freedom of expression and information.* The implications of these rights in the context of the HIV epidemic are explained above, in the section on ‘Education and information.’

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<sup>150</sup> Commission on Human Rights, Resolutions 1995/44 of 3 March 1995 and 1996/43 of 19 April 1996.

*Freedom of assembly and association.* The right to peaceful assembly and association, provided by Article 20 of the United Nations Universal Declaration on Human Rights (UDHR) and by Article 22 in the ICCPR, has frequently been denied to civil society organizations working on human rights and HIV.

*Right to work.* This right, enshrined in Article 23 of the UDHR and Articles 6 and 7 of the International Covenant on Economic, Social and Cultural Rights (ICESCR), entails the right of every person to access employment without any precondition except the necessary occupational conditions. This right is violated when an applicant or employee is required to undergo mandatory testing for HIV and is dismissed or refused employment on the ground of a positive result. The right to work further guarantees the right to safe and healthy working conditions. Where a possibility of HIV transmission exists, states should take measures to minimize these risks, rather than deny PLHIV the right to work.

*Right to enjoy the benefits of scientific progress and its applications.* This right, set forth in Article 27 of the UDHR and Article 15 of the ICESCR, obliges the state to ensure that treatment and participation in clinical trials are made available equally to marginalized and vulnerable populations. This right is particularly relevant in view of scientific and pharmaceutical advances made in diagnosis and treatment, as well as in the development of a vaccine and new prevention tools such as microbicides.

*Right to freedom of movement.* This right, found in Article 12 of the ICCPR and Article 13 of the UDHR, encompasses the right of everyone to freely choose his/her place of residence within a country, as well as the rights of nationals to enter and leave their own country. Restricting liberty of movement or choice of residence for PLHIV, as well as restricting travel, are discriminatory and violate this right.

*Right to an adequate standard of living and social security services.* This right, found in Article 25 of the UDHR and in Articles 9 and 11 of the ICESCR, stipulates that states should ensure that PLHIV are not discriminatorily denied an adequate standard of living or social security services. Families, caregivers and children affected by HIV should be protected from food insecurity and impoverishment resulting from living with HIV infection.

*Right to participation in political and cultural life.* This right, found in Article 25 of the ICCPR and Article 15 of the ICESCR, is essential for ensuring the participation of those most affected by HIV in all aspects of HIV-related policies and programs.

*Right to liberty and security of person.* This right, found in Article 9 of the ICCPR, means that the right to liberty and security should not be mitigated based on a person's HIV-status (e.g. by placing an HIV-positive individual in quarantine or isolation). Compulsory HIV testing can also constitute a deprivation of liberty and a violation of the right to security of person. Respect for the right to physical integrity requires that testing be voluntary and undertaken with the informed consent of the person.

*Freedom from cruel, inhuman or degrading treatment or punishment.* This right, found in Article 5 of the UDHR and Article 7 of the ICCPR, provides for the state to ensure that prisoners have access to HIV-related information, education and means of protection (such as condoms and clean injection equipment) as well as voluntary counselling, testing and treatment.

All these provisions from international human rights treaties have direct implications for people affected by the epidemics – both those living with HIV and their families.

This list is adapted from *Handbook on HIV and human rights for national human rights institutions*, Geneva, OHCHR/UNAIDS, 2007, available at <http://www.ohchr.org/Documents/Publications/HandbookHIVNHRIs.pdf>

