

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.⁴⁵ 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 Sandkjær, '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.

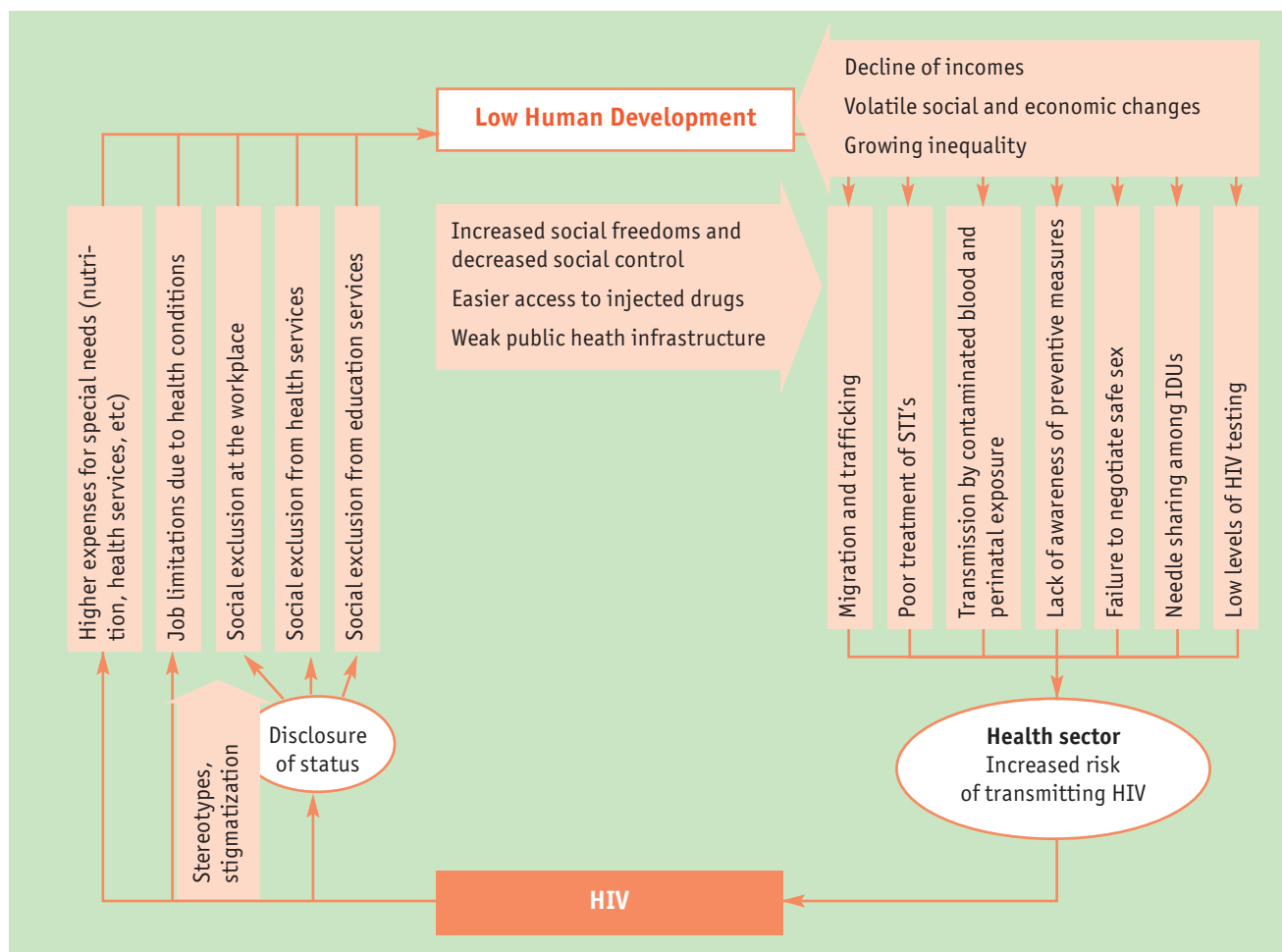
This cycle of mutual reinforcement is outlined in a ‘macro model’ of factors linking human development and HIV in Eastern Europe and the CIS (Figure 2.1). It visualizes the fact that the determinants of social exclusion are arguably the same determinants of HIV risk. This model underscores the UNDP rationale 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.⁴⁶ 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.

