The disaster of HIV

According to the United Nations, a disaster is any “serious disruption of the functioning of a society, causing widespread human, material or environmental losses which exceed the ability of a society to cope using only its own resources” (OCHA, 1996). There is no doubt that HIV meets this definition.

Although it was intended to refer primarily to ‘natural’ disasters such as earthquakes and droughts, in certain contexts HIV is either the primary or one of the leading factors behind a “serious disruption of the functioning” of a society or community. HIV has had society-wide catastrophic effects in several distinct parts of the world – in many sub-Saharan African nations, in particular – and among numerous specific communities, for example, sex workers and men who have sex with men (MSM), at a global level.

A group of researchers writing in the British Medical Journal concluded: “HIV/AIDS, which has a long (approximately ten years) latency period from infection to death, is comparable to other so-called ‘slow onset disasters’ (e.g., famine) that often have an insidious onset, but can have death rates and secondary consequences no less devastating than classic acute onset disasters (e.g., floods)” (Stabinski et al., 2003).

Jargon and theoretical analysis aside, the facts alone serve to reinforce the classification of HIV epidemics as disasters for many nations and communities. The scale and scope of personal tragedy are massive and relentless. UNAIDS estimates that some 2.1 million people around the world died of AIDS in 2007, bringing the total number of deaths from HIV infection since 1981 to more than 25 million (UNAIDS, 2007a). Perhaps 2.5 million more contracted HIV in 2007 alone, which translates into an estimated 6,800 or so new infections every day (UNAIDS, 2007a). At the end of 2007 an estimated 33 million people around the world were living with HIV (UNAIDS, 2007a).

HIV as a national and society-wide disaster

More than a quarter century after HIV was first identified, adult HIV prevalence has never exceeded 0.1 per cent in many nations, while in a handful of southern African countries it is higher than 20 per cent. There are cases in every country in the world but there is not a global epidemic, or therefore a global disaster. HIV is a disaster in national contexts – that is, from an overall, society-wide perspective rather than purely personal – only where it has become generalized and widely pervasive. The one region where that has occurred is sub-Saharan Africa, home to about two-thirds of the world’s HIV-positive individuals (UNAIDS, 2007a). (Asia is the continent with the second highest number of HIV cases. In comparison with much of Africa, however, national HIV
prevalence rates are quite low throughout most of Asia. That is because the populations of many Asian nations are so large that prevalence is low even when absolute numbers of HIV cases are similar to those found in some high-prevalence African countries.

The devastation wrought by HIV over the past 25 years in several countries in southern and eastern Africa is unprecedented. At least one adult in ten is living with HIV in nations that include Botswana, Lesotho, Malawi, Mozambique, Namibia, South Africa, Swaziland, Zambia and Zimbabwe. Adult HIV prevalence is not far below 10 per cent in Cameroon, the Central African Republic, Kenya, Tanzania and Uganda, among other countries.

Millions of people have already died from HIV-related illnesses, and millions more with the virus live in fear that they soon will. HIV is considered the primary factor behind most of the dramatic negative demographic changes in recent years throughout the region. Life expectancies have plunged over the past two decades in several nations, including Botswana, Lesotho, Swaziland and Zambia: in those countries, the ‘average’ child born in the past few years cannot expect to live to 40 (US Census Bureau, 2004).

Even the World Bank’s optimistic *Africa Development Indicators 2007* report, released in November 2007, acknowledged that sobering trend: “Between 1990 and 2005 life expectancy at birth in Sub-Saharan Africa declined from 49.2 years to 47.1. Although life expectancy increased in 25 countries [such as Ghana, Guinea and Senegal] by an average of eight years, it declined in 21 more populous countries [including Kenya, Mozambique, South Africa and Tanzania, among others] by an average of four years. HIV/AIDS, malaria, and armed conflict have contributed to these falling life expectancies” (World Bank, 2007a).

The findings of a 2007 United Nations Development Programme (UNDP) report on Namibia illustrate the disconnect between improved macroeconomic indicators (as highlighted by the World Bank in its recent development report) and negative demographic and health measures in many nations with high HIV burdens (UNDP, 2007).