## Annex 2: Further reading related to recommendations presented in the “Conclusions” chapter

- UNAIDS (2007). Reducing HIV Stigma and Discrimination: A critical part of National AIDS programmes. Geneva: Joint United Nations Programme on HIV/AIDS. A resource for national stakeholders in the HIV response.
- International Labour Organization (2001). Code of Practice on HIV/AIDS and the World of Work. Geneva: ILO.
- Interagency Standing Committee (2004). Guidelines for HIV/AIDS interventions in emergency settings. Geneva: UNFPA.
- International Institute for Educational Planning/UNESCO (2003). HIV/AIDS and education. A Strategic Approach. Paris: IIEP/UNESCO.
- UNDP (2004). HIV and Human Development in Central and Eastern Europe and the Commonwealth of Independent States. Reversing the Epidemic – Factors and Policy Options. Bratislava: UNDP.
- World Health Organization (2005). Policy and programming guide for HIV/AIDS prevention and care among injecting drug users. Geneva: WHO.
- Horizons Program (2002). HIV/AIDS-related stigma and discrimination: A conceptual framework and an agenda for action. New York: The Population Council.
- World Health Organization and UNAIDS (2000). Guidelines for Second Generation HIV Surveillance. WHO and UNAIDS. Geneva: WHO and UNAIDS.
- UNAIDS (2006). International Guidelines on HIV/AIDS and Human Rights, 2006 Consolidated Version. Geneva: UNAIDS.
- UNESCO (2008). EDUCAIDS: Framework for action. New York: UNESCO.
- UNAIDS (2008). Progress on implementing the Dublin Declaration: on partnership to fight HIV/AIDS in Europe and Central Asia. Geneva: UNAIDS.
- United Nations (2001). General Assembly Special Session Declaration of Commitment (2001)
- UNAIDS (2008). UNAIDS Policy Brief on the Criminalization of HIV Transmission. Geneva: UNAIDS
- Inter-Parliamentary Union/UNAIDS/UNDP (2007). Taking action against HIV: A handbook for Parliamentarians. Geneva: IPU/UNAIDS/UNDP



## Annex 3: International Guidelines on HIV and Human Rights

### Background and summary of the Guidelines

1. This document consolidates the Guidelines adopted at the Second International Consultation on HIV/AIDS and Human Rights, held in Geneva from 23 to 25 September 1996, and revised Guideline 6 on access to prevention, treatment, care and support adopted at the Third International Consultation on HIV/AIDS and Human Rights held in Geneva from 25 to 26 July 2002. The purpose of these Guidelines is to assist States in creating a positive, rights-based response to HIV that is effective in reducing the transmission and impact of HIV and AIDS and is consistent with human rights and fundamental freedoms.
2. The elaboration of such guidelines was first considered by the 1989 International Consultation on AIDS and Human Rights, organized jointly by the then United Nations Centre for Human Rights and the World Health Organization.<sup>151</sup> The United Nations Commission on Human Rights and its Sub-Commission on Prevention of Discrimination and Protection of Minorities repeatedly reiterated the need for guidelines. Increasingly, the international community recognized the need for elaborating further how existing human rights principles apply in the context of HIV and for providing examples of concrete activities to be undertaken by States to protect human rights and public health in the context of HIV.
3. The purpose of these Guidelines is to assist States in translating international human rights norms into practical observance in the context of HIV. To this end, the Guidelines consist of three parts: first, Guidelines for State action comprising action-oriented measures to be employed by Governments in the areas of law, administrative policy and practice that will protect human rights and achieve HIV-related public health goals; second, recommendations for dissemination and implementation of the Guidelines; and third, international human rights obligations and HIV, which describes the human rights principles underlying a positive response to HIV.
4. The Guidelines recognize that States bring to the HIV epidemic different economic, social and cultural values, traditions and practices – a diversity which should be celebrated as a rich resource for an effective response to HIV and AIDS. In order to benefit from this diversity, a process of participatory consultation and cooperation was undertaken in the drafting of the Guidelines, so that the Guidelines reflect the experience of people affected by the epidemic, address relevant needs and incorporate regional perspectives. Furthermore, the Guidelines reaffirm that diverse responses can and should be designed within the context of universal human rights standards.
5. It is intended that the principal users of the Guidelines will be States, in the persons of legislators and Government policymakers, including officials involved in national AIDS programmes and relevant departments and ministries, such as health, foreign affairs, justice, interior, employment, welfare and education. Other users who will benefit from the Guidelines include inter-governmental organizations (IGOs), non-governmental organizations (NGOs), networks of persons living with HIV (PLHIV), community-based organizations (CBOs), networks on ethics, law, human rights and HIV and AIDS service organizations (ASOs). The broadest possible audience of users of the Guidelines will maximize their impact and make their content a reality.
6. The Guidelines address many difficult and complex issues, some of which may or may not be relevant to the situation in a particular country. For these reasons, it is essential that the Guidelines be taken by critical actors at the national and community level and considered in a process of dia-

