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BLAME AND BANISHMENT

The underground HIV epidemic affecting children in Eastern Europe and Central Asia

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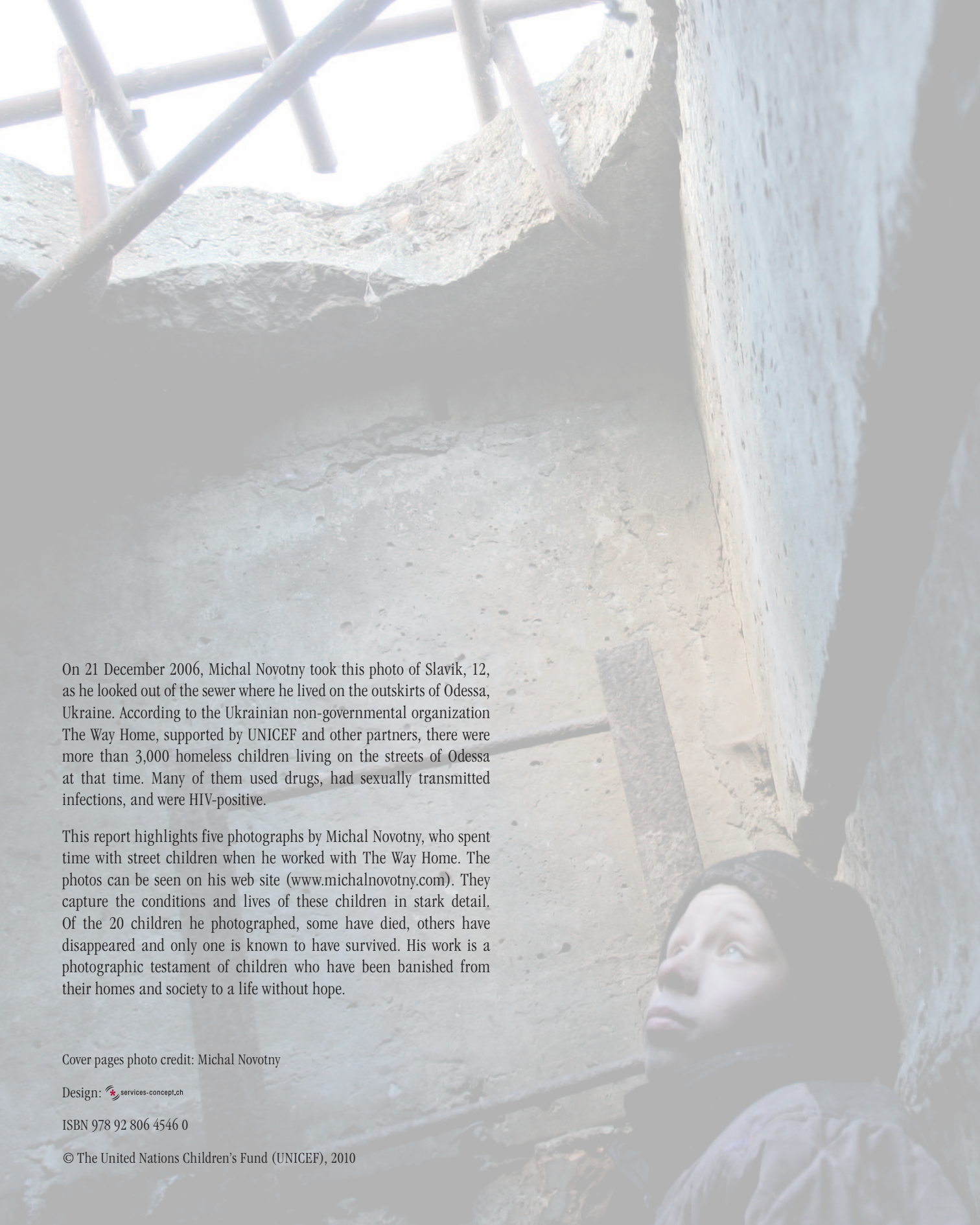

On 21 December 2006, Michal Novotny took this photo of Slavik, 12, as he looked out of the sewer where he lived on the outskirts of Odessa, Ukraine. According to the Ukrainian non-governmental organization The Way Home, supported by UNICEF and other partners, there were more than 3,000 homeless children living on the streets of Odessa at that time. Many of them used drugs, had sexually transmitted infections, and were HIV-positive.

This report highlights five photographs by Michal Novotny, who spent time with street children when he worked with The Way Home. The photos can be seen on his web site (www.michalnovotny.com). They capture the conditions and lives of these children in stark detail. Of the 20 children he photographed, some have died, others have disappeared and only one is known to have survived. His work is a photographic testament of children who have been banished from their homes and society to a life without hope.

Cover pages photo credit: Michal Novotny

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"To live without hope is to cease to live."

F. M. Dostoevsky

Fyodor Mikhaylovitch Dostoevsky (1821–1881), Russian novelist, author of Crime and Punishment, Notes from the Underground, *and many other masterpieces. His work often described the lives of those who were outcast from society.*

This report is dedicated to children living with HIV in Eastern Europe and Central Asia and to all those trying to make a difference in children's lives. Fragments of some of their stories are told in this report, but many more of their stories remain untold, hidden or silenced. Some of the children featured in the stories and photographs are no longer alive.

This report is dedicated to their memory.

UNICEF hopes that this report may help bring a ray of light into the lives of those children and families still with us.

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Every reasonable effort has been made to verify the accuracy of data and of all the information presented in this report. The opinions expressed in this publication are those of the contributing authors and do not necessarily reflect the policies or the views of UNICEF.

The electronic version of this report and a number of other related materials, including additional information on many of the personal interest stories and materials presented in this report, can be accessed and downloaded from the UNICEF CEE/CIS web site: www.unicef.org/ceecis.

Foreword

Eastern Europe and Central Asia continue to see rapid increases in HIV infections among men, women and children. Despite some notable successes in responding to the epidemic, it is unlikely that the Universal Access targets and the Millennium Development Goals (MDGs) related to HIV/AIDS will be achieved. Access to antiretroviral treatment is still among the lowest in the world, and stigma and discrimination that violate the basic rights and dignity of people living with and affected by HIV, including children, are hampering further progress in prevention, care and support.

This report brings to life the experiences of children, families and young people living with HIV. It gives voice to their stories of despair, stigma and social exclusion, as well as to their courage and hope. It explores the systemic failures in responding to their needs and outlines some good practices. It also describes the contradictions that children and young people, particularly those who are most at risk of HIV, face on a daily basis: societies insist that they conform to social norms, yet exclude them and brand them as misfits; health and social protection systems do not serve their needs and diminish their chances of living normal lives, but blame them when they fail to cope. The report also features some compelling photographs of the realities of living on the edge.

Policy reforms, programmatic shifts and a reallocation of resources to strengthen health and social protection systems are required if the further spread of the epidemic is to be halted. Reforms must aim to expand and grant equitable access to services for all, including those who are currently excluded and missed. Successes in HIV prevention, treatment and care can only be increased and sustained if they are underpinned by social environments that advance human and child rights, gender equality and social justice.

Blame and Banishment is a call to address the remaining gaps in the response to HIV in the region. It is a call for protecting the rights and dignity of children and young people who are vulnerable, at risk and living with or affected by HIV. It is also a call to build an environment of equity, trust and care rather than blame and banishment.

Steven Allen
Regional Director
UNICEF Regional Office for CEE/CIS

Abbreviations and Acronyms

AIDS	acquired immune deficiency syndrome
ART	antiretroviral therapy
ARV	antiretroviral (ARV) drugs
CEE/CIS	Central and Eastern Europe/Commonwealth of Independent States
ECUO	East Europe & Central Asia Union of People Living with HIV/AIDS
GDP	gross domestic product
HIV	human immunodeficiency virus
IDU	injecting drug user
MARA	most-at-risk adolescent
MARP	most-at-risk population
MCH	maternal and child health
MDGs	Millennium Development Goals
MSF	Médecins Sans Frontières
MSM	men who have sex with men
NGO	non-governmental organization
P2P	parent to parent
PLHA	people living with HIV/AIDS
PMTCT	prevention of mother-to-child transmission (of HIV)
STI	sexually transmitted infection
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
WHO	World Health Organization
YFHS	youth-friendly health services

Children, AIDS and exclusion: An introduction

The story of the HIV epidemic in Eastern Europe and Central Asia is one of courage and commitment, but also of blame and banishment. Too often, those living with HIV have been silenced and excluded, and risky behaviours borne of futility and hopelessness have been sanctioned or repressed. As in other parts of the world, the shame and fear associated with AIDS have led to discrimination and denial, sometimes extreme. Evidence has been repressed, misconceptions rationalized, and the distress of those affected by HIV ignored. Although valuable national and local responses to HIV have been mounted, effective HIV treatment and prevention programmes have largely failed to reach those who are most vulnerable, in particular young people. The insidious consequence of this has been a hidden epidemic which disproportionately strikes young people, adolescents and children.

The central challenge of responding to HIV in most countries of the region is the need to come to terms with an epidemic that mostly affects people deemed by society to be 'delinquent' or 'anti-social'. Every day, children and young people engage in behaviours that put them at risk of HIV infection. In some cases, peer pressure, curiosity or just the natural recklessness of their age leads them to experiment with drugs or sexuality without thinking of the consequences. But many have been driven to the edge by social, economic and family problems. Few educational and employment opportunities, as well as weakening family and social support structures, have led to disillusionment and defiance in many young people, often expressed via increased risk-taking behaviour. Whatever the reasons, effective solutions cannot rest on social condemnation and exclusion.

Hope for the future lies in new models of integrated services for women, children and young people that are being developed by both civil society organizations and governments. Based on principles of respect and understanding, and focused on reducing risk and harm, these new service approaches are essential if children, young people and adults are to avoid being infected and if those living with HIV are to receive the support and care they need.

Care and compassion, not blame and banishment, must dictate how the realities of affected children and young people are addressed. Without greater solidarity and social acceptance, their suffering, often perceived as self-inflicted, falls into the moral gap between what is simply acknowledged and what constitutes an imperative to act.

This report is about changing that.

A growing epidemic affecting young people…

Eastern Europe and Central Asia are the only parts of the world where the HIV epidemic remains clearly on the rise. Increases of up to 700 per cent in HIV infection rates have been found in some parts of the Russian Federation since 2006.[1] Over the past decade, there have also been important increases in HIV incidence in Central Asia and in the Caucasus, much of which remains under-reported.

The HIV epidemic in the region is driven by an explosive mix of injecting drug use and, more recently, sexual transmission. Children and young people, including those living on the streets, constitute a group whose risk of contracting HIV is particularly high. Today, one third of new HIV infections in the region are among the 15–24 age group and more than 80 per cent of people living with HIV in the region are under 30 years old.[2]

The region is home to 3.7 million people who inject drugs, representing almost one quarter of the world total. Some 1.8 million of these live in the Russian Federation and close to 300,000 each in Azerbaijan and in Ukraine.[3] The highest prevalence of injecting drug use in the adult population worldwide is now found in Azerbaijan (5.2 per cent), Georgia (4.2 per cent), Russian Federation (1.8 per cent) and Ukraine (1.2 per cent).[4]

The average age of injecting drug users (IDUs) in the region is very low, with the age of initiating injecting still decreasing in a number of countries. In Moscow, Russian Federation, in 2005 the average age of injection start-up was 16 years old.[5] A UNICEF assessment in The former Yugoslav Republic of Macedonia found a growing number of 12- and 13-year-olds already using drugs.[6] Some 80 per cent of sex workers in Central and Eastern Europe are also young people, with female drug users often selling sex to support their drug use and that of their male partners.[5]

Women, who now account for some 40 per cent of new cases compared to just 24 per cent under a decade ago,[7,8] are increasingly affected by HIV, as are children. The total number of HIV-positive pregnancies has doubled during the past five years. Although rates of mother-to-child transmission of HIV have declined significantly as a result of effective implementation of national prevention of mother-to-child transmission (PMTCT) programmes, HIV infection still remains a significant problem among drug-dependent pregnant women and their newborns, who tend to be missed by services.