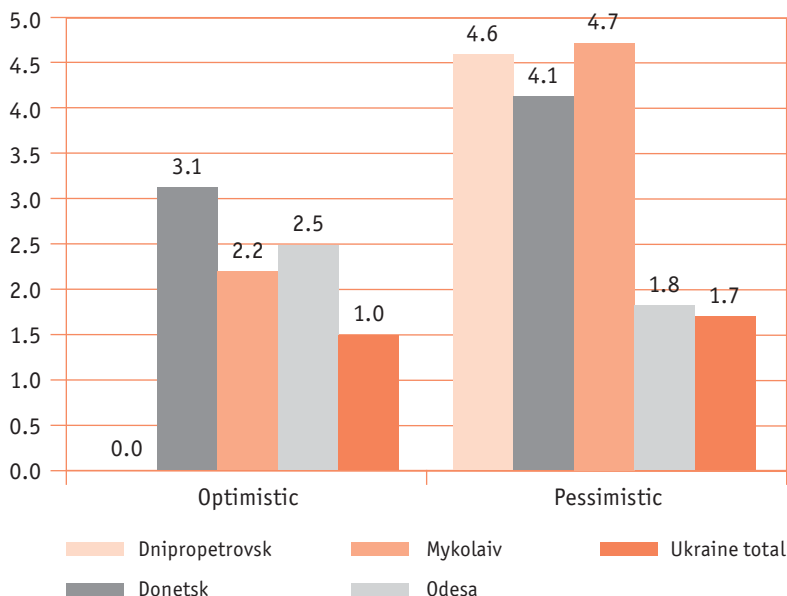
related costs, and budget revenue losses may reach 2.4 to 13.2 billion drams (\$7.8 to \$42.9 million), depending on the scenario.

In **Ukraine**, a similar study was carried out in 2006 to assess the demographic and macroeconomic 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

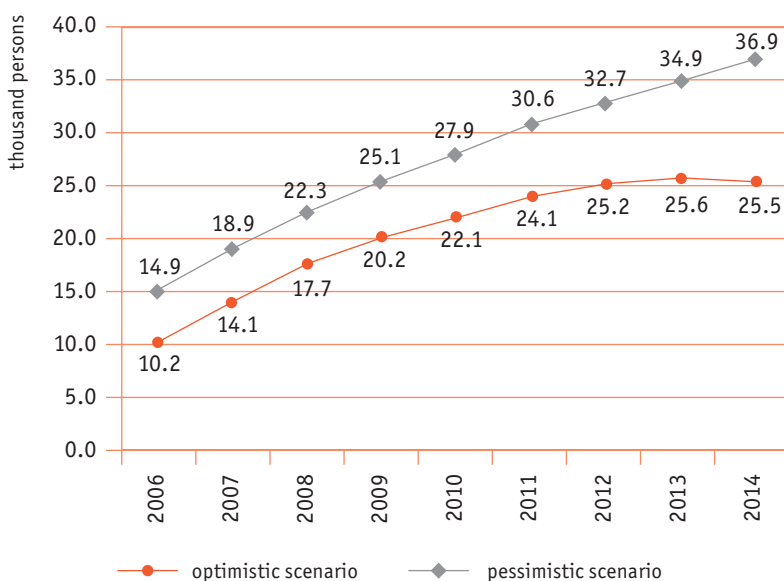
⁴⁶ Ben Slay, UNDP Bratislava Regional Centre, ‘Demographic trends in CIS countries – How favourable? How irreversible?’ Unpublished draft.

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.

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



A more recent model developed in 2007 in collaboration between the International Labour Organization, Deutsche Gesellschaft Für Technische Zusammenarbeits (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.⁴⁷ 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.⁴⁸

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.