According to the report, entitled *Trends in Human Development and Human Poverty in Namibia*, the average income in Namibia increased from 5,500 Namibian dollars (US$ 700) in the early 1990s to nearly 10,500 Namibian dollars (US$ 1,340) in 2004. However, the report also noted that average life expectancy in Namibia had decreased by more than ten years since 1991 – a “direct result of the HIV/AIDS epidemic, which represents the greatest cause of death in the country”. The report concluded: “The single greatest threat to the expansion of human capabilities in Namibia today remains the HIV/AIDS epidemic, which, through its impact on mortality, is undermining human development objectives” and thereby reversing the positive effects of development.
World Health Organization (WHO) data and projections further illustrate the extent of HIV’s impact on individual and public health (WHO, 2006). A report from November 2006 compared DALYs (disability adjusted life years), a common health measure used by researchers and statisticians. As noted in WHO’s definition of DALY, the higher the number, the more serious the problem (WHO, 2006). For HIV and AIDS, the estimated DALYs in 2005 were just 63 in high-income countries, yet 2,205 in low-income countries. Projections for 2030 are even worse, with the measure staying the same – 63 in high-income countries but reaching 5,081 in low-income countries.

The cumulative devastation has made HIV a fully-fledged social and economic crisis in these high-prevalence countries (Whiteside and de Waal, 2003; Whiteside, 2002). Yet this overall impact is sometimes obscured by promising-sounding data and developments at the macroeconomic level. When the World Bank released its *Africa Development Indicators 2007*, Obiageli Ezekwesili, the Bank’s Vice President for the Africa Region, observed: “Over the past decade, Africa has recorded an average growth rate of 5.4 percent, which is at par with the rest of the world” (World Bank, 2007b).

Yet what the Bank calls an “encouraging trend” is mostly due to surging global demand and higher prices for raw materials such as oil and minerals. In few countries do those benefits reach the whole of society, beyond relatively small business and government elites. As noted in a *New York Times* article about the Bank’s report, “Africa still occupies the bottom rung of the world’s economic ladder. Forty-one percent of sub-Saharan Africans live on less than $1 [US] a day – an improvement from 47 percent in 1990, but still the world’s worst poverty rate” (LaFraniere, 2007).

Indeed, reflecting on the lives of most people living in sub-Saharan Africa raises more alarm than hope. In the hardest-hit nations, hard-won gains in living standards have stagnated or even fallen. The virus is directly responsible for restraining and reducing human and resource capacities across societies because HIV infections and AIDS deaths are common among workers of all qualifications and expertise, and in all industries. Coupled with the high costs of caring for people living with HIV, those capacity constraints lead to withered health and education systems, declining food security, skilled labour shortages and an increasingly ramshackled infrastructure. Little has changed since the following observation was noted in a UNDP report in 2001:

“The devastation caused by HIV/AIDS is unique because it is depriving families, communities and entire nations of their young and most productive people. The epidemic is deepening poverty, reversing human development achievements, worsening gender inequalities, eroding the ability of governments to maintain essential services, reducing labour productivity and supply, and putting a brake on economic growth. These worsening conditions in turn make people and households even more at risk of, or vulnerable to, the epidemic, and
sabotages global and national efforts to improve access to treatment and care. This cycle must be broken to ensure a sustainable solution to the HIV/AIDS crisis.”

(Loewensen, 2007)

Measures and indicators of disaster in highest-prevalence nations

The wrenching, complex and wide-ranging impact of HIV in the hardest-hit nations can be seen in a host of other trends, measures and indicators. Combined, they are the building blocks of the HIV disaster. Among the more notable are the following, some of which expand upon capacity constraints referred to previously.

Macroeconomic dislocation and priority-shifting

When HIV epidemics become generalized, HIV often has a direct (and negative) economic impact. In general, it

- reduces or slows growth in the supply of labour, particularly skilled labour (through increased sickness and mortality)
- lowers productivity (due to HIV-related illnesses among members of the active workforce and relatives they may be caring for)
- damages governments’ economic health.

The impact referred to in the final bullet point above tends to occur when two negative developments occur simultaneously. The first, falling tax revenues, results from stagnant or declining growth coupled with a smaller pool of workers to tax (Quattek, 2000). The second is the increased public spending needed – the level of which depends on internal and external pressure and available resources – to deal with expanding HIV epidemics. Moreover, the perceived lack of economic stability or adequate skilled labour capacity also limits the ability of many countries with major HIV epidemics to attract much-needed foreign direct investment.

Some companies in high-prevalence regions have tried to counter the negative direct and indirect effects of HIV on their businesses. A growing number of leading firms in the sub-Saharan Africa, including South African-based Anglo-American (a mining company) and Vodacom (telecommunications), offer in-house medical insurance schemes that provide anti-retroviral treatment (ART) and other HIV-related care to employees and their families. In the absence of such programmes, most individuals in need would be forced to rely solely on public sector systems that face critical supply and capacity shortages.