Since 2006, there have been new reports of children contracting HIV in health settings due to unsafe injection practices, poor management of blood products and outdated clinical

practices. As a result, 'outbreaks' of HIV infection among children have been confirmed in Kazakhstan, Kyrgyzstan and Uzbekistan.

Children and HIV in context…

In Eastern Europe and Central Asia, most children infected through mother-to-child transmission have been diagnosed in the past five years. However, children have always been a prominent part of the epidemic in the region. The first reports on HIV/AIDS among children came in the early 1990s with the opening of post-Ceausescu Romania. The world was shocked by reports of HIV infections caused by untested blood and unsafe injections involving more than 10,000 children. But that was just the beginning...

The HIV epidemic became established in Eastern Europe and Central Asia in the mid-1990s, at a time of dramatic social and political change following the collapse of the Soviet Union. Two aspects of this historical and socio-economic context merit particular attention.

Fragile societies, fragile families

First, the effects of transition had a substantial impact both on individuals and the state. The transition left many states fragile. Ethnic conflicts erupted in a number of areas, including the Caucasus, Moldova, Tajikistan and the former Yugoslavia. In 1998, a major economic shock pushed the Russian Federation, and subsequently Ukraine, into deep recession. The 'colour revolutions' in Kyrgyzstan, Georgia, and Ukraine were visible manifestations of the political changes sweeping through the region. These events, combined with a focus on economic recovery, contributed to social issues, in particular those involving children, being pushed to the bottom of the agenda.

Recent improvements in household incomes across the region have masked widening gaps between those who have benefited from change and others who have been left behind. Social protection systems, which have rarely been high on regional reform agendas, have mostly not prioritized social assistance for families, community-based services, or child benefits. Levels of public health expenditure have remained extremely low in a number of countries. In principle, health services are meant to be universal and free of charge. In reality however, these services have often been compromised, especially for the poor, by high informal payments and poor quality of service delivery.

Confronted with economic hardship, rising unemployment, social pressures and the crumbling of established social safety nets, many families found themselves unable to cope

with the difficulties of socio-economic change and transition. These constraints, combined with widespread consumption of alcohol and drugs, reduced the capacity of many to protect their children. For some children from troubled families, the streets became their home or source of livelihood, and risk behaviours became a part of their daily lives. At their height, these street children were estimated to number a staggering one to four million.

Today, while there are no reliable estimates on the numbers of children on the streets, the vulnerabilities of children and families remain largely the same. The current economic and political crises in the region have revealed fragile foundations. According to the World Bank,[9] some 50.1 million people are now estimated to be living beneath the poverty line. Social reforms have stalled and social welfare budgets are being cut back.

A difficult political inheritance

The second challenge of addressing the HIV epidemic in the region has been a political legacy of authoritarianism and control. Faced with an epidemic that mostly affects socially excluded populations such as drug users and sex workers, post-Soviet systems and mindsets have found it difficult to tailor inclusive responses to meet the specific needs of marginalized groups and those living with HIV. Rigid social controls have often led to denunciation and blame of those who fail to conform, or who are caught up in systemic failures. In these circumstances, the stigma and discrimination related to fear and ignorance about HIV find reinforcement in official attitudes of intolerance, and in existing public prejudice against those whose behaviour is seen as 'anti-social' or 'immoral'. Children born to HIV-positive mothers suffer the consequences of these prejudices, experiencing a much higher likelihood than other children of being abandoned at a hospital, or being left to live in isolation at a specialized care institution.

Negative attitudes and the denial of uncomfortable social realities lie at the root of children and young people's vulnerability to HIV infection and continue to be major barriers to addressing the real needs of children and their families. Policies and programmes remain strongly influenced by the legacy of the past and continue to ignore clear evidence about what constitutes an effective response as well as the everyday realities of those affected by HIV. As a result, opportunities for progress are being missed, allocation of resources often fails to match needs, and interventions may even aggravate the problems they are intended to alleviate.

Children and young people are being failed by this response.

"Without children, it would be impossible to love humanity in the same way..."

F. M. Dostoevsky

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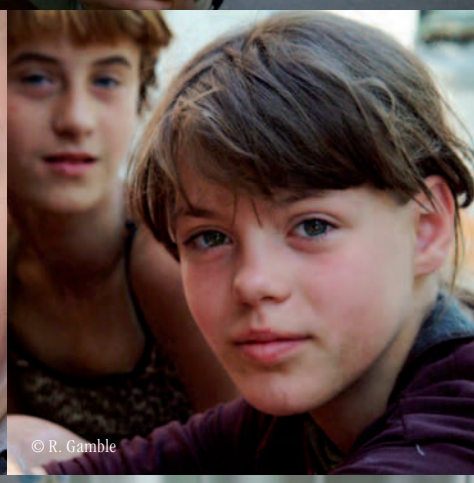
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© UNICEF/NYHQ2005-1796/G.Pirozzi. Ukraine, 2005

Sasha, aged 15 months and HIV-positive, was abandoned at birth. He sits alone in his crib at a state-run baby home.

© UNICEF/NYHQ2005-1814/G. Pirozzi

SECTION I Abandoned into state care…

"When still only a small baby, Anna travelled from her home town in the south of Russia to a distant place… It was not a pleasant trip, in particular because her mother wasn't with her. The journey ended at Anna's new home: a large imposing building with many windows. Inside, she joined her new brothers and sisters and a different sort of life began for her. That day, Anna was just 14 weeks old. Ten months later she was confirmed as being HIV-positive.

She never left her new home and grew accustomed to a life without love, isolated from the outside world… She was afraid of strangers but liked helping the staff take care of the dozens of other HIV-positive children who had also been abandoned to a similar fate…"

Across Eastern Europe, children born to HIV-positive mothers have a much higher risk than others of being abandoned at or soon after birth. Their removal from their mother, their family and community is an expression of both the stigma surrounding the HIV disease and of the multiple hardships that overwhelm many disadvantaged women.

Currently, the region has the highest rates of family separation in the world, with approximately 1.3 million children deprived of parental care and isolated from family and community, even though the vast majority still have biological parents.[10,11] The relinquishment of children to institutional care is an established solution for families in distress – a practice that has historic roots and continues to the present day, despite strong evidence of its negative consequences for children's well-being. The practice is often portrayed as being in the best interests of the child, with pregnant young women who use drugs being convinced that they cannot be good mothers. Relinquishment is in part due to a residual trust placed in these institutions by populations themselves, frontline service providers and policy makers. But it is also due to the lack of support for families under stress and to unfinished reforms in social welfare and protection services.

As a result, an increasing number of children in the region have become 'social orphans' – children who live in state institutions while their parents are still alive.

Families in distress

Ideally, families should serve as the first line of protection for children. However, in Eastern Europe and Central Asia, many years of social, economic and political instability and hardship have taken their toll on the family's role in protection and caring for children. Due to high rates of unemployment and the current economic crisis, labour migration is widespread in the region, leaving many children in the care of single parents, or unattended for long periods of time.[12] The use of drugs and alcohol is pervasive, divorce rates are high, and reports of domestic violence and abuse are widespread.

Alexandra, 17 months, stands in her crib, in a home for children orphaned or abandoned because of AIDS, in the western port city of Kaliningrad, Russian Federation.

© UNICEF/NYHQ2004-0698/G. Pirozzi

All over the region, the economic and social stability of the family is under threat, compromising its pivotal role in supporting, protecting and nurturing children and youth. At the same time, efforts to strengthen families have not figured prominently on state agendas. While countries in Eastern Europe and Central Asia inherited a strong welfare orientation, declines in revenue due to economic transformation and slow institutional reform have meant that governments have not been able to implement strong social policy interventions to protect or cushion families as they did in the past.[11] The lion's share of public expenditure on social protection goes towards old age pensions, while only much smaller allocations and subsidies are available to needy families with children, or those living with HIV.

Alla, five years old, born to HIV-positive parents, has spent all her life in institutions.

© UNICEF Russia

In Belarus, Bulgaria and The former Yugoslav Republic of Macedonia, in 2005–2006, pensions represented 8.5 per cent of GDP; however, expenditure on family allowances accounted only for 0.1–1 per cent of GDP.[11]

In many countries, targeting efficiency tends to be poor and allocations so insignificant that they do little to alleviate the financial stress experienced by families.[13] Reports also indicate that some families of children living with HIV choose to forgo subsidies due to concerns about confidentiality and discrimination.

Institutions providing care

Overwhelmed, many families in difficulty, especially those supporting the double burden of HIV/AIDS and financial hardship, turn to state institutions for respite or to have them act as parental substitutes and raise their children.

The infrastructure of institutional care remains as that of the Soviet era. Infants who are left in maternities are transferred to baby homes (*Dom Ribyonka*) where they stay until the age of three. If they are not adopted during these early years they are transferred to children's homes (*Dyetski Dom*) for the next four years and then onwards to 'internats' for 7- to 18-year-olds. This movement through different institutional settings leaves many children poorly equipped to cope or find jobs once they leave and highly vulnerable to abuse and exploitation. Young people graduating from these institutions have much higher rates of alcoholism, drug use, criminal behaviour, unemployment, imprisonment and suicide than their peers.

For children with HIV who live in institutions, the chances of being adopted are particularly slim as a result of widespread prejudice. Elena, from Ukraine, who adopted two HIV-positive girls (aged 6 and 7), shares her experience:

> *"From the moment I saw them, I immediately knew that I would love them like my own children. Imagine my surprise when the adoption agency tried to convince me not to take these two girls! They said to me, 'Why would you want such a headache, you should take some other children.'"*

Despite growing availability of alternative family-based solutions, residential care is not diminishing. In recent years, the proportion of children in residential care has increased

Health-care worker in the Russian Federation with an HIV-positive child.

© UNICEF Russia

in 11 out of 17 countries in the region. The overall rate of children living in formal care has risen from 1,503 per 100,000 in 2000 to 1,738 in 2007.[14]

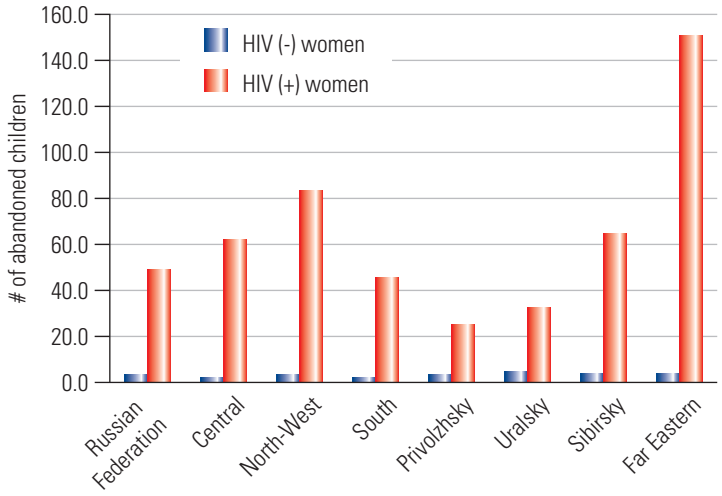
The unremitting inflow of children into institutionalized care is encouraged by a pervasive belief, shared by state workers, residential staff and parents alike, that children will receive a better upbringing in an institution than within a 'troubled', 'asocial' or dysfunctional family.[15]

At the same time, this relinquishment of children reflects both an absence of services that would enable problems to be identified early on, and a failure to implement effective preventative measures to strengthen family capacity to care and provide for children.[2,11] Weak linkages between health and child protection services in supporting mothers and families with infant disabilities or HIV infection are also recognized as factors leading to relinquishment. Without counselling and support, parents may feel they do not have the capacity or means to provide appropriate care. Professionals in both the health and child protection sectors express concerns that the other sector is insufficiently informed about the services they offer and the problems they encounter. This also leads to inaccurate information being provided to those wishing to access the services, resulting in missed opportunities for early identification and timely referral of cases.