<sup>151</sup> Report of an International Consultation on AIDS and Human Rights, Geneva, 26 to 28 July 1989 (HR/PUB/90/2).

logue involving a broad spectrum of those most directly affected by the issues addressed in the Guidelines. Such a consultative process will enable Governments and communities to consider how the Guidelines are specifically relevant in their country, assess priority issues presented by the Guidelines and devise effective ways to implement the Guidelines in their respective contexts.

7. In implementing the Guidelines, it should be borne in mind that achieving international cooperation in solving problems of an economic, social, cultural or humanitarian character and promoting and encouraging respect for human rights and for fundamental freedoms for all, is one of the principal objectives of the United Nations. In this sense, international cooperation, including financial and technical support, is a duty of States in the context of the HIV epidemic and industrialized countries are encouraged to act in a spirit of solidarity in assisting developing countries to meet the challenges of implementing the Guidelines.

8. HIV continues to spread throughout the world at an alarming rate. The widespread abuse of human rights and fundamental freedoms associated with HIV has emerged in all parts of the world in the wake of the epidemic. In response to this situation the experts at the Second International Consultation on HIV/AIDS and Human Rights concluded the following:

(a) The protection of human rights is essential to safeguard human dignity in the context of HIV and to ensure an effective, rights-based response to HIV and AIDS. An effective response requires the implementation of all human rights, civil and political, economic, social and cultural, and fundamental freedoms of all people, in accordance with existing international human rights standards;

(b) Public health interests do not conflict with human rights. On the contrary, it has been recognized that when human rights are protected, fewer people become infected and those living with HIV and their families can better cope with HIV and AIDS;

(c) A rights-based, effective response to the HIV epidemic involves establishing appropriate governmental institutional responsibilities, implementing law reform and support services and promoting a supportive environment for populations vulnerable to HIV and for those living with HIV;

(d) In the context of HIV, international human rights norms and pragmatic public health goals require States to consider measures that may be considered controversial, particularly regarding the status of women and children, sex workers, injecting drug users and men having sex with men. It is, however, the responsibility of all States to identify how they can best meet their human rights obligations and protect public health within their specific political, cultural and religious contexts;

(e) Although States have primary responsibility for implementing strategies that protect human rights and public health, United Nations bodies, agencies and programmes, regional intergovernmental bodies and non-governmental organizations, including networks of people living with HIV, play critical roles in this regard.

9. There are many steps that States can take to protect HIV-related human rights and to achieve public health goals. The 12 Guidelines elaborated by the Consultations for States to implement an effective, rights-based response are summarized below.

**GUIDELINE 1:** States should establish an effective national framework for their response to HIV which ensures a coordinated, participatory, transparent and accountable approach, integrating HIV policy and programme responsibilities across all branches of government.

**GUIDELINE 2:** States should ensure, through political and financial support, that community consultation occurs in all phases of HIV policy design, programme implementation and evaluation and that community organizations are enabled to carry out their activities, including in the field of ethics, law and human rights, effectively.

**GUIDELINE 3:** States should review and reform public health laws to ensure that they adequately address public health issues raised by HIV, that their provisions applicable to casually transmitted diseases are not inappropriately applied to HIV and that they are consistent with international human rights obligations.

**GUIDELINE 4:** States should review and reform criminal laws and correctional systems to ensure that they are consistent with international human rights obligations and are not misused in the context of HIV or targeted against vulnerable populations.

**GUIDELINE 5:** States should enact or strengthen anti-discrimination and other protective laws that protect vulnerable populations, people living with HIV and people with disabilities from discrimination in both the public and private sectors, ensure privacy and confidentiality and ethics in research involving human subjects, emphasize education and conciliation, and provide for speedy and effective administrative and civil remedies.