Although these companies’ programmes are important and welcome, they cover a relatively small percentage of people and thus do not represent a long-term solution.
Unemployment rates are quite high throughout much of the region – with estimates ranging from 25 per cent to 40 per cent in South Africa, by far the largest economy in the region – and only a small percentage of those who are employed work for private firms with the financial capacity to provide comprehensive medical coverage. By far the majority of HIV-affected people, and essentially all of the poorest, must rely on the public sector or services provided by donors.

**Increasingly burdensome public sector healthcare costs**

In contrast to many wealthier countries which have private and public health insurance schemes and where much of the population can afford to purchase healthcare, most people in sub-Saharan Africa are poor and must rely on the government or other funding entities for all their healthcare needs.

Therefore, the costs of HIV-related care and services represent a major financial burden for governments in many countries, even though most receive aid and other forms of assistance from multilateral agencies, donors and other external sources.
The provision of ART – which has become increasingly available to those in need over the past five years – represents a growing share of healthcare budgets. The extent of financial and human resources needed to provide ART and related health services will only rise as treatment access is expanded and (hopefully) sustained. In Tanzania, for example, it has been estimated that providing ART to all those who need it would require the full-time services of almost half the existing healthcare workforce (UNAIDS, 2006). Public expenditure must also be allocated for other key HIV-related services, including education and awareness campaigns, building clinics and hiring, training and paying the salaries of healthcare workers and counsellors. Most governments of those nations critically impacted by HIV are already struggling to meet these demands.

The negative economic impact on individuals and families

HIV also imposes significant economic burdens at more basic levels – on individuals, families and communities. Those affected by HIV must devote often scarce personal resources on purchasing medicines, hospital visits and funeral costs, among other things (Whiteside and de Waal, 2003; Whiteside, 2002). At the same time, their income levels may be reduced by illness or death among wage earners or relatives’ need to focus on caregiving. As a result, they are unable or unwilling to spend money on other needs.

A study in South Africa found that already poor households coping with HIV-positive family members were forced to reduce spending on many necessities, including clothing (by 21 per cent) and electricity (by 16 per cent). Moreover, “two-thirds of households in the survey reported loss of income as a consequence of HIV/AIDS” and “[a]lmost half reported not having enough food and that their children were going hungry” (Kaiser Family Foundation, 2002).

Food insecurity

As examined in greater detail in Chapter 6, food insecurity is a direct outcome of HIV epidemics in some areas. In Malawi, for example, chronic and devastating food shortages in recent years stem in large part from diminished agricultural output due to HIV and AIDS (BBC, 2005). The situation is not expected to improve. UNAIDS has projected that by 2020, Malawi’s agricultural workforce will be 14 per cent smaller than it would have been without HIV and AIDS (UNAIDS, 2006).

The agency’s report added that reductions in the size of agricultural workforces – albeit due not only to HIV but also to population shifts from rural to urban areas for the sake of greater work opportunities – would probably exceed 20 per cent by 2020 in other countries, including Botswana, Mozambique, Namibia and Zimbabwe.
Human capacity shortfalls in healthcare and education sectors

HIV disproportionately affects young adults – individuals who should be in their prime productive years. Not only do those individuals and their families suffer, so do societies that desperately need their income-generating capacities and intellectual and social capital for overall development purposes – now and in the future (UNAIDS, 2006; de Waal, 2003).

Two sectors most critically affected are healthcare and education. In many nations, including Malawi and Zambia, the epidemic is reducing the supply of qualified health workers even as it prompts increased demand for health services. In Botswana, for example, an estimated 17 per cent of the healthcare workforce was ‘lost’ to AIDS between 1999 and 2005 (UNAIDS, 2006).

Education systems face similar crises when experienced teachers become sick or die. Such developments have reversed any results of the longstanding efforts to respond to an inadequate supply of teachers in many African countries. Much of the current evidence indicates that the situation will remain grim for the foreseeable future, especially in countries and regions with slow or substandard scale-up of HIV treatment and care services. A study in South Africa found, for example, that 21 per cent of teachers aged 25 to 34 are living with HIV (UNAIDS, 2006).