HIV and abandonment

For children infected or affected by HIV the likelihood of being abandoned is higher than for other children (see Figure 1). Although HIV *per se* may not be the main reason for abandonment, HIV tends to be a marker for a number of other factors of exclusion and vulnerability. In the Russian Federation and Ukraine, about 6 to 10 per cent of children born to HIV-positive mothers are abandoned in maternity wards, paediatric hospitals and residential institutions, with little opportunity for foster care, adoption or family reunification.[16,18] While the relative proportion of children abandoned at birth by these mothers has been decreasing, the number of HIV-positive pregnancies has grown, creating a steady increase in the cumulative numbers of children abandoned to state care overall.

Figure 1. Abandonment of infants after delivery per 1,000 live births, Russian Federation, 2008



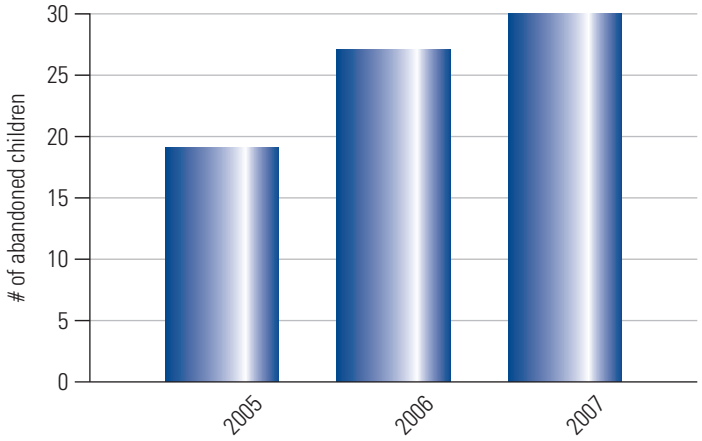
Source: Shinkareva I. Statistics of child abandonment/relinquishment in maternities in Russian Federation. *TB/HIV bulletin #8*, Tver, Russian Federation, 2009

The reasons for infant and child relinquishment by HIV-positive women are complex. An in-depth qualitative study of HIV-infected mothers, their families and health-care workers from four regions in the Russian Federation concluded that HIV was not the primary reason for infant abandonment.[17] Rather, the key factors increasing the likelihood of abandonment were: unwanted pregnancy, poverty, lack of family support, drug and alcohol use, fear of the infant having birth defects or disabilities, and an inability to support the costs of caring. Of these, the strongest predictor was unwanted pregnancy. Some women also reported being advised or pressured to abandon their babies by their own families or by health-care professionals, although in certain cases other family members willingly assumed the role of caregiver.

Similar factors for abandonment have been indicated in other studies, with single parenthood and the fact of already having one or more children also being identified as factors that elevate risk.[18] Among injecting drug users (IDUs), abandonment of infants is prevalent, and in the case of IDU HIV-positive women in St Petersburg, on the rise (see Figure 2 below). Infant abandonment soon after delivery may be precipitated by the woman's need to leave the hospital to seek drugs. Unintended pregnancy, poor access to existing abortion services and frequent alienation from family members also contribute to high rates of abandonment among this group. Widespread negative attitudes of medical professionals towards

HIV-infected pregnant women and mothers, and the stigmatizing and discriminatory treatment of drug-using women further increase the likelihood of abandonment.[19]

Figure 2. Child abandonment among IDU HIV-positive women, St Petersburg, Russian Federation, 2005–2007



Source: Kissin et al., Abstracts, Second Eastern Europe and Central Asia AIDS Conference, Moscow, 2008

In Moldova, mothers who leave their children said they had been influenced by shame and negative attitudes towards single mothers and disabled children.[15]

In Georgia, almost half of mothers at risk of relinquishing their newborn reported a feeling of helplessness and lack of family support. Many were afraid of domestic violence or rejection and felt lonely and inadequate.[20]

Maternity hospitals are the first point of infant abandonment. However, few hospitals in the region provide health worker training on how to identify and counsel pregnant women or new mothers at risk of infant relinquishment. But with growing recognition that the post-natal phase is a vital period of attachment and infant development, an increasing number of hospital-based initiatives to support and encourage pregnant women and new mothers to keep their babies are showing results.[15]

Throughout the region, important reforms have been taking place in child-care systems. Countries of the region, including Armenia, Belarus, Georgia, Kazakhstan, Moldova, the Russian Federation and Ukraine, have started to introduce reforms in the child-care and social protection systems. Although most countries are still struggling with high rates of

children entering into the formal care system, reforms are starting to take hold. These include changes to the basic structures, services and organization of child-care systems with the aim of decreasing the number of children in residential care, preventing family separation and increasing the proportion of children cared for in a family-type environment. Strategies include introducing modern approaches to social work and supporting families to prevent family separation and abandonment. Similarly, efforts are being made to link de-institutionalization with the introduction of new alternative family-based care services to ensure that children who are already in the formal care system and families who are most at risk are the first to benefit from new services.

However, many of these changes are still both slow and insufficient, and many do not reach HIV-infected and affected children. There is an urgent need to strengthen family capacity to provide the care and support that these children need.

Supporting families to take care…

Within the context of child-care reforms in many countries of the region, support to biological families to keep their children, prevention of abandonment, and the development of family-based care alternatives to institutionalization have increasingly been a focus. UNICEF has been a key partner in many such initiatives.

In Ukraine, for example, almost 90 per cent of maternities have established linkages with social services to address child abandonment. A number of 'Mother-Baby Centres' have been opened by state social services to support new mothers in difficult circumstances. Many of the mothers are teenagers or single women who have been rejected by their families. Reports show that over 60 per cent of mothers who are in contact with the centres change their minds about abandoning their babies.

Similarly, projects led by NGOs, such as the MAMA+ project of Health Rights International with the Ukrainian Foundation for Public Health, have provided support for HIV-positive and drug-using pregnant women and mothers to enable them to keep their children. A range of client-oriented services are provided, including day-care centres, family visits, referrals to health-care facilities and drug and alcohol addiction counselling.

The All-Ukrainian Network of People Living with HIV/AIDS has also taken action to find family-based care options for abandoned HIV-positive children living in institutions. Finding adoptive parents has been particularly challenging as a result of many legal obstacles, widespread social misconceptions about HIV, and the high levels of stigma and ignorance associated with the disease. As expressed by one of the project coordinators from the Network: *"We have looked for adoptive parents for over two years. It is extremely difficult to find such people. We believe we need to find such families and provide them with all the necessary support. The majority of HIV-positive kids have suffered through living in orphanages and need special care."*

At an orphanage for children affected by HIV/AIDS.

© ANTI AIDS Foundation

Denis, 12, injects a self-made drug based on ephedrine, known as 'baltoushka', to his friend, while Konstantin, 17, looks on. Photographed in an abandoned house where they lived in Odessa, Ukraine, on 17 June 2006. The whereabouts of both boys are unknown.

© M. Novotny

SECTION II The stories of most-at-risk adolescents are stories of broken dreams…

"They got my brother Farkhod addicted to heroin, as well as one of the girls, Dilafuz, who is such a nice girl. First, they (relatives) asked them to prepare the drug-mix and injection. But then they offered it to her (Dilafuz) to try it herself. Then heroin was hard to get and they sent Dilafuz, who was 15 years old at the time, to Dushanbe. She crossed the border, but on her way back was caught by customs. She was told that they would detain her for three days, but, instead, they kept her for a week and raped her all that time. Her grandmother, an IDU too, came to pick her up. After that Dilafuz started smoking heroin, then making injections, and selling herself. People in the village started calling her ***'a girl for a dose'****."*

From an interview with a health worker describing what happened to his brother and a young woman in his village in Uzbekistan.

"I was young, a teenager. I was in love with my boyfriend who injected drugs. I wanted to be with him and his friends so I asked him to give me an injection. At first he did not want to do it but I kept insisting and nagging him. I was curious and I wanted to be part of the group. So I kept going back. Finally he gave me an injection and I felt so sick. They thought they got rid of me and that I would not come back… but I did. I went right back the next day…"

From an interview with a young female ex-IDU working as an outreach worker in Moldova.

Whether we like it or not…

Regardless of whether parents, teachers, neighbours or friends approve or disapprove, regardless of whether behaviours are voluntary or forced, legal or criminalized – every day thousands of adolescents in the region put themselves at risk of HIV infection. At the same time, there is widespread reticence within society at large to openly discuss these high-risk behaviours, or to do so without passing judgment.

Ivan, 14, prepares a self-made drug based on ephedrine, known as 'baltoushka'. Photographed in an abandoned house where he lived in Odessa, Ukraine, on 17 June 2006. Ivan's whereabouts are unknown.

© M. Novotny

Behaviours that put adolescents and young people most at risk of HIV include engaging in multiple unprotected sexual partnerships and injecting drugs with non-sterile equipment. A host of factors, situations and circumstances influence risk taking. Peer pressure, curiosity, and thrill seeking sometimes lead to experimentation with drugs, alcohol and sexuality. Similarly, family problems may trigger or accelerate risk taking among youth, with many at-risk youths in Eastern Europe and Central Asia reporting poor relationships with parents and other family members. Deeper structural issues such as unemployment, poverty, crime, trauma, illegal status, conflict, and marginalization also drive risk taking, with substantial numbers of young people turning to drugs and sex work as a means of coping or escape.

Who is at risk?

Assessing the size of the population of adolescents and young people at greatest risk of HIV and their contribution to the AIDS epidemic is complex. The issue can be addressed in two different ways. One is by estimating what is the proportion of most-at-risk populations (MARPs) who are minors. For example, what proportion of IDUs are adolescents or what proportion of females selling sex are minors? The other is by looking at what proportion of broader adolescent populations engage in behaviours that put them at high risk of HIV infection. For example, what proportion of Roma adolescents sell sex or what proportion of institutionalized young people inject drugs? Both approaches capture 'most-at-risk adolescents' (MARA). While their risk profiles may differ, the imperative for prevention, treatment and support is equally urgent.

The situation among MARA is particularly bleak. In Ukraine, adolescent girls aged 10–19 who sell sex comprise an estimated 20 per cent of the female sex-worker population. Moreover, in 2006, HIV prevalence among females aged 15–19 selling sex exceeded 19 per cent compared to 1.4 per cent in the general adult population.[21] Many of these adolescents and young women do not seek the help of services as they fear police harassment or being sent to state institutions. Worrisome evidence across the region suggests that risk behaviours are increasing among younger cohorts. In Tajikistan, for example, recent initiates to injecting drug use are twice as likely to be HIV-infected as those with longer injecting histories, implying riskier HIV behaviours and potentially less use of harm reduction services than older, more established users.[22]

Risk is exacerbated by the overlapping vulnerabilities that young people experience. Figuring among the most-at-risk are adolescents and youth from disadvantaged or troubled families, those who have dropped out of school or are unemployed, juvenile offenders engaging in petty crime, or those 'graduating' from institutions unprepared and without support to face life on their own. They are young people whose rights to care and protection have been violated, and who suffer indignity, social injustice and exclusion on a daily basis.