**GUIDELINE 6 (as revised in 2002):** States should enact legislation to provide for the regulation of HIV-related goods, services and information, so as to ensure widespread availability of quality prevention measures and services, adequate HIV prevention and care information, and safe and effective medication at an affordable price.

States should also take measures necessary to ensure for all persons, on a sustained and equal basis, the availability and accessibility of quality goods, services and information for HIV prevention, treatment, care and support, including antiretroviral and other safe and effective medicines, diagnostics and related technologies for preventive, curative and palliative care of HIV and related opportunistic infections and conditions.

States should take such measures at both the domestic and international levels, with particular attention to vulnerable individuals and populations.

**GUIDELINE 7:** States should implement and support legal support services that will educate people affected by HIV about their rights, provide free legal services to enforce those rights, develop expertise on HIV-related legal issues and utilize means of protection in addition to the courts, such as offices of ministries of justice, ombudspersons, health complaint units and human rights commissions.

**GUIDELINE 8:** States, in collaboration with and through the community, should promote a supportive and enabling environment for women, children and other vulnerable populations by addressing underlying prejudices and inequalities through community dialogue, specially designed social and health services and support to community groups.

**GUIDELINE 9:** States should promote the wide and ongoing distribution of creative education, training and media programmes explicitly designed to change attitudes of discrimination and stigmatization associated with HIV to understanding and acceptance.

**GUIDELINE 10:** States should ensure that Government and the private sector develop codes of conduct regarding HIV issues that translate human rights principles into codes of professional responsibility and practice, with accompanying mechanisms to implement and enforce these codes.

**GUIDELINE 11:** States should ensure monitoring and enforcement mechanisms to guarantee the protection of HIV-related human rights, including those of people living with HIV, their families and communities.

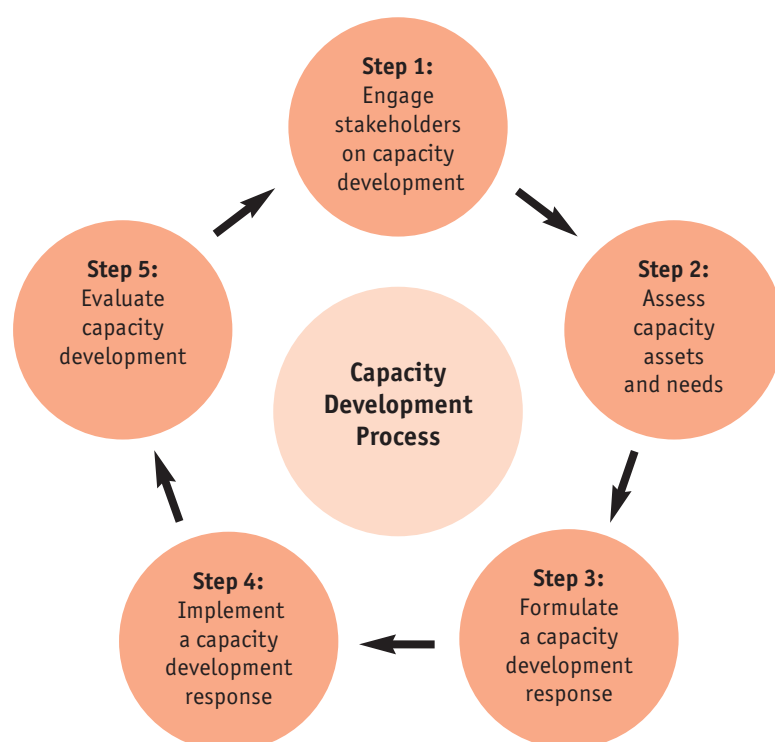
**GUIDELINE 12:** States should cooperate through all relevant programmes and agencies of the United Nations system, including UNAIDS, to share knowledge and experience concerning HIV-related human rights issues and should ensure effective mechanisms to protect human rights in the context of HIV at international level.