Growing numbers of children orphaned by AIDS

The November 2007 World Bank report estimated that there are currently some 15 million children (defined as those younger than 18) orphaned as a result of AIDS (World Bank, 2007a). Of those, some 12 million live in sub-Saharan Africa; the number of children orphaned by AIDS in each of five countries alone (Kenya, South Africa, Tanzania, Uganda and Zimbabwe) tops 1 million. Given the concentration of HIV among young men and women, the number of orphans is expected to continue increasing in the most heavily affected nations. In South Africa, for example, the age groups with the highest HIV prevalence are 25–29 (for women) and 30–39 for men (Shishana et al., 2005). A majority of those individuals will become sick and die in the near future unless access to appropriate treatment improves substantially (see Box 2.1).

Gender-related obstacles

Women comprise half of all people living with HIV worldwide, but in most societies they face significant legal, political, social and economic obstacles to obtaining appropriate access to HIV prevention, treatment and care. Their vulnerability is particularly acute in sub-Saharan Africa. Across the region overall, an estimated 61 per cent of
Box 2.1 ‘Auntie Elizabeth’ and the orphans

Around 4.6 million children in the southern Africa region have lost their parents to the AIDS pandemic. In many rural areas, entire villages have been decimated. Very often, only the children remain – and they are sometimes infected with the virus too, struggling to survive as best as they can.

The picture is much the same in urban areas. This is the reality for five of the nine children in the care of Elizabeth Magalefa, a dynamic 37-year-old who lives in Mabopane, some 30 kilometres from the South African capital Pretoria.

Far from the grand buildings and luxury shopping centres that are springing up on the outskirts of the city, Elizabeth tells her story in the modest, dilapidated garage, where she lives with her brothers and the children. “When my sister died of AIDS in March 2003, her partner of the time disappeared overnight, and I had no choice but to take in her five children, who would otherwise have been left to fend for themselves,” she said.

“The youngest, aged 10, is also HIV positive. Happily, he is much better now, thanks to the anti-retroviral treatment that he is receiving,” explained the young woman who, in spite of the great difficulty of feeding such a big family, always has a radiant smile on her face that lights up the room the family is crammed into.

“I have been through difficult times, and things are still not easy,” she continued. “Fortunately, I now receive support from South African Red Cross Society volunteers, who come to see us regularly.”

Each week, Patricia Sebiji pays the family a visit. This South African Red Cross Society (SARC) volunteer also lives in Mabopane and is all too familiar with the problems that people in the community face. She makes sure that both the grown-ups and the children have what they need, providing food assistance and blankets, if necessary. She also watches out for any secondary effects of the little boy’s ART. If she were to notice anything, she would send him straight to the nearest hospital.

When necessary, the Red Cross also pays school fees for children who do not receive a grant from the state. Dikeledi, who is 18, is lucky that she is supported by her aunt, but there are thousands of children who have to leave school each year to provide for their brothers and sisters.

“Well, an important part of my work when I visit the family is to provide advice on health matters, particularly sex education, to prevent unwanted pregnancies and ensure that they all know how to protect themselves against becoming infected with HIV,” explained the volunteer.

“Patricia also provides the family with psychological support,” added David Stephens, who is in charge of the SARC health programme. “Many of these orphans have psychological problems stemming from the loss of their parents and also from the discrimination that they often suffer within their own communities.”

The Red Cross encourages depressed and parentless children to go to Red Cross youth camps to alleviate their loneliness, get away from their environment and meet with other young people.

“It is true that the neighbours are sometimes wary of us, even in our area, as if the fact that members of our family have died of AIDS poses some kind of danger to them,” confided the woman they call ‘Auntie Elizabeth’. “My neighbours’ children would never
all people living with HIV are women – a share that rises to as high as 75 per cent among HIV-positive individuals aged 15 to 24 (UNAIDS, 2007a).

As the report of the Special Rapporteur to the UN Commission on Human Rights states:

“The vulnerability of women and girls to HIV and AIDS is compounded by other human rights issues including inadequate access to information, education and services necessary to ensure sexual health; sexual violence; harmful traditional or customary practices affecting the health of women and children (such as early and enforced marriage); and lack of legal capacity and equality in areas such as marriage and divorce.”