Overlapping risks and vulnerabilities

Many adolescents and young people experience overlapping risks and vulnerabilities for HIV…

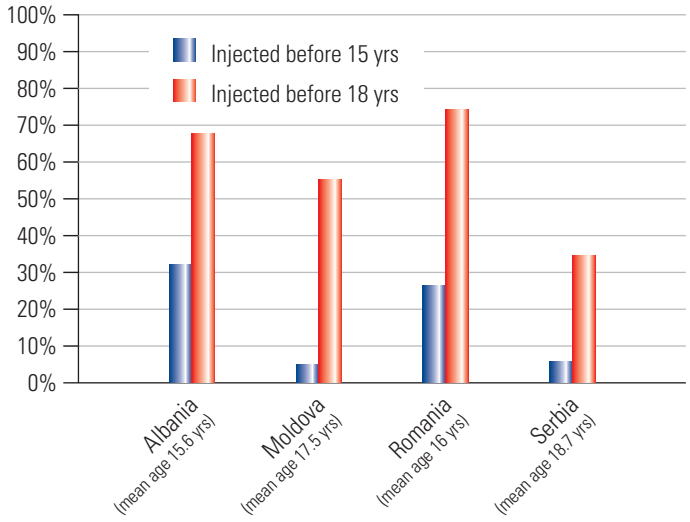
- In a survey carried out in 2008, among 300 young (25 years or younger) female sex workers in Romania, 21 per cent were under the age of 18. Almost a quarter had never been enrolled in school, and a disproportionate number were from the Roma ethnic group (27 per cent). In the capital city, Bucharest, 44 per cent of surveyed sex workers also reported injecting drug use. Although younger respondents in the study (under 18) were less likely to be injecting drug users, they exhibited higher sexual risk behaviour. For instance, they were less likely to use condoms with commercial or casual partners, less likely to have had an HIV test, and were less knowledgeable about HIV transmission.[23]
- In Bosnia and Herzegovina, half of injecting drug users surveyed in Sarajevo reported having had sex for the first time before the age of 15.[24]
- Across 25 cities in Ukraine, 31 per cent of girls aged 15–19 selling sex reported starting to sell sex between the ages of 12 and 15 years.[25]
- A study in Montenegro of 288 Roma youths aged 15–24 indicated extremely low school enrolment rates, especially among girls. Forty-four per cent of the young Roma women, and 22.3 per cent of the young men had never been to school. Half of the sample was married, and 83.3 per cent of married females had ever been pregnant. Knowledge of HIV transmission was poor, with less than one in four under-18-year-olds correctly informed, although males were significantly better informed than females.[26]

Young women discussing HIV prevention among peers as part of a government-supported programme in Tajikistan.

© UNICEF Tajikistan

Risk behaviours are often initiated early. In a multi-country study of IDUs aged 15–24, up to 30 per cent of the young users reported age of first injection as less than 15 years (see Figure 3).[27]

Figure 3. Age at first injection among injecting drug users (IDUs) aged 15–24 years



Young drug injectors at higher risk

The largest contributor to HIV transmission in Eastern Europe is injecting drug use. A UNICEF multi-country study of young injectors (aged 15–24) found that younger drug users tend to have poorer access to harm reduction services, and in some cases practice higher-risk behaviours.[30] For example, among Romanian injectors, 26.3 per cent of under-18-year-olds were found to have shared injecting equipment in the past month, while fewer than 20 per cent of those 18 and older had done so. In Moldova, where close to a third of the IDUs surveyed were younger than 18, adolescents were more reluctant to obtain clean injecting equipment from exchange programmes, drop-in centres, or outreach workers compared to adults (11.4 per cent vs. 28.6 per cent). Similarly, in Serbia, outreach workers or exchange programmes were a significantly more common source of needles and syringes among older users than younger ones (24.7 per cent vs. 4.8 per cent); younger users were more likely to obtain needles from acquaintances. Adolescents were also less likely to have ever had an HIV test; for instance, in Albania although just over a third (37.3 per cent) of surveyed IDUs had ever had an HIV test, none of those under 18 years old had done so.

Fortunately, some innovative efforts, not only to prevent HIV and reduce harm of drug injecting but also to reduce initiation into injecting among youth, are beginning to emerge. In Albania, for example, UNICEF and NGO partners are piloting an HIV prevention programme to 'break the cycle' of initiation into drug injecting. Most young people are introduced to injecting drugs not by dealers but by peers and siblings, who often then regret their role in perpetuating the vicious cycle of addiction and risk. The 'Break the Cycle' programme recruits IDUs through methadone substitution treatment services and mobile outreach teams, with the aim of promoting non-injection messages and behaviours and dissuading established IDUs from initiating others into injecting.

Adolescents selling sex: Service provision and empowerment

An innovative service delivery model has been developed in Mykolayv, one of the cities in Ukraine most affected by HIV, where one fifth of female sex workers are adolescents – 98 per cent of whom have engaged in unprotected sex during the previous year, while 16 per cent have injected drugs.[25]

With the aim of reducing risk and vulnerability, non-governmental organization (NGO) outreach workers bring girls to a drop-in centre that offers a safe space, counselling, and referral to governmental health and social services. Work with child protection services, the police and the education sector is undertaken to foster a more supportive environment for these girls at risk, and they are empowered to actively participate in service planning, implementation and evaluation.

Mobile phones are used to facilitate contact – to invite them to project events, remind them about appointments with health-care and social workers, enable emergency calls (in case of detention, abuse, conflicts) and to provide phone-based counselling. These phones, an everyday feature of the youth subculture, have proved to be a very efficient communication tool, allowing girls to openly discuss their risk behaviour and seek advice as needed. In Mykolayv, 90 per cent of adolescents selling sex now have mobile phones and regularly communicate with staff and each other. Demand for the services has far exceeded expectations. The involvement and support of the Mykolayv municipal authorities have been critical to the centre's success, and will ensure sustainability in the future.

Young MSM: Hidden and underserved

Throughout the region men who have sex with men (MSM) constitute one of the most hidden segments of society. HIV infections among MSM are systematically under-reported.[28] Little is known about their risk behaviour including the extent of their involvement in commercial sex. Assessments conducted with MSM in several countries of the region indicate that same sex relationships start at a young age. In a study among 500 MSM in Serbia, close to half reported first male-to-male sex before the age of 18, and 22 per cent of the respondents in Belgrade before the age of 15.[29] Young MSM in the region report having problems with

self-acceptance, lack of information and access to services. Given widespread homophobia, they fear disclosing their identity and sexual orientation. Mistrust in government services is high because of judgmental attitudes and lack of confidentiality. As expressed by a young MSM from Moldova:

> *"I wish for a service that will truly keep all secret… not look at you strangely… the provider should be engaged in solving the patient's problem with a kind attitude."*

Unmet needs of the marginalized

HIV/AIDS programming for youth in the region has largely focused on prevention education aimed at the general population of young people using information campaigns, school and life skills-based curricula, and to some extent peer outreach and youth-friendly services. Even peer-led programmes in the region tend to focus on young people in formal settings, such as schools and youth clubs. Many of these mainstream interventions, however, fail to adequately address the specific risk behaviours and environments of especially vulnerable young people and tend to be insensitive to the many factors that influence their risk taking. Too often, a 'moralistic' stance is assumed that 'risk taking should not occur', and evidence on effective approaches to support and prevention is overlooked.

Much more needs to be done to improve the appropriateness of services for young people and their access to them. The large majority of interventions for vulnerable or high-risk groups in the region are oriented towards adult populations. Civil society organizations working with at-risk populations are often reluctant to provide services to under-age populations for fear of legal or other repercussions, such as accusations by the public of promoting risky behaviours to minors. In some cases a 'don't ask, don't tell' approach is employed – services are provided without asking questions – however, the problem remains hidden and underground.

At the same time, young drug users may be reluctant to access adult services because of concerns about privacy and confidentiality, or because they feel that peer education messages, designed for older users, are irrelevant to them. Oftentimes, they are right. For example, very few interventions in the region specifically target recent initiates to injecting drug use or those who inject only occasionally. A needle and syringe exchange has little to offer young people who use drugs but do not inject. Methadone treatment may be inappropriate for non-dependant drug injectors. As a result, rates of drug use and HIV risk behaviour are increasing in younger populations.

Protection or punishment?

In many countries of the region, drug use, sex work and male-to-male sex are considered illicit or deviant behaviours. Historically, the main systems that deal with young people engaging in these behaviours are the police, juvenile correctional systems and psychiatric clinics. While these systems are meant to be protective, in practice they are often punitive and fail to defend children's rights.

A frequent approach taken by police in dealing with youth engaged in illicit behaviour has been one of 'raids' whereby minors are caught, registered, monitored, and in certain cases, sent to detention centres. Repressive police practices are common, and represent a significant barrier to establishing relationships of trust with at-risk and vulnerable young people, and discourage them from seeking contact with services.

Adolescent girls who sell sex on the streets of Bucharest talking to a young outreach worker.

© UNICEF Romania

In a recent multi-country study among most-at-risk young people, female sex workers in Romania reported the highest rates of police harassment (86.9 per cent), followed by IDUs in Romania (76.0 per cent), street children in Ukraine (73.9 per cent) and IDUs in Serbia (60.9 per cent) and Moldova (48.0 per cent). In Romania, interaction with the police appears to be associated with risky injecting practices; among IDUs reporting police harassment or arrest in the past year, 21.7 per cent reported sharing injecting equipment in the past month compared to 8.6 per cent who were not harassed by police.[31]

Countries of the region have been engaging in reform of their juvenile justice systems and are signatories of the Convention on the Rights of the Child, which recommends establishing a separate justice system for juveniles who break the law, including drug laws. However, the reality is that most countries still apply adult criminal justice procedures to juvenile drug use offenders. In six countries in the region, simple use and possession of drugs are considered crimes and aggressive law enforcement is common.[31] Few have fully implemented systems that support rehabilitation or offer alternative sentencing so that imprisonment becomes a last resort. Medical and psychological assistance is not always available to juveniles in pre-trial detention. Once incarcerated, dangers of abuse and neglect, exposure to criminal influences, and high levels of tuberculosis and HIV risk jeopardize their mental and physical health, and hamper their reintegration into society.

The requirement of parental consent is another key barrier to seeking or receiving services for at-risk minors, especially in an environment where children hide their risk behaviour from parents, or where parents are disengaged from a child's care or are in conflict with the child. Some countries in the region (including Bosnia and Herzegovina, Ukraine and others) have been working on policy changes that would lower the age of parental consent for adolescents seeking selected medical services. This is particularly important when it comes to HIV testing.

Building trust – building services

There is evidence suggesting a link between socially disadvantaged and/or dysfunctional families and risky behaviours among adolescents and young people. Recognizing this, countries in the region are introducing reforms in child and social protection systems to support children, young people and families in crisis. For example, the government of the Russian Federation has established a nationwide 'Foundation for Children in Crisis Situations', which supports children and parents facing problems such as violence and abuse,

Boys and men gather outside the 'Your Victory' Centre in Ukraine, which provides shelter and services for injecting drug users, some of whom are HIV-positive. Kirill, 13, (front row, with guitar) was using drugs and living on the streets for two years. He was sent to the shelter by his mother.

drug and alcohol dependence and risk of loss of child custody. The Foundation encourages local initiatives that promote policy change and provide support to families in crisis through job skills training, improving parenting skills as well as introducing modern approaches to social work, such as home visitation and integrated case management, to improve family capacity to care for children. In other countries, programmes have focused on harm reduction through outreach to marginalized young people as an approach to increasing their inclusion into society and access to services. Similarly, 'second chance' programmes have supported excluded young people to rebuild their lives, and increase their resilience and capacity to cope. While these new initiatives develop models that lead the way towards broader systemic reforms designed to support children and young people in crisis, including those most at risk of HIV, their scope and coverage are still insufficient to cover existing needs.