## Annex 4: Capacity development in the context of HIV

Capacity development is indispensable for increased development effectiveness and the achievement of the Millennium Development Goals. While financial resources are vital, they are not enough to bring about lasting improvements in people's lives. Enhancing countries' ability to plan, implement and review effective development strategies and programmes requires supportive laws, policies and procedures, well-functioning organizations, and educated and skilled people.

Capacity development helps to strengthen this foundation. UNDP defines capacity development as "the process through which individuals, organizations and societies strengthen and maintain the capabilities to set and achieve their own development objectives over time". It is the 'how' of making development work better and is positioned front and centre in UNDP's work, as articulated in its Strategic Plan 2008-2011. In placing support to capacity development at the heart of its mandate and functions, UNDP is responding to growing demand from countries around the world. This demand is articulated in an increasing number of national and local development strategies and is reflected in UN Development Assistance Frameworks (UNDAF). The 2007 UN Triennial Comprehensive Policy Review also sounds a persistent call by member states for the UN development system to deliver on national capacity development. This Review "Recognizes that capacity development and ownership of national development strategies are essential for the achievement of the internationally agreed development goals..." and "Calls upon the United Nations development system to further support capacity-building and capacity development of developing countries, upon their request, to effectively coordinate and evaluate the impact of external development assistance in line with national development plans and priorities." In addition, the Paris Declaration and Accra Agenda for Action stemming from the High Level Forums on Aid Effectiveness also