(UN Economic and Social Council, 2004)

Women are particularly vulnerable to HIV because of cultural mores and their economic dependence on men. Girls are less likely to receive education than boys (in many African countries they are taken out of school early to care for relatives sick and dying from AIDS) yet education is known to protect against HIV (UNAIDS, UNFPA and UNIFEM, 2004). It is a ‘crisis of gender inequality’ (UNAIDS, UNFPA and UNIFEM, 2004) because women generally have less power over their bodies and lives than men. Women, whether single or married, are unable to negotiate the use of condoms. In many Asian countries, for example, increasing numbers of married women are becoming infected because their husbands visit sex workers; marriage increases the vulnerability of many women to HIV. Sexual violence is a major threat to girls and women; rapists and violent partners do not use condoms (see Box 2.2).
Box 2.2 The impact of violence on HIV

Violence – physical, sexual and psychological – is a global pandemic that affects everyone – children, women and men. Within the world of HIV, violence can be both a cause and a consequence of HIV infection.

The complex relationship between HIV, violence and gender discrimination is often neglected in prevention and response programmes. Too often ‘gender’ is considered by humanitarian agencies to encompass the needs of women and girls only; in real terms, the unique needs of boys and men are excluded. Men who have sex with men who are HIV positive are more at risk of psychological, physical and sexual assault than their HIV-negative peers (Greenwood et al., 2002). In addition, children who are trafficked, abused or orphaned by AIDS are more likely to face violence, exploitation, stigma and discrimination which increase their risk of sexual violence and thus HIV (Rothschild and Nordstrom, 2006; Yamashita, 2007).

Gender and choice

While many HIV prevention programmes are predicated on the belief that people who are infected with HIV have a choice in whom, when and under what terms they have sex, the reality is very different for those experiencing violence, especially sexual violence. A study from South Africa (WHO, 2004) shows that women who experience coerced sex by intimate partners use condoms nearly six times less consistently than women who are not coerced. In the coastal areas of Kenya, it was found that 30 per cent of girls aged 12–18 years are involved in the sex trade; no condoms were used in 32 per cent of all sexual penetrative acts and 42 per cent of all anal sex acts (Jones, 2007).

Another study from South Africa (Human Rights Watch, 2005) highlights the fact that women in physically violent relationships were 48 per cent more likely to be infected with HIV than women in non-violent relationships.

A woman from Uganda describes her experience: “He would beat me to the point that he was too ashamed to take me to the doctor. He forced me to have sex with him and beat me if I refused. This went for every [wife]. Even when he was HIV positive he still wanted sex. He refused to use a condom. He said he cannot eat sweets with the paper [wrapper] on” (Karanja, 2003).

Violence and fear

Violence continues to affect its victims throughout their lives. A woman from Swaziland recalls: “When I was diagnosed I had a partner. The relationship became more violent – he said I brought a new problem into the family. The violence became more, he had other relationships. You get told off because you have HIV” (ICW and GCWA, undated).

Women are often reluctant to disclose that they are HIV positive because they are afraid of abandonment, rejection, discrimination, violence, upsetting family members and accusations of infidelity from their partners, families and communities (ICW and GCWA, undated).

“He was abusive before I had told him I was HIV positive, and afterwards, well, the beatings got worse... They happened more regularly. I say that because I remember his statement, ‘I should kill you since you’re trying to kill me’” (amfAR, 2005).

Thus fear also prevents HIV-positive people from accessing care, treatment and support. Often people feel it is better to ‘not
Children and men
The risk of violence based on discrimination and a lack of social support not only makes women vulnerable but also children and groups of men, such as men who have sex with men. Human Rights Watch describes an example: “Jamaica’s growing HIV/AIDS epidemic is unfolding in the context of widespread violence and discrimination against people living with and at high risk of HIV/AIDS, especially men who have sex with men” (ICW, 2005).

Stigma against MSM is widespread, with discrimination prevalent in numerous countries – often supported by laws and social customs that declare sexual behaviour between men as illegal, with sanctions that include prison. Violence against MSM may be tolerated with no consequences by state authorities.

Children are the smallest, weakest and least powerful members in any society. This is compounded by their dependency on adults not only for life and safety but also for justice. Often children’s voices are denied and they are the least able to defend themselves against violence. The UN World Report on Violence against Children reveals that 150 million girls and 73 million boys are sexually abused in any given 12-month period around the world (Pinheiro, 2006). A study from India showed that of a sample size of 12,447 children more than 50 per cent were sexually abused (Kacker, Varadan and Kumar, 2007).

A 9-year-old girl relates her experience of contracting HIV through sexual abuse: “What transpired after that shall remain forever inscribed in my mind. I was bloodied and aching all over. Then he was ordering me out of the truck. I jumped into the mud and my school bag landed with a thud at my feet as he threw it after me. In the weeks that followed I had many nightmares about the incident. I found myself hating all men, including those male teachers I had used to admire so much. I felt dirty all the time and could still smell my rapist on me. The result of the [medical] examination shocked me more than the rape itself. Not only was I pregnant but I had also been infected with HIV” (UNICEF, 2006).