Another important area of innovation in the region is the establishment of youth-friendly health services. These have marked a major shift in the orientation and attitudes of health services towards a 'client-oriented' approach that aims to facilitate access and meet the real needs of adolescents and young people. Such services are operating with more or less success across the region. In the Russian Federation, 117 youth-friendly service facilities have been established in 28 regions across the country, providing reproductive health and sexual health services, information, counselling and psychological support to approximately 1.5 million young people. Initiatives like these are critical to youth at risk who have been marginalized by legal, social and economic dynamics beyond their control. However, to be effective, they require that service providers acknowledge young people's complex and challenging realities. Ensuring good standards and quality of care in these services is also important, particularly if they are to reach those most at risk.

The need for quality, client-centred services is especially urgent for adolescents and young people living with HIV in the region. The challenge for health and social services is to ensure timely diagnosis of HIV, access to antiretroviral treatment and psychosocial support to empower adolescents to cope with issues such as disclosure of HIV status, adherence to treatment, positive sexuality and reproductive health. It is important to strengthen partnerships between service providers, caregivers and HIV-positive adolescents, their families, schools and communities.

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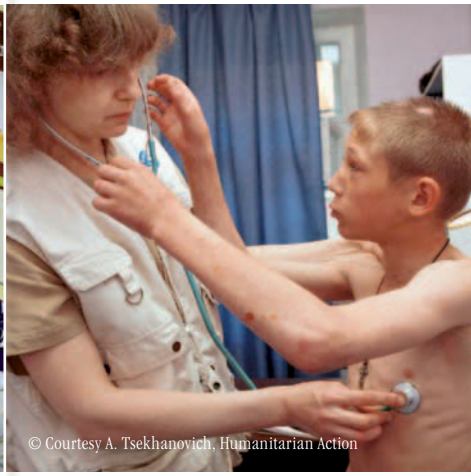
© Courtesy A. Tsekhanovich, Humanitarian Action

HIV prevention counselling, educational materials and youth-friendly services.

Youth-friendly health services – friendly to MARA?

There are numerous examples of adolescent/youth-friendly health services (YFHS) in the region that have been successful in introducing 'client-oriented' approaches and in providing mainstream young people with information, reproductive health services, and prevention information and counselling for HIV and sexually transmitted infections (STIs). Some have also managed to reach and effectively serve the needs of MARA.

In **Moldova**, the Atis youth-friendly health centre in Balti is part of a network of 12 YFHS established in recent years in the country. While most youth-friendly health services are run out of health facilities, Atis started out as an NGO involved in community-based outreach among at-risk and vulnerable adolescents. This unique history gives Atis an advantage in knowing how to access and respond to the needs of hard-to-reach adolescents.

Atis is known for providing services and support in a friendly, non-judgmental way, which is often not the case in more traditional health services. *"When I went to the family doctor in the town clinic, they only wanted to get rid of me,"* says Tamara, an HIV-positive young person from Balti. *"Here at the [Atis] clinic, the doctors treat me without applying judgments."* Alex, another young person says, *"I tried getting a consultation elsewhere, but it did not help me…here, it's the attitude that matters."*

According to Olga Shciogolev, a therapist at Atis, *"There are children who come here who cannot even explain the problem they have… we work with children living on the streets, with victims of domestic violence, males having sex with males, trafficked women and girls. We counsel adolescents giving birth and thinking of abandoning their babies. We understand that adolescents are not able to cope with their problems independently. That is why we also work a lot with parents…"*

Between 2005 and 2009, Atis served 26,000 young people in Balti, including 4,200 most-at-risk adolescents, providing them with health services, information, counselling and social assistance.

In **Tajikistan**, youth-friendly health services have been developed with a specific focus on serving the HIV/STI prevention and treatment needs of adolescents and young females selling sex. The services, based at state-run STI clinics, have been linked to a network of other relevant medical and social services. Among the more than 1,300 clients served in a year, almost 1,000 were tested for STIs and 245 for HIV; of these, 17 per cent tested positive for STIs and 1.4 per cent tested positive for HIV.[32] The centre has been able to build a relationship of trust with its young clients. As expressed by an adolescent girl selling sex from Dushanbe, *"In the beginning I did not believe that the medical check-up, the treatment and condoms would really be free of charge and anonymous. I thought it was another trap by the police. I agreed to go there with an outreach worker for the first time but now I go there alone and encourage my friends to use the service as well."*

Equally importantly, sound monitoring, evaluation and costing studies have encouraged the government to scale up service delivery from three to eight youth-friendly service sites throughout the country. As expressed by a high-level government official, *"This is one of the rare projects that clearly demonstrates the cost-benefit ratio of interventions which, in the long-term, can lead to savings in the health sector… and we are fully supportive of scaling it up and ensuring future funding."* (Mr Shavkat Sokhibov, Deputy Minister of Finance, Tajikistan)

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Adolescents from the region – at risk, vulnerable and in need of love, protection and support…

"Yana hardly said a word, but she cried a lot…" A street child in Odessa, Yana died at the age of 13, HIV-positive and addicted to drugs. UNICEF photo of the year award, 2005.

© David Gillanders

SECTION III Children of the streets: The end of childhood…

"Yana was just eight years old when she started living on the streets. Her father, an alcoholic, died young and she was separated from her mother who was sent to jail. Originally from Moldova, one of the poorest countries in Europe, Yana wandered through several towns and eventually ended up on the streets of Odessa, Ukraine. Her 'home' was a makeshift shed in a park. A group of 20 street children built the hideout themselves, the youngest only six years old. They begged, stole and prostituted themselves to survive. Drugs helped them cope with their lives. Through sharing needles they also shared HIV. Yana fell sick and died at the age of 13 on the streets of Odessa, addicted to drugs and infected with HIV…"

Today, street children in the region are dying of AIDS and drug use in much the same way as they died of cold, famine and typhoid in the twentieth century. A recent study of 15- to 19-year-old street children in St Petersburg, involving 313 participants, found that almost 40 per cent of them were HIV-positive. Injecting drug use was found to be the strongest risk factor, with a greater than twentyfold increased risk of HIV. More than half of them (51 per cent) had experience of injecting drug use; 96 per cent were sexually active; and 24 per cent had more than six sex partners per year.[33] High levels of HIV prevalence have also been found among street children in studies in Odessa and Donetsk, Ukraine.[34]

The phenomenon of street children is not new and has deep historical roots in the region. During the last century, millions of children were pushed onto the streets during periods of war, civil unrest and famine. However, as these children were not supposed to exist in a 'developed socialist society', there were no official statistics about them. The problem was kept 'under control' through a network of state-run institutions for orphans and neglected children. Institutionalization was believed to be the best approach to ensuring the well-being of children otherwise doomed and exposed to the dangers of living on the street. The approach included a police-run department in charge of collection and placement of children who ran away from homes or orphanages, and a network of closed boarding institutions where children aged 5–17 were placed. There was little accountability or questioning of any abuses taking place in such institutions.

Taras, 17, cries after Denis, 12, who was not able to find a vein to inject him a self-made drug based on ephedrine, known as 'baltoushka'. Photographed in an abandoned house where they lived in Odessa, Ukraine, on 16 June 2006. Taras died of an overdose in 2008. Denis' whereabouts are unknown.

© M. Novotny

Pathways to the streets…

With the greater democratization of society since the 1990s, the issue of street children has become more visible, partly due to lesser state controls and increased availability of data. Throughout the region, the number of street children increased as a result of the pressures of rapid social change and economic adversity. Extreme poverty continues to push children onto the streets so that they can earn money rather than go to school. A 2008 study of street children in four cities in Georgia revealed that 90 per cent had to earn an income for themselves or their families. Half of all street children were illiterate and 60 per cent never entered a classroom.[35]

While there are no reliable estimates of how many children are without adult supervision, living and/or working on the streets, experts agree there are probably over one million in the region.[36] The large majority end up on the street as a result of running away from physical and psychological abuse within families, or from state-run orphanages and shelters. Many children in state-run institutions are 'social orphans', meaning they have a living parent whose parental rights were taken away either because of alcohol, drug use or legal problems with the authorities. Domestic violence and alcoholism among parents are frequent causes of homelessness among children in the Russian Federation.[37]

In 2007, the Ministry of the Interior of the Russian Federation reported that they were monitoring 173,000 parents and guardians of minors identified as 'at risk' of abusing or neglecting their children and 77,000 families were deprived of their parental rights.[38]

Once on the streets, sex and drugs become part of these children's daily reality and other street dwellers compose their social network. Almost all street children report being sexually active and the majority have multiple partners, both through sex among peers and through selling sex.

A UNICEF and partners' study among street children in Ukraine in 2009 showed high levels of vulnerability to HIV.[39] A sample of over eight hundred 10- to 19-year-olds who spend over half their time on the streets were surveyed in four cities. The findings show high rates of a range of HIV risk behaviours. Injecting drugs was reported by 15.5 per cent of the sample and close to half had shared equipment at least once in the past month. About 10 per cent of the boys reported ever having had anal sex with a man or boy, and both boys (16.5 per cent) and girls (56.7 per cent) reported having received payment or gifts in exchange for sex. Rates of forced sex were also high, reported by 11.2 per cent of boys and 52.2 per cent of girls. Among sexually active girls, 18.3 per cent reported ever having been pregnant and, among these, 68.2 per cent had obtained abortions.

For many street children, substance use, including glue sniffing, alcohol and self-made drugs, is a 'solution' to their hardship, providing an easy means to escape the harsh daily realities of hunger, poor living conditions, sexual violence and abuse, fear and loneliness.

In the words of Vladik, 11, living on the streets of Odessa, drug use transforms his reality:

> *"The world changes before your eyes. You look at a picture of an elephant and suddenly you see that it smiles at you and splashes water all over you with its trunk. You can actually feel your wet clothes…"*

But drugs also kill. One of the most affordable and dangerous substances used by many street children in Moldova and Ukraine is a home-made amphetamine-like preparation, called 'baltoushka', that is administered by injection several times per day. In addition to the risk of HIV due to unsafe injection practices, its use is associated with abscesses and skin burns at injection sites, partial loss of cognitive functions, brain damage and Parkinsonism. Other effects include loss of appetite and the decreased feeling of hunger that so many street children experience in the absence of regular meals. Other types of home-made,

low-cost, injectable drugs with similarly toxic effects have also been reportedly used in countries throughout the region.

Social attitudes towards street children have also changed over time. Whereas in the past such children would be seen as destitute and needing help, the predominant perception today is that they are outcasts, beggars and petty criminals that society needs to 'clean up'. As unequivocally stated in a billboard that recently appeared on the streets of St Petersburg, taking children off the streets is seen as an issue of home security.

Services that are offered to street children have been increasing both in numbers and coverage. However, a key challenge for these is to build relationships of trust and to be accepted by the children. Even when the children are informed of the existence of such services, they often believe that contacting them will lead to negative consequences. Thus, when needing help, these children are more likely to turn to each other than seek help from social services or civil society organizations.

But not all is bleak. Creative initiatives undertaken by civil society organizations as well as by some state-run social services are trying to address the needs, rights and aspirations of street kids. The Way Home, in Odessa, is one such civil society organization that reaches out to children on the streets using a 'social patrol' network of mobile outreach workers. In addition to food and counselling, they provide individual 'case management', accompany children to health services, and provide housing, education and support through a residential programme that offers street children a 'second chance' to rebuild their lives.

Billboard on the streets of St Petersburg, Russian Federation: "Let's reduce the numbers of unsupervised and homeless children – for the security of our citizens – as part of the state system of prevention of offences."

© A. Tsekhanovich

Lena, 15, rebuilding her life…

"I lived with my mother and stepfather in a small apartment, went to school and enjoyed sports.