**Figure A4.1 UNDP Capacity Development Process**

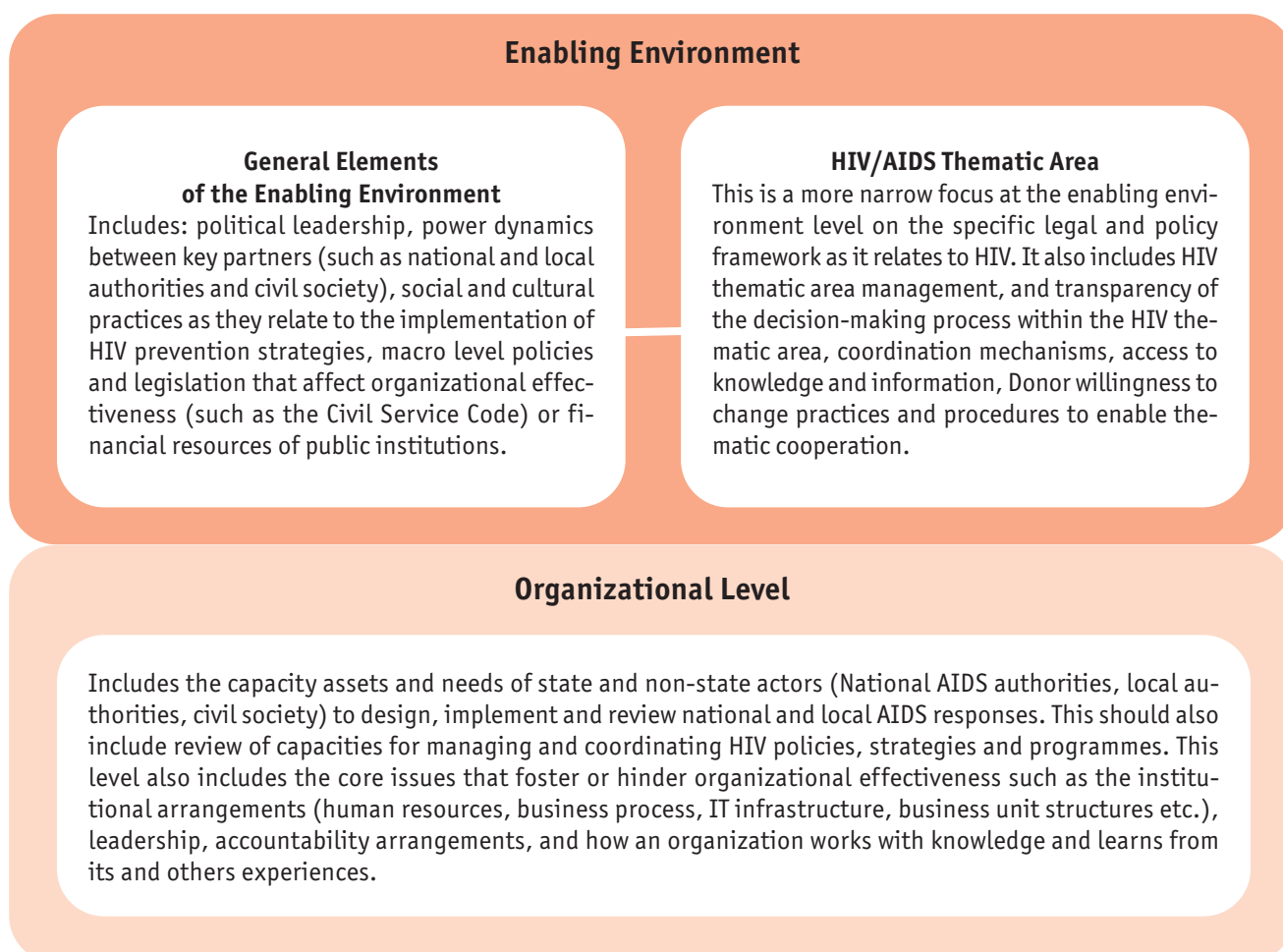


stress that “Without robust capacity – strong institutions, systems, and local expertise – developing countries cannot fully own and manage their development processes.”

Capacity development demands a shift in the business-as-usual approach to development assistance, away from a technical assistance input-driven modality to working with what influences larger development outcomes. This shift is based on the recognition that conventional technical assistance often disregards, or even hurts, the growth, retention and effective use of national capacity; the consequence being further dependency on aid and the reliance on external expertise and decision-making processes to move forward national development agendas. First and foremost, capacity development gives practical grounding to the principle of national ownership and moves away from international expert capacity substitution and donor- or supply-driven solutions. Rather than going around national systems for a ‘quick win’ capacity development favors strengthening those systems. As such, capacity development is mid and long term focused, though it does recognize the need to balance this with ‘quick wins’ to ensure momentum is maintained and that stakeholders stay committed. Capacity development also focuses more on the enabling environment and organizations within which capacity exists, such as for example, the legal and regulatory framework, labor market trends, institutional governance, culture and other local conditions which are all factors that influence capacity for better or worse. It also links the systemic with the organizational with the individual level of capacity, gets away from the singular focus on individual skills and goes beyond training.

The diagram below illustrates the UNDP capacity development process.

**Figure A4.2. UNDP Capacity Development Process tailored to the HIV context**





## Supporting capacity development to promote an effective national response to AIDS

UNDP recognizes that addressing HIV contributes to achieving the Millennium Development Goals, particularly targets relating to reducing poverty, achieving universal primary education, promoting gender equality, reducing child mortality, improving maternal health and combating tuberculosis. As a Cosponsor of the Joint UN Programme on HIV/AIDS (UNAIDS), UNDP's support to a response to AIDS is guided by the UNAIDS division of labour, which assigns specific responsibilities to each of the ten UNAIDS Cosponsors and the UNAIDS Secretariat in line with organizational mandates.

Under the UNAIDS division of labour, UNDP is the lead organization for addressing dimensions of AIDS relating to development planning and mainstreaming; governance of AIDS responses; and law, human rights and gender, including sexual minorities. In addition, UNDP contributes to public health and development partnerships through an important collaboration with the Global Fund to Fight AIDS, Tuberculosis and Malaria, as well as other public health programmes.