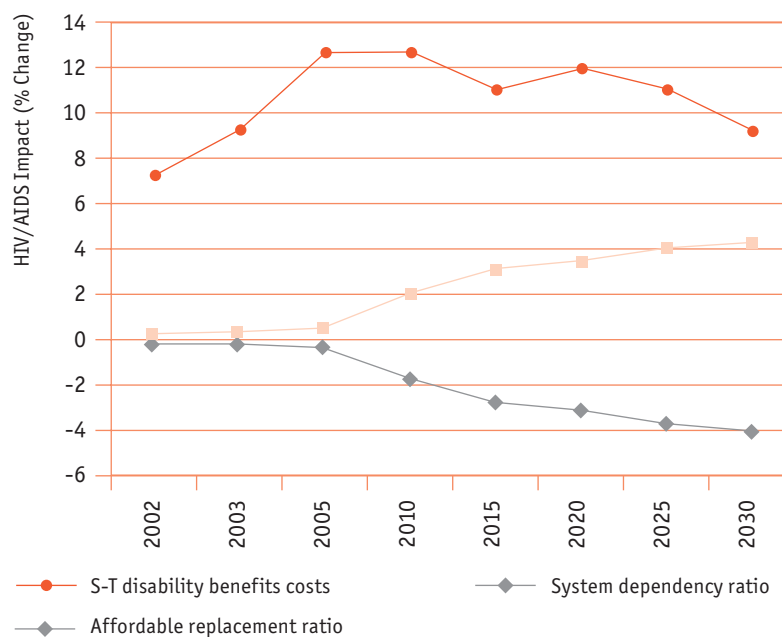
47 "The Socio-economic Impact of the HIV/AIDS Epidemic in Ukraine: Prognosis, Modeling, Evaluation" ILO, GTZ, 2007.
 48 "The Socio-economic Impact of the HIV/AIDS Epidemic in Ukraine: Prognosis, Modeling, Evaluation" ILO, GTZ, 2007.

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. Mashkilleysen 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:

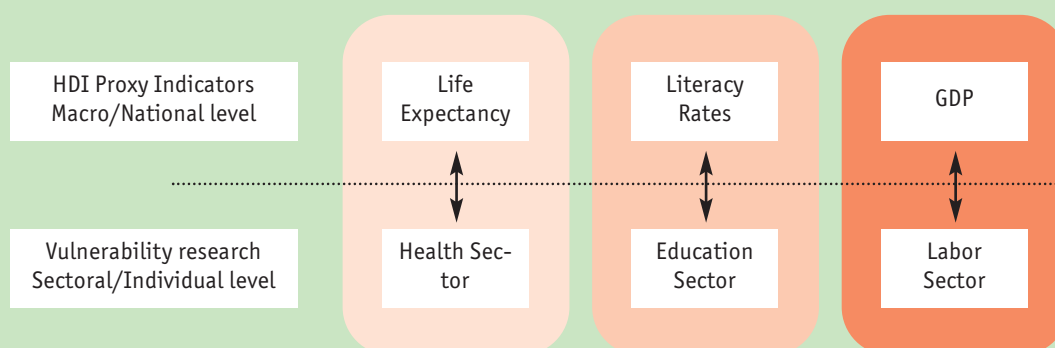
- To elicit detailed and rich descriptions of stigma, discrimination, and exclusion among people living with HIV within selected locations in the region;
- To identify barriers to the full social integration of people living with HIV, structured around three key sectors – the health, education and labour 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.⁴⁹

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.⁵⁰ 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.⁵¹

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 2003.⁵² 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".⁵³ 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".⁵⁴ 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.⁵⁵