When I was 13, my mother died in a car accident and my stepfather became my guardian. The financial situation in the family became hard as my mother had been the main bread-winner for the family. My stepfather couldn't find a job. He began drinking, and drunkards, thieves and prostitutes became part of his circle. The apartment became a dump. My stepfather got offers to use me as a prostitute. He agreed and I was raped repeatedly. I thus became the main source of money for him. What happened damaged my health.

Tutors from The Way Home visited me at the hospital and after the treatment was finished they brought me to the shelter. I like being here very much. No one offends me, there are many interesting classes and study groups. I go to the local school and would like to become a doctor for children in the future."

Art class for children from families in crisis at NGO 'The Way Home' in Odessa, Ukraine.

© The Way Home

Dasha is HIV-positive and, like many other HIV-positive children, has faced stigma and discrimination. UNICEF's 'Vitamin Fairy', a colorful children's cartoon, story book and a calendar, developed with the Kazakh Union of PLHA, helps her take her antiretroviral medications every day.

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SECTION IV Living with HIV: Society, systems and a daily search for hope...

"My husband beat me, turned his back on me and told me to go and live where I found AIDS. He threw me out of the house with my sick child and the rest of the children. My former colleagues did not allow me to go back to work. Everyone in the village made gestures with fingers and crossed the street. I was banished from the village... I barely survived..."

From an interview with Dilfruz, a young mother whose child was infected with HIV at a local hospital in Kyrgyzstan.

"When Olimbi tried to enrol her HIV-positive children into school, she faced massive protests from other parents. She was even physically threatened. The words of one of the parents still haunt her: 'You should take your children with you and kill yourselves, all of you, and leave us and our children alone.' That hurt. 'It is part of our lives now. In every step we take, we face this kind of mindset.'"

From an interview with Olimbi, an HIV-positive mother from Albania.

The challenges faced by Dilfruz and Olimbi are typical of the region where many children and families affected by HIV face stigma and isolation. In the cases of Dilfruz and Olimbi, their stories took new turns. Dilfruz was lucky as her father-in-law came to look for her in the village where she took refuge. He brought her and her three children back to his house and now treats all of his 12 grandchildren with the same love and care. Dilfruz is proud to have been able to give support to other women facing similar situations to her and who have contacted her for advice and counsel. As for Olimbi, she was able to convince the local school authorities and the Ministry of Education to take action. A number of information sessions were organized for parents and her children were subsequently admitted to school on equal terms with the other children. But Olimbi's courage went beyond fighting for her own children. She established the Albanian network of people living with HIV and has been a key advocate of HIV care, treatment and support. Her main concern recently has been how to go about helping parents disclose HIV status to children.

In Eastern Europe and Central Asia, people living with HIV are often ignored and socially condemned. As in many other parts of the world, fear, ignorance and prejudice have led to attitudes of blame and rejection that have ruined the lives of many children and families affected by HIV/AIDS. Social exclusion, which is one of the root causes of HIV risk, is also a major consequence of HIV infection.

Opinion surveys reveal widespread public attitudes in which people living with HIV are seen as 'social misfits' and outcasts who have lost the right to be treated as ordinary human beings. A recent six-country study in the region found that many people living with HIV fear social stigma more than the health consequences of the disease.[40] HIV stigma builds on existing negative beliefs and reinforces discrimination against groups that are already marginalized. HIV-positive drug users and commercial sex workers are considered to have 'got what they deserved' or to have 'only themselves to blame'.

Negative social attitudes, in which HIV is seen as retribution for dangerous and 'anti-social' behaviour, are aggravated by a political and cultural legacy that tends to adopt a punitive approach to those who violate social norms. Official interventions are often motivated by an ideology of 'fixing the individual' through banishment or punishment, rather than 'fixing the problem' by lending a helping or supportive hand. A prevailing view is that drug users, sex workers and HIV-positive women are 'unfit mothers' or incapable of being competent parents, with the consequence that many feel pressured, shamed or coerced to abort, or to give up their children to the care of the state. Institutions are viewed as venues for a 'corrective process', and since many children will never 'be made normal', these become their permanent homes.

For 10-year-old Karina, living with HIV often means coping with solitude.

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In general terms, responsibility for the spread of HIV is seen to lie exclusively with those who are infected, who must then assume the consequences of their acts – a mindset that also provides the rationale for criminalization of HIV transmission. People living with HIV are viewed as 'sources of infection' that need to be controlled and having little to contribute to society. The idea that the epidemic can be better contained by supporting those at risk or living with HIV is a new one, and only slowly gaining ground.

Irina's hard choice...

For most people an HIV-positive diagnosis results in deep shock. Stigma and exclusion often undermine the essential support that family members can provide at this time of greatest need. The story of Irina is one example:

Irina, a young woman from Ukraine, used to inject drugs. She managed to stop using drugs and got married. Because of the stigma surrounding drug use, she chose not to tell her husband about her past life. Soon afterwards, she became pregnant.

An HIV test at the antenatal clinic revealed she was HIV-positive. The news came as a great shock. Again, because of the stigma associated with HIV, and fear that her husband would leave her and her children, she chose not to tell him about the diagnosis. Irina secretly took antiretroviral (ARV) prophylaxis to prevent HIV transmission to her baby. Her child was born free of HIV.

Three years later when she became pregnant again, her immune system was found to be depressed. The doctor recommended that she initiate highly active ARV treatment, both for the sake of her own health and that of her future child. This meant that she would have to bring home large quantities of ARV medications to take every day. Irina refused. She was too afraid that her husband would realize that something was wrong and would find out that she was HIV-positive.

Despite numerous sessions with health-care workers, psychologists and peer counsellors, Irina would not change her mind. Her main concern remained that her husband would leave her, and that her children would then lose not only their mother but also their father and might end up in an institution.

Irina gave birth to twins. Both were HIV-positive.

Leaks in the system

> *"All that may come to my knowledge in the exercise of my profession, I will keep secret and will never reveal."*

Excerpt from the Hippocratic Oath

Recognition of the importance of keeping information about an individual's health confidential is as old as the Hippocratic Oath, and is one of the guiding principles in medicine. Yet, often in the region, HIV patients, both adults and children, face situations in which information on their status is shared beyond those who need to know.

One incident spells it out: *"There was a case of a girl who didn't know her diagnosis. She found out when she saw 'HIV' written on the door of her hospital room. She wanted to commit suicide as a result... When we went back to the hospital two or three months later, we still saw 'HIV' written on doors."*[41]

Fear of breaches in confidentiality sometimes leads to extreme measures. In some countries, patients are not guaranteed the right to confidentiality of their medical records, and employers may access the information. In these circumstances, the repercussions of having contracted infectious diseases such as syphilis, HIV or tuberculosis may be so severe that patients will avoid seeking care, or pay bribes to health-care workers in order to receive testing or treatment without it being recorded.[42]

When combined with widespread stigma, the inability to protect confidentiality affects people's lives beyond just their health. Even when social protection schemes are available for families with HIV, there are numerous reports of people preferring to forgo HIV-specific benefits or services for fear of the social ostracism that would result if their status became known. As expressed by a social worker from Romania, *"When people come to get their subsidies they stand in the hallway and employees call out, 'Let the AIDS patients come in.' … Out of the fifty-five birth families that we work with there are over twenty who refuse to take subsidies for fear of breaches of confidentiality."*[41]

In many countries, the design of systems is such that confidentiality is inherently difficult to maintain. For example, in order to receive social benefits, families may have to prove every year that a disability is still present, namely that their child is still HIV-positive. Facing annual review commissions unnecessarily expands the number of people who know about a person's HIV status.

Mandatory registration for many health and social programmes sets a high threshold that dissuades many from seeking preventive or treatment services, particularly vulnerable populations. Drug user registration laws have their roots in legislation developed during the Soviet era with a view to enforcing tight monitoring and control of drug users, often in close cooperation with the police. In many countries, doctors are also required to routinely report those seeking treatment for substance abuse to law enforcement authorities. Rather than a route to assistance and care, registration is therefore perceived as a form of 'branding' of social troublemakers and a potential source of prohibition of their basic rights. For example, on the grounds of their drug use alone, those registered can lose custody of their children. This further diminishes their chances of social reintegration and discourages many from seeking treatment and support.[43]

Weaknesses in health-care settings have resulted in outbreaks of HIV among children. The issue has been widely reported by the international media, including the BBC, The New York Times, Reuters, Pravda and others.

Children with a *'plus'* status: Unwelcome in schools

As a result of stigmatization, children, young people and families affected by HIV are often denied access to services and support, and their special needs are ignored. Although most countries have introduced formal legislation preventing discrimination against people living with HIV, its application is hindered by public attitudes. Reports from the region bear witness to HIV-infected and affected children being refused entry to school and kindergartens, and thereby being deprived of the education they are entitled to. As expressed by one mother: *"All kinds of excuses are used for refusing admission – from 'lack of a free spot available' to direct refusals like 'go to another kindergarten'."* There are also reports of violations of privacy and stigmatization when a child's status is revealed to classmates and teachers. According to Alla, the foster mother of an HIV-positive child:

> *"Someone broke the confidentiality of my son's HIV status. We only realized this when we saw other children constantly avoiding him. He has no friends. He sits alone. Nobody wants to share his desk with him. His classmates say that he is 'disgusting' and refuse to play with him. His only friend is his brother. Every day for us is a constant struggle because we have to prove that we are 'normal' and that others don't need to be afraid of us."*

Tamara, a young HIV-positive mother hides her status to protect her HIV-negative son from stigma at his school.

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Working against stigma in education settings in the Russian Federation

In Eastern Europe and Central Asia, as in many other parts of the world, going to school or kindergarten for children living with HIV means hiding or facing ill-treatment from teachers and peers.

In the Russian Federation, access to kindergartens and schools for HIV-positive children is jeopardized by the pervasive stigma associated with the disease. To help them benefit from early childhood development opportunities in kindergartens and to allow them to study in a non-discriminative environment, UNICEF cooperated with the National Ministry of Education and Science and regional education departments in seven of the most heavily affected regions of the country including Chelyabinsk, Irkutsk, Orenburg and Samara. The aim of the programme was to raise educators' awareness of HIV and of Russian laws that prohibit discrimination against people living with HIV.

A special advocacy, communication and capacity-building programme was developed for use with administrators in the education sector, parents, teachers and caregivers. Some 2,050 schools, kindergartens and residential institutions, with over 400,000 students aged 3–18 years, were reached. A total of 8,380 educators received HIV education and tips on how to support HIV-positive learners in the classroom. After the training, more than 90 per cent of teachers and caregivers (compared to 45 per cent before) reported that they would not object to having an HIV-positive child in the classroom, and would support and protect her or him against discrimination. Such attitude changes are an initial step in the long process of reversing widespread social prejudice and improving the lives of HIV-positive children.

Two training kits, 'Positive Children', were designed, one for schools and preschools and another for residential institutions that care for children born to or abandoned by HIV-positive parents. The kits include a Trainer's Guide, a set of slides, a documentary, an Information Booklet for Educators and Caregivers, and a set of tips for school/residential institution management and teachers/caregivers. These are available at www.unicef.ru.

Prejudice in health-care settings

In health services throughout the region, there are widespread reports of negative attitudes towards people living with HIV, who experience rejection as well as a lack of responsiveness towards their needs. Outside of the more specialized HIV services, health providers often have insufficient information or training on HIV prevention and treatment. This results in reluctance to treat HIV-positive people, both because of the inability of health workers to protect themselves from infection and because they lack the confidence, tools, and resources to treat these patients. Ignorance reinforces discrimination and mistreatment towards people living with HIV.