In line with this division of labour, and as outlined in the UNDP Strategic Plan 2008-2011, UNDP's support to a response to AIDS focuses on four key outcomes:

- *Development planning and mainstreaming:* Integrating AIDS responses into poverty reduction strategies, national development plans and macroeconomic processes.
- *Governance of AIDS responses:* Strengthening national capacity for inclusive governance and coordination of AIDS responses, and increasing participation of civil society and people living with HIV in the design, implementation and evaluation of AIDS programmes.
- *Law, human rights and gender:* Promoting the human rights of people affected by HIV and sexual minorities, addressing gender-related vulnerability to HIV, and assisting countries in the use of flexibilities in international intellectual property rules (namely TRIPS) to improve access to affordable AIDS medicines.
- *Public health and development partnerships:* Strengthening national capacities for implementation of funds and programmes financed through multilateral funding initiatives and public health partnerships, including the Global Fund to Fight AIDS, Tuberculosis and Malaria.

## Points of entry

UNDP recognizes that capacity resides at different levels – enabling environment, organization and individual – which can each serve as the point of entry for a capacity assessment. The UNDP Capacity Assessment Framework is specifically tailored to assess capacity assets and needs within the enabling environment and at the organizational level. Within the context of HIV, the Capacity Assessment Framework can be further adapted and focused to include a specific examination of the HIV thematic context.

## Annex 5: Research methodology

Guided by the UNDP core mandate to focus on development implications of HIV, this research examined general patterns of stigma and specific challenges in accessing health care, education and employment among people living with HIV in selected sites of the region. The research was carried out between March and August 2007. Although the findings do not provide a comprehensive description of the region as a whole, they try to illuminate phenomena and trends that may occur among people living with HIV in Eastern Europe and the Commonwealth of Independent States.

This research, with overall scientific guidance by Don Operario from Oxford University, was carried out by six country-based research teams consisting of community- or university-based researchers in collaboration with a local HIV-focused non-governmental organization in each country. The teams were supported by local and regional UNDP staff and international experts on HIV research. Each country team received intensive training to follow a standardized methodology, covering research aims and objectives, participant recruitment, data collection protocols, data analysis and research ethics. Research protocols were reviewed and approved by local ethical review boards in each country. The decision to work with national research institutions was taken with the hope that the report would benefit from local expertise and that incorporating these institutions would build national capacity and promote national ownership of the initiative.

The research design consisted of five phases:

1. A comprehensive literature review on national HIV and AIDS epidemiology and HIV-relevant health policies;
2. Identification of specific in-country locations with high concentrations of HIV prevalence, for the purpose of developing targeted participant recruitment plans (community mapping exercise);
3. In-depth qualitative interviews with people living with HIV (with the aim of representing high-risk, local social demographic and populations at risk);
4. Focus-group discussions with representatives of mirror institutions in the health, educational and labour sectors (government officials, health care providers (doctors, nurses and psychologists), social workers, employers, colleagues at work, teachers, parents, schoolmates, the police and others); and
5. Roundtable discussions to present research findings to national stakeholders.

Research phases were modified at the national level to fit the context and specificities in the each of the countries.

Research was conducted in Estonia, Georgia, Russia, Turkey, Ukraine and Uzbekistan. These countries were selected to represent different epidemiological contexts within Eastern Europe and the Commonwealth of Independent States. The countries selected included those with the highest regional HIV prevalence (Russia, Ukraine, Estonia), emerging concentrated epidemics (Georgia, Uzbekistan), and low-level prevalence (Turkey).

In addition to differences in epidemiological profiles, the countries also differ in terms of geo-political context, including members of the CIS, a new European Union member and a European Union candidate country. Further, recent political instability (Georgia, Turkey and Ukraine experienced political turmoil during the course of the research) and religion influence the contextual conditions (Turkey and Uzbekistan have majority Muslim populations, while the other four countries are predominantly Christian). All countries except Turkey were part of the Soviet Union.

Characteristics of individual participants living with HIV are presented in Table A5.1. Although these descriptive data are not representative of the study sites, the sample variability is worth noting. Many participants did not describe themselves according to the populations at risk of injecting drug users, men who have sex with men (MSM) or sex workers.