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

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

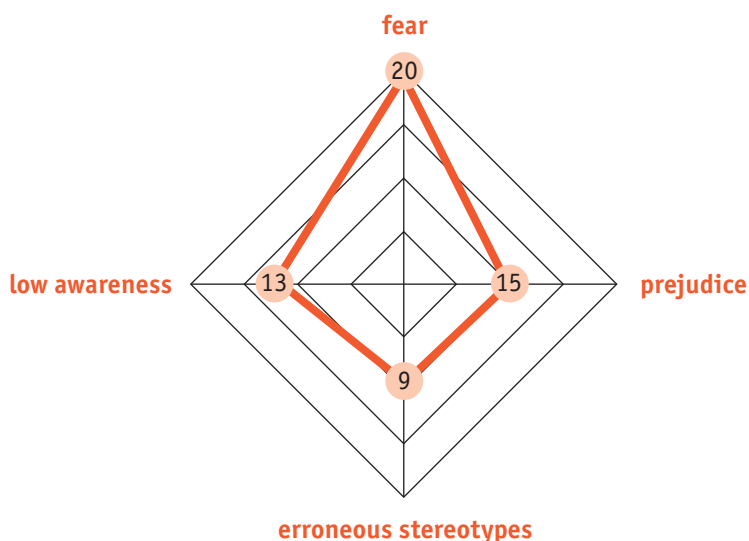
53 This phrase is attributed to Jonathan Mann in Parker and Aggleton, 'HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action' in *Social Science and Medicine*, 57 (2003), p. 13.

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.⁵⁶ 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.⁵⁷ 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)



⁵⁶ 'Evaluating the vulnerability of people living with HIV in Ukraine,' UNDP: Kiev, 2008.
⁵⁷ 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
Individual	<ul style="list-style-type: none"> • Self-perceived stigma restricting choices regarding work/school • Depression, anxiety; potential for disease progression/decline 	<ul style="list-style-type: none"> • Early entry of children and youth into the workforce, restricting educational opportunities • Reluctance to seek care in formal sector drains family resources for home care
Family (affected individual)	<ul style="list-style-type: none"> • Loss of primary income • Push deeper into poverty • Lack of resources • Orphans and vulnerable children 	<ul style="list-style-type: none"> • Withdrawal from economic activity for caretaking or secondary stigma • Differential treatment of orphans by family – forced into economic activity, internal migration rather than education
Institution	<ul style="list-style-type: none"> • Prohibited access to schools, jobs, health care, insurance through compulsory testing/notification • Absenteeism due to illness • Health care costs, if provided by the institution • Interpersonal relationships (trust, morale) 	<ul style="list-style-type: none"> • No/limited access to micro-credit or market-level resources (e.g., farmers unable to sell food products at the market due to stigma) • Religious institutions denying socioeconomic support/ educational opportunities to affected families • Absenteeism due to caretaking, with further implications for stigma
Structure/society	<ul style="list-style-type: none"> • Individual consequences of laws: privacy, access to health care thus affecting economic opportunities • Driving people into informal/ illegal/ unregulated economies (sex work, drugs) • Loss of savings/pension revenue 	<ul style="list-style-type: none"> • Migration restrictions leading to reduced remittances to families • Restricted marriage for people living with HIV, thereby limiting access to pensions/land • Driving people into informal/ illegal/ unregulated economies (sex work, drugs) • Loss of savings/pension revenue

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

The collective benefits of including the excluded

Social exclusion is a process through which people experience marginalization in economic, social and cultural life.⁵⁸ 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

⁵⁸ 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.⁵⁹ 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’

⁵⁹ Disclosure might boost CD4 cell count, Reuters Health, Will Boggs, 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. Sørensen, "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 8th 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**

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.

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

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.⁶⁰

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

⁶⁰ 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)

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.

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 –

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

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 children born to women living with HIV have

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.