For children and young people who come from marginalized populations or who engage in behaviours that are condemned by society, the judgmental attitudes and the limited capacity of health-care providers to address their needs are key obstacles to seeking care. When faced with rejection, young people, who usually only have limited experience in navigating health and social services and mostly distrust official service providers, refuse to attend. Prejudice and stigma therefore reinforce an existing reluctance on their part to seek prevention, treatment or care. A young boy living on the streets of Kyiv sums it up: ***"They don't talk to the dirty."***

Health systems: When old models no longer work

As the burden of HIV/AIDS in the region continues to grow, systems designed 20 years ago to monitor HIV as a "socially dangerous and rare disease" are starting to crack. In most countries of the Commonwealth of Independent States, the health system response to the epidemic was to create specialized AIDS centres in large urban areas. These centres reflected 'vertical models' of health-care delivery and a disease-based approach to health care provision inherited from the past, very much in line with the way the region responded to diseases such as syphilis and tuberculosis. Initially the AIDS centres were established to monitor spread of the disease, but later their functions evolved into also providing clinical care. Often poorly equipped and understaffed, many are located in places that are hard to reach for vulnerable populations and for women with infants and small children.

Now, as the epidemic spreads from large cities into smaller towns and rural areas, the centralized system of service provision is cracking under the weight of an increasing demand for services. In 2008, antiretroviral therapy (ART) coverage among adults in the region was estimated to be only 22 per cent, the second lowest in the world.[44]

The centralization of care provision at AIDS centres results *de facto* in the exclusion of HIV-positive people from services at other health facilities. AIDS centres have become places where all people living with HIV, including children, are routinely referred to for any health condition, and where they are able to access care without stigma and discrimination. However, going to a specialized 'AIDS centre' is stigmatizing in its own right, and has become a barrier to access, especially for young people.

The main success of health systems in the region has been the high level of coverage of services to prevent mother-to-child transmission of HIV (PMTCT) and access to paediatric AIDS treatment. An estimated 94 per cent of pregnant women have access to ARV prophylaxis. For HIV-positive children, ART coverage is estimated to be 85 per cent.[44] These

results have been realized largely as a result of the integration of PMTCT with already well-developed maternal and child health (MCH) services.

Remaining challenges in PMTCT in the region today include improvement of primary prevention of HIV infection among young women of childbearing age, and the prevention of unintended pregnancies among HIV-positive women. The region is characterized by high pregnancy termination rates. The proportion of pregnancies among HIV-infected women ending in termination is difficult to compare across countries as the ways in which these data are collected vary and are influenced by HIV testing policies. In the Russian Federation in 2007 and 2008, 40 per cent and 38 per cent respectively of all pregnant women testing positive for HIV terminated their pregnancy. Women receiving HIV testing included both women attending antenatal care and those seeking terminations of pregnancy. In Ukraine, data on terminations of pregnancy among HIV-infected women are available only for those women with a known HIV infection status from before pregnancy, with rates of termination of 9 per cent in 2007 and 14 per cent in 2008 reported. In Kazakhstan, where all pregnant women were tested for HIV, 34 per cent of pregnancies in HIV-positive women ended in termination in 2008 and 38 per cent in 2009.[45] There are also numerous anecdotal reports of HIV-infected women being recommended to have an abortion by health-care providers. Such practices reflect both a lack of knowledge and training, with respect to the risks of mother-to-child transmission of HIV and the benefits of prevention, as well as the discriminatory attitude towards HIV-positive women held by some providers.

Enhancement of the quality of PMTCT interventions, and better outreach to marginalized and most-at-risk populations who tend to be missed by services, is critical. In addition, it will be important to provide a continuum of care for women and children, and to scale up a number of services including early infant diagnosis, early initiation of ART for infants, and the provision of ARVs for parents.

Two-year-old Myshko is one of the few HIV-positive children in Ukraine who have been adopted.

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Drug users who happen to get pregnant or pregnant women with a drug-using problem?

In the dual epidemic of HIV and drug use affecting the region, drug-using pregnant women face multiple barriers linked to their drug use, to HIV and to gender discrimination. Negative attitudes of health workers and people in the community often compel them to hide their drug addiction from care providers in antenatal clinics. Because they tend to present for services late in pregnancy or only at delivery, the opportunity to receive effective PMTCT is often missed. Even in cases where drug use is disclosed or identified during pregnancy, limited referrals are available to services that provide the high-quality specialized care required to address pregnancy, drug use and HIV in an integrated manner. Instead, vertical, compartmentalized care systems address each of these problems separately. For example, opioid substitution can help stabilize drug use and improve pregnancy and neonatal outcomes, including the prevention of HIV infection. But even in countries where treatment is legal and available, only very few pregnant women are able to benefit from it.

The challenge today is to change the attitudes of both society and health-care professionals so that these women are treated as 'pregnant women who have a problem of drug use' and who need to be treated with dignity and respect, rather than just 'drug users who happen to be pregnant', with all that this implies.

Under pressure: Finding whom to blame...

The reaction to weaknesses in the health system and in the provision of prevention and care services is sometimes one of hiding data, laying blame and, in extreme cases, criminalizing individual health workers, rather than addressing the underlying systemic causes of the problems. Deliberate concealment and manipulation of data in order to avoid the appearance of problems have been reported at all levels of the health system. According to information provided by the World Health Organization (WHO), only two cases of HIV were reported in Turkmenistan by 2008, whereas unofficial reports indicate a substantial and unaddressed epidemic in progress.[46] Initiatives to improve quality of care, such as anonymous maternal mortality audits, have been introduced only recently. In a number of countries, moving away from a punitive approach, towards the use of data as a tool to inform quality improvements in service provision, remains a challenge.

An outreach worker talking to pregnant women

© Sophie Pinkham

In Central Asia, many children living with HIV have become infected through unsafe blood transfusions

and the use of unsterile injection equipment in hospital settings. Health services are still characterized by inadequate staff capacity, outdated clinical practices and infection control procedures, erratic supplies, and a punitive attitude towards health workers that instils fear and encourages deviousness. The 'outbreaks' of HIV infection, affecting several hundred children in Kazakhstan, Kyrgyzstan and Uzbekistan, mostly in towns along drug trafficking routes, have served to highlight some of these deficiencies. As news spread of HIV infections in hospitals, trust between patients and the health system broke down, and many families refused to take their children to hospital for fear of their contracting HIV.

Health services were unprepared to address the needs of these newly infected children and, because of discrimination against them, many families were forced to move homes. A number of the children died. As the health system struggled to respond to the outbreaks, the focus turned towards finding whom to blame. In all three countries where outbreaks took place, a significant number of doctors and nurses were fired, convicted and given prison sentences. Arguments in court highlighted poor hygiene practices, reuse of syringes and catheters, and unnecessary blood transfusions, motivated in part by the desire to generate additional income to supplement very low wages. Parents spoke of 'pervasive corruption' and 'government neglect'.

Positive initiatives announcing new equipment and improvements in infection control measures were offset by the negative focus on individual blame. In many people's minds, HIV became associated with being sent to prison. Anecdotal reports indicated that in some cases fear of additional prosecutions resulted in doctors simply stopping all HIV testing of children in hospitals so as to avoid further problems, or introducing HIV testing upon entry into hospital for all children. Instead of focusing on ensuring access to quality treatment for the infected children and sustainable support for their families, or on mass communication to change attitudes in the community towards HIV, the emphasis was put on finding whom to blame.

Yet, slowly, attitudes are changing and the focus on blame and criminalization is being questioned. Indira, a mother of an HIV-infected child from Kazakhstan, sums it up: *"I did not want to press charges against doctors in court. I saw what the other parents have gone through. It was terrible. Some of them even physically attacked the doctors... Now you will not find the guilty, all are afraid. I still do not know who exactly infected my child. He did not receive a blood transfusion, just injections. Some nurses used the same syringe, that's all. The result is known: 146 HIV-infected children... Yes, the management is guilty, but there is no point putting them into jail, that will not solve anything, and moreover these doctors also have children... What we need now is to avoid such errors happening in the future, we need support in making sure we have full access to treatment and support for our children."*

A six-year-old girl embraces a social worker on the playground at the City Centre of Social Services for Youth in Kyiv, Ukraine. The girl is HIV-positive and lost her parents to AIDS.

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SECTION V Forces for change

"I really did not believe that I would reach this age and this state of well-being: I go to the gym, I feel okay, and no one can tell that I am affected by something such as HIV. I work, I go to school, I learn, I do the most 'normal' things possible. I wish to have a family and to remain as I am now – with enthusiasm."

Marius, 23, infected with HIV as a two-year-old boy, Romania.

After meeting with people like Marius in Romania, Kanat, the father of a two-year-old HIV-positive child in Kazakhstan, was inspired and found hope for his son...

Challenging the blaming, the fears and anxieties that are at the basis of negative social attitudes to those affected by HIV is critical if countries in the region are going to continue to make progress in controlling the epidemic. Bringing about change will also require both policy and legal reforms. However, these will have little impact unless they are broadly rooted in social values and system changes.

Education and public information campaigns as well as the creation of an open dialogue among all stakeholders can play an important role in transforming individuals' and societal attitudes in order to understand and redress the injustice of stigma and exclusion. The activism and advocacy of people living with HIV in many countries of the region has been an excellent example of mobilization by those affected and has resulted in better access to treatment and support for people living with and affected by HIV. Beyond that, encouraging positive action and involvement also requires the mobilization of many different stakeholders, including health and social workers, community leaders and youth organizations. As the example below shows, parents can also become an inspired force for change.

One promising example in the region is the Parent to Parent Network (P2P), established by UNICEF and the East Europe & Central Asia Union of Organizations of People Living with HIV/AIDS (ECUO).

Kanat openly talks about the HIV-positive status of one of his children and helps other parents overcome stigma related to HIV infection in Kazakhstan.

© Kanat

Bringing hope, getting organized: The Parent to Parent (P2P) Network

The idea of creating a P2P network was built from several prior initiatives supported by UNICEF. When the outbreak of HIV infection among children in South Kazakhstan occurred in an environment of fear and serious misinformation, UNICEF took a group of parents to visit Romania. A major outbreak of nosocomial transmission affecting more than 10,000 children took place there in the late 1990s. This visit – where parents met adolescents who were infected as young children – gave them hope and empowered them to start ARV treatment for their own children, something which they previously did not believe in. Later, those parents from Kazakhstan met with parents from Kyrgyzstan who in turn had faced a nosocomial transmission of HIV among their children one year later. These interactions formed the first P2P exchange that resulted in transfer of 'know-how' and hope between empowered parents from the two countries.

In March 2010, UNICEF, together with ECUO, organized the first ever encounter of parents and caregivers of HIV-positive children from 10 countries of the region. The discussions among parents and caregivers led to the realization that many problems as well as solutions can be shared across countries. It was agreed that P2P, as an organized community of parents, represents an excellent platform to advocate for children and families affected by HIV/AIDS. Initial activities of P2P include the creation of a communication network across the region. This has already resulted in exchanges on state-of-the-art information related to the treatment and care of HIV-positive children, sharing on how best to approach disclosure of HIV status to children, and the development of tools and proposals to influence policies and system changes for the benefit of children and families. P2P also plans to establish a mechanism to report child rights violations, and to help identify solutions to problems that hamper child survival, development and full integration into society.

Looking ahead

Children and young people are among the most vulnerable in society, but at the same time represent its greatest hopes for a better future. They need to be nurtured, supported and protected. Today, however, too many children living in Eastern Europe and Central Asia find themselves excluded from society and denied equal opportunities to realize their full potential. HIV is both a cause and a consequence of this exclusion.