Table A5.1. Characteristics of individual participants

	Estonia	Georgia	Russia				Turkey	Ukraine	Uzbekistan	Total
			Moscow	Penza	Chelyabinsk	Irkutsk				
<b>Gender</b>										
Male	8	14	8	8	7	8	9	18	11	91
Female	9	7	10	10	11	10	7	17	10	91
<b>Age</b>										
Under 25	7	5	13	7	10	7	1	7	0	57
26-40	10	12	4	9	8	11	14	22	16	106
40-50	0	4	1	2	0	0	1	6	5	19
<b>Target group</b>										
IDU	11	11	6	4	6	9	0	11	16	74
SW	3	2	4	0	1	4	2	3	4	23
MSM	2	2	5	0	0	5	3	2	1	20
Other	1	6	3	14	11	0	10	19	3	67
<b>Occupation</b>										
Employed	11	4	18	14	2	8	11	16	9	93
Unemployed	4	17	0	1	16	1	4	19	10	72
Other	2	0	0	3	0	9	1	0	2	17
<b>Education</b>										
Beyond high school	0	11	5	2	a	5	8	4	2	37
High school	3	10	6	12	a	7	2	27	17	84
Less than high school	14	0	0	0	a	0	6	4	2	26
<b>ARV treatment</b>										
Receiving	2	16	a	2	6	4	11	7	6	54
Not receiving	15	5	a	16	12	14	5	28	15	110
<b>Marital status</b>										
Unmarried	16	6	7	8	3	5	10	16	16	87
Divorced	0	2	3	4	0	1	3	8	0	21
Married	1	13	4	6	8	3	3	11	5	54
<b>Geographical location</b>										
Urban	13	11	14	18	18	18	13	27	21	153
Rural	4	10	a	0	0	0	3	8	0	25
<b>Total number of in-depth interviews</b>	17	21	18	18	18	18	16	35	21	182

Note: Some columns do not sum to 100% due to missing data.  
a – Data not collected.

## Annex 6: List of NGO partners and sociological institution representatives involved in the research

Riina Raudne	National Institute of Health Development	Estonia
Katri Abel	National Institute of Health Development	Estonia
Ketevan Melikadze	Consultant, Strategic Research Center	Georgia
Natela Sakhokia	Director, Strategic Research Center	Georgia
Izoleta Bodokia	Director, NGO Aids Patients Support Foundation	Georgia
Nino Chichinadze	Strategic Research Center	Georgia
Elena Pakhomova	All-Russian Public Opinion Research Center (VCIOM)	Russia
Nikolay Popov	Head of International Department, All-Russian Public Opinion Research Center (VCIOM),	Russia
Sergey Smirnov	Director, Community of PLHIV	Russia
Anastacia Makryashina	Community of PLHIV, NGO	Russia
Sofia Kruglyakova	All-Russian Public Opinion Research Center (VCIOM)	Russia
Dmitry Polikanov	All-Russian Public Opinion Research Center (VCIOM)	Russia
Aytul Kasapoglu	Sociology Association	Turkey
Elif Kus	Sociology Association	Turkey
Feryal Turan	Sociology Association	Turkey
Nilay Cabuk	Sociology Association	Turkey
Arzu Kayki	Project Coordinator, Positive Life Association	Turkey
Cigdem Simsek	Positive Life Association	Turkey
Natalya Kharchenko	Executive Director, Kiev International Institute of Sociology	Ukraine
Olga Zhmurko	International Institute of Sociology	Ukraine
Viktoriya Zakhosha	Head of Department, Kiev International Institute of Sociology	Ukraine
Olena Davis	Project Manager, Coalition of HIV-service NGOs	Ukraine
Irina Pinchuk	Director, State Social Services for Family, Children and Youth	Ukraine
Alexey Polkovanov	Deputy Director of the Social Research Agency ITA FACT	Uzbekistan
Timur Abdullaev	Chair of NGO 7Ishonch va Khaet	Uzbekistan
Shuhrat Abdullayev	Director of the Social Research Agency ITA FACT	Uzbekistan
Sergei Petaev	NGP Ishonch va Khaet	Uzbekistan

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