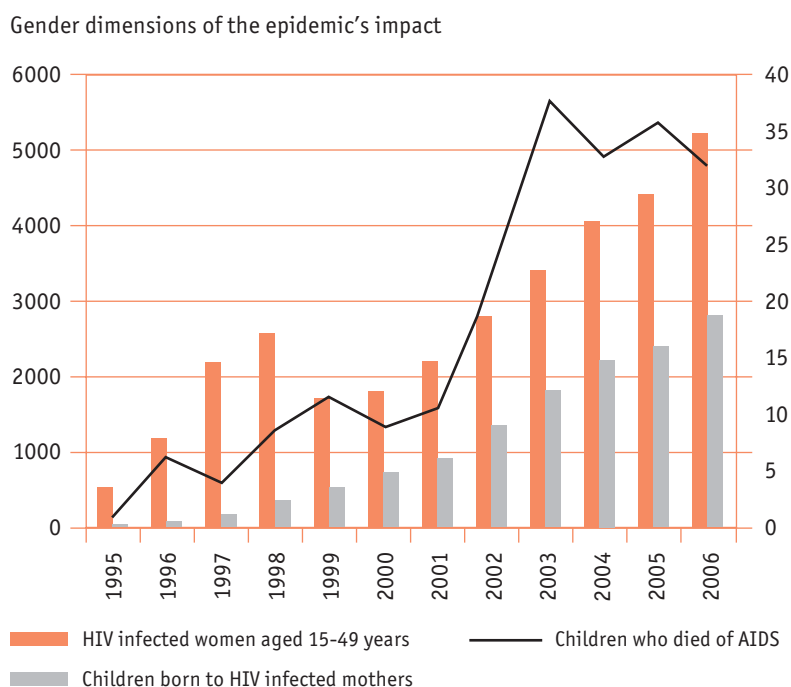
– Person living with HIV from Russia

Source: Regional HIV Vulnerability study, UNDP (2007)

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.⁶¹ 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

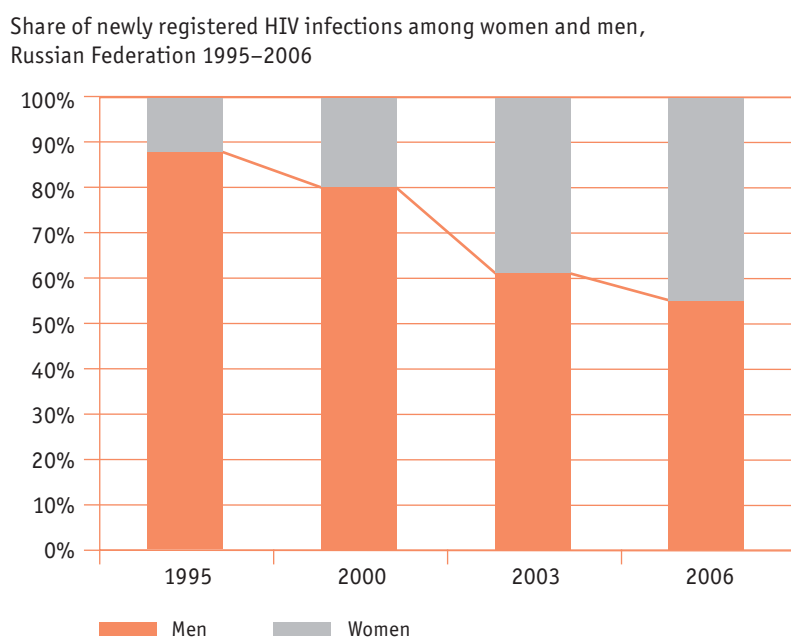
⁶¹ EuroHIV 2007, Eastern Europe and Central Asia, AIDS Epidemic update, Regional Summary, UNAIDS/WHO, 2007, p. 2.

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).



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.



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 52/4 on "Women, the Girl Child and HIV,"⁶² 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.⁶³ 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,

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

⁶³ 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.⁶⁴ 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

⁶⁴ 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' needs⁶⁵.</p> <p>Limited and inadequate sexual health education for girls, including information about pregnancy and reproduction, hygiene and sexually transmitted infections.⁶⁶</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.⁶⁷</p>	<p>Boys exposed to gender stereotypes of culturally acceptable sexual behaviours.⁶⁸ 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.⁶⁹</p>
15-24	<p>Sexual and reproductive rights for women are not upheld. Females internalize the idea of subjecting themselves to males' sexual interests.⁷⁰</p> <p>Unwanted or forced marriage and bride kidnapping without consent are still practiced in some areas.⁷¹</p> <p>Targets for human trafficking: Female trafficking has increased in the past decade throughout the region.⁷²</p> <p>Girls are expected to abstain from premarital sexual intercourse.⁷³</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.⁷⁴</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.⁷⁵</p> <p>Low efficacy to use condoms, especially with husbands.⁷⁶</p> <p>Pressure to reproduce and raise children.</p> <p>Poor implementation of laws to protect the rights of women.⁷⁷</p>	<p>Pressure to economically support family⁷⁸ 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.⁷⁹</p> <p>Social norms that promote men's use of violence in the domestic setting.⁸⁰</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.