As this report documents, the rapid spread of the HIV epidemic in the region is partly a consequence of social systems that are struggling, and often failing, to cope with rapid change. But it is also a result of widespread social resistance to acknowledging the rights, needs and aspirations of children, young people and adults who are at risk, infected, or affected by HIV. Public prejudice, moralistic judgments and stigma are fuelling the dual epidemics of drug use and HIV in the region and driving young people – particularly those most at risk and vulnerable – underground. Major systemic weaknesses are undermining the delivery of quality health and social services, and punitive approaches are discouraging open discussion of the failures that need to be addressed. To date, in key areas of policy and of programme implementation, evidence-based approaches and international protocols have often been slow to take hold. Strong cultural attitudes about what young people *ought* to be doing override evidence-informed approaches to what they *are* doing. As a result, services that respond to their real needs fail to be delivered. In these circumstances, the social challenges for those affected by HIV are at least as significant as the health implications of the disease.

Responding effectively to the HIV epidemic in Eastern Europe and Central Asia will require a paradigm shift from blame and exclusion to support and inclusion. A rights-based approach provides the basis for that shift. As stipulated in the Convention on the Rights of the Child, all rights apply to all children without exception, and States have an obligation to protect all children from discrimination and to take positive action to promote their rights. In building and sustaining the response to HIV, governments must take the lead in developing approaches that are firmly rooted in the needs and rights of children and young people.

Looking ahead, priority areas for action include the strengthening of integrated health and social support for vulnerable families; expansion of evidence-based prevention efforts for reducing risk, harm and vulnerability among young people; and ensuring universal access to care, treatment and support for those living with and affected by HIV. Positive action by both governments and civil society organizations, working together with people living with HIV and affected communities, will be critical in building the supportive and inclusive

environment that is required to prevent further spread of the epidemic. Listening to and involving children and young people, so as to better respond to their concerns and promote their human rights, is at the core of what is required.

Change will require a collective effort at all levels of society, from individuals and families, to local authorities and top level policy makers to ensure respect and dignity for all children and all people. As expressed by Eleanor Roosevelt, one of the authors of the United Nations Universal Declaration of Human Rights:

> *"Where, after all, do universal human rights begin? In small places, close to home – so close and so small that they cannot be seen on any maps of the world... Such are the places where every man, woman and child seeks equal justice, equal opportunity, equal dignity without discrimination."*

As this report documents, important steps have already been taken by some countries to develop health, education and social protection services that reach and serve children and young people, including those most at risk and vulnerable. These initiatives require further support, scale-up and strengthening. But as the target dates for achievement of the Millennium Development Goals and other globally agreed objectives approach, the likelihood of their being met in the region is threatened by delays of urgently needed reforms in health and social systems. Renewed commitments by both national political and community leaders will be required if progress is to be made.

Developing a rights-based response to meet the needs of children and young people will also require additional funding. Combined international investments in HIV in the entire region do not come close to investments in a single country such as Ethiopia that has a similar number of new HIV infections annually as the Russian Federation or Ukraine, and which also falls amongst the top twelve most affected countries in the world. Resource needs are now further threatened by the financial crisis and by a number of countries in the region becoming ineligible for funding from the Global Fund to Fight AIDS, Tuberculosis and Malaria. In these circumstances, much greater political leadership, national investment and support from partner countries will be required if responses are even to be sustained.

Bold action for the well-being of children and young people is about building a better understanding of their real needs and protecting their rights. It is about challenging the cultural alibis that are evoked to justify not knowing or not caring. And it is also about forging a collective effort to understand, provide support and include – rather than exclude, blame and banish.

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References

1 Vitek C. Update on the epidemiology of the HIV epidemic in Eastern Europe and Central Asia presented at the Third Eastern European and Central Asian AIDS Conference, Moscow, October 2009.

2 WHO and UNAIDS. Progress on Implementing the Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia. Geneva, 2008.

3 Mathers B, et al. HIV prevention, treatment and care for people who inject drugs: a systematic review of global, regional and national coverage. *The Lancet*, *375(9719):1014–28*, March 2010.

4 International Harm Reduction Association. The Global State of Harm Reduction 2010.

5 Eurasian Harm Reduction Network. Young people and injecting drug use in selected countries of Central and Eastern Europe. 2009, p. 30.

6 Stojanovik N, Dokuzovski D. The FYR of Macedonia: Most-at-risk Adolescents and Young People, HIV and Substance Use. UNICEF mission report. 2006.

7 UNAIDS. 2008 Report on the global AIDS epidemic. Geneva, 2008, p. 53.

8 UNAIDS. The changing HIV/AIDS epidemic in Europe and Central Asia. Geneva, 2004, p. 5.

9 Chen S, Ravallion M. The developing world is poorer than we thought, but no less successful in the fight against poverty. Policy Research Working Paper. World Bank. 2008.

10 UNICEF. Regional Office for CEE/CIS, Child Protection. http://www.unicef.org/ceecis/protection.html. *Accessed May 2010*.

11 UNICEF. Child Well-Being at a Crossroads: Evolving challenges in Central and Eastern Europe and the Commonwealth of Independent States. Innocenti Social Monitor 2009. UNICEF Innocenti Research Centre. Florence.

12 UNICEF. Children and young people living or working on the streets: The missing face of the HIV epidemic in Ukraine. Kyiv, 2006.

13 UNICEF. Understanding child poverty in South-Eastern Europe and the Commonwealth of Independent States. Innocenti Social Monitor 2006. UNICEF Innocenti Research Centre. Florence.

14 UNICEF. TransMONEE 2007 Features: data and analysis on the lives of children in CEE/CIS and Baltic States. UNICEF Innocenti Research Centre. Florence.

15 Moestue H. Infant and young child relinquishment in the CEE/CIS: a review of the literature. UNICEF CEE/CIS. Geneva, 2010, pp. 30–32.

16 Shinkareva I. Statistics of child abandonment/relinquishment in maternities in Russian Federation. *TB/HIV bulletin #8*. Tver, Russian Federation, 2009.

17 Hillis SD, Rakhmanova A, Vinogradova E, et al. Rapid HIV testing, pregnancy, antiretroviral prophylaxis and infant abandonment in St Petersburg. *International Journal of STD & AIDS, 18(2):120–122,* 2007.

18 Shapoval A. Socioeconomic profile of HIV+ mothers including those who abandon their infants in Ukraine. Abstract. XVII International AIDS Conference, August 2008, Mexico City.

19 Preventing Child Abandonment and Improving the Living Conditions of the Children Born to HIV-Infected Women in Russia. Policy Brief 2(3). Transatlantic Partners Against AIDS. April 2005.

20 UNICEF. Children on the Brink. A Focused Situation Analysis of Vulnerable Excluded and Discriminated Children in Romania. Bucharest, 2006.

21 Teltschik A, Balakireva O, Sereda Y, Bondar T, Sakovych O. Most-at-risk adolescents: the evidence base for strengthening the HIV response in Ukraine. UNICEF and Ukrainian Institute for Social Research. Kyiv, 2008.

22 Thorne C, Ferencic N, Malyuta R, Mimica J, Niemetz T. Central Asia: hotspot in the worldwide HIV epidemic. *The Lancet Infectious Diseases*, *10(7):479-488*, July 2010.

23 Lazar F, Buzducea D, Grigora V, Preda M, Busza J. Risk factors for HIV transmission among adolescent and young female sex workers in Romania. Manuscript submitted to *Sexually Transmitted Infections Journal*, 2010.

24 HIV and Risk, Behaviours among Injecting Drug Users In Sarajevo, Banja Luka and Zenica 2007. Report on results: biological and behavioural survey among injecting drug users. UNICEF Bosnia and Herzegovina, 2007.

25 UNICEF, Ukrainian Institute for Social Research. Desk research report – a review of the evidence on HIV/AIDS and most-at-risk adolescents and young people in Ukraine. 2008.

26 Montenegro Institute for Public Health, UNICEF, London School of Hygiene and Tropical Medicine. Knowledge and behaviour of Roma youth living in collective centres in relation to HIV/AIDS. Podgorica, Montenegro, 2009.

27 Douthwaite M, Busza J. Data analysis on multi-country study of IDU 15–24 in E Europe: Factsheets on Albania, Moldova, Romania and Serbia. Available at http://www.unfpa.org/public/iattyp/pid/5525#research. *Accessed May 2010*.

28 WHO. HIV and other STIs among MSM in the European Region – Report on a technical consultation organized by the WHO Regional Office for Europe. Bled, Slovenia, 2008.

29 Prvulovic M, et al. HIV prevalence study and risk behaviours among MSM in Belgrade and Novi Sad, in Research among populations at increased risk of HIV and people living with HIV. Ministry of Health, Serbia. 2008.

30 Busza J, Ferencic N, Nary P. Adolescents and Risk in Eastern Europe: Assessing Harm Reduction Needs. Presentation at the International Harm Reduction Association Annual Conference, Bangkok, Thailand, 2009.

31 Busza J, Douthwaite M. Police harassment of most-at-risk young people in Eastern Europe. Abstract accepted by the XVIII International AIDS Conference. Vienna, July 2010.

32 UNICEF. Youth Friendly Health Services in Tajikistan – Experience of Three Pilot Cities in 2006 and 2007. Dushanbe, Tajikistan, 2009.

33 Kissin D, Zapata L, Yorick R, Vinogradova E, Volkova G, Cherkasova E, Lynch A, Leigh J, Jamieson D, Marchbanks P, Hillis S. HIV seroprevalence in street youth, St Petersburg, Russia. *AIDS*, *21(17):2333–2340*, November 2007.

34 Studies conducted by Health Rights International and partners. Personal communication. Unpublished. 2009.

35 UNICEF, Save the Children, USAID. Comprehensive assessment of street children in Georgia. 2009.

36 Zaretsky V, Dubrovskaya M, Oslon V, Holmogorova A. Ways to solve the orphanhood problem in Russia. Moscow: Voprosy Psychologii. 2002.

37 WHO, Regional Office for Europe. Interpersonal Violence and Alcohol in the Russian Federation. Policy Briefing. 2006.

38 Ministry of Health and Social Development. Interview in the Tribuna newspaper with M Gordeeva, Director of All Russia Foundation for support to children in difficult life circumstances. 2009.

39 Busza J, Balakireva O, Teltschik A, Bondar T, Sereda Y, Meynell C, Sakovych O. Street-based adolescents at high risk of HIV in Ukraine. *Journal of Epidemiology and Community Health*, 2010 (in press).

40 UNDP. Regional Human Development Report: Living with HIV in Eastern Europe and the CIS. December 2008.

41 Human Rights Watch. Life Doesn't Wait, Romania's Failure to Protect and Support Children and Youth Living with HIV. August 2006.

42 Médecins Sans Frontières. Turkmenistan's Opaque Health System. April 2010, p. 9.

43 Open Society Institute. The Effects of Drug User Registration Laws on People's Rights and Health. Key Findings from Russia, Georgia, and Ukraine. 2009.

44 WHO, UNAIDS, UNICEF. Towards Universal Access. Scaling up priority HIV/AIDS interventions in the health sector. Progress report. September 2009.

45 Thorne C, et al. Implementing PMTCT and paediatric HIV care, support and treatment in low prevalence and concentrated epidemic settings in Eastern Europe and Central Asia – a review. UNICEF. 2010.

46 WHO country info, quoted in Médecins Sans Frontières. Turkmenistan's Opaque Health System. April 2010, p. 11.

“To live without hope is to cease to live.”

F. M. Dostoevsky

Zhana, 14, standing in the sewer where she lived on the outskirts of Odessa, Ukraine. Photographed on December 21, 2006. Zhana has not been seen since 2007. Her whereabouts are unknown.

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United Nations Children’s Fund (UNICEF)
Regional Office for CEE/CIS

Palais des Nations
CH – 1211 Geneva 10
Switzerland

For further information please contact:
nferencic@unicef.org
www.unicef.org/ceecis

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