Steps forward
Violence prevention can be better linked to HIV prevention through several concrete steps (adapted from GCWA, undated):

- Increase support for programmes that address the linkages between violence and HIV through bilateral and multilateral funding mechanisms
- Maximize coordination between AIDS and violence prevention services, particularly in countries and communities highly affected by these intertwined epidemics, and remove barriers to integrating these essential services on the ground
- Integrate violence prevention, including the protection of children, into HIV prevention programmes from assessments, policies and education to accountability systems
- Provide dedicated funding and support to evidence-based programmes seeking to stop violence and reduce its impact. The Global AIDS Alliance calls for dedicated budgets of 4–10 per cent
- Provide funding for research and evaluation of programme strategies to reduce violence – against women, children and vulnerable men – and its links to HIV.
Poverty – and it is estimated that 70 per cent of the world’s poorest people are female – often pushes women into transactional sex, bartering for food or other necessities of life or into sex work. In many countries, when husbands die, widows have no rights to property or land and are thrown out of their homes. So sex work may be the only alternative to starvation.

The AIDS epidemic has many effects on women. They are usually the carers in the family and if the husband is ill or working away from home, the women grow the bulk of the family’s food supply. Women living with HIV face even more stigma and discrimination than men.

**Psychological impacts**

HIV epidemics can have profound mental health consequences. Even if they have no symptoms, people living with HIV in all parts of the world have more reason than most to be concerned about their future health and well-being; in consequence, they may suffer from a host of psychological ailments including anxiety and depression.

Their situation may be exacerbated by HIV-related stigma and discrimination and suffering and death among spouses, children, parents, other family members, friends and colleagues.

The scope and extent of such psychological trauma have received little attention in most of sub-Saharan Africa, where HIV prevalence is highest, and services and expertise to treat depression and most other mental health concerns are limited in the region (Baingana, Thomas and Comblain, 2005).

The negative psychological impacts of HIV extend beyond those who are living with the virus. Many HIV-negative individuals – especially those in high-prevalence areas – face the same kinds of loss, anxiety and worry as their HIV-positive counterparts. Children are perhaps the most vulnerable; as one observer noted, their “psychological vulnerability begins long before the death of a parent”, and an important factor in their mental health “is the mental health of their parents” (Whitman, 2005).

The potential impact on children is much wider as well: “The health and mental health of ill or depressed caregivers, unable to provide basic nurturing and stimulation, can have a profound impact on children’s developing brains – their cognitive, emotional and social development” (Whitman, 2005).

In such instances, children’s opportunities and ability to integrate into society are severely constrained. They may be unable or unwilling to attend school, for example, which only serves to further isolate them from their communities and limit their future chances of finding work and social involvement.
HIV as a disaster among specific groups

HIV is a disaster among specific communities and population groups not just in sub-Saharan Africa, but in numerous countries elsewhere around the world. This section concentrates on two such groups: injecting drug users (IDUs) and men who have sex with men.

Such communities, which are considered to be at ‘higher risk’ in terms of contracting HIV and dying from AIDS, generally meet one or more of the following criteria:

- They have higher than average HIV prevalence in comparison with the general population in a country.
- They engage in practices that may heighten their risk of contracting HIV.
- They are poorer than the general population on average.
- They face extensive and potentially debilitating economic, political, legal and/or social barriers, many of which are related to stigma and discrimination.
- Their access to adequate social and welfare services, including healthcare, is far lower than among members of the general population. As such, their ability to obtain vital HIV prevention and care services usually ranges from insufficient to impossible.

IDUs, MSM, migrants, mobile workers, prisoners and sex workers are among the key groups of people for whom HIV has had a disastrous worldwide impact, because in most settings they generally meet all the criteria listed above. However, it is important to note that other sections of the population also face many of the same social and economic challenges but they are more properly categorized as part of the general population rather than specific, key groups. For example, women, young people and the poor are frequently considered to be at relatively heightened risk of contracting HIV and as being vulnerable to other developments, such as abuse and denial of care, that negatively affect their health.

Injecting drug users

Sharing and re-using contaminated injection materials are among the most efficient methods of transmitting HIV and other blood-borne diseases, especially hepatitis C. Thus HIV spreads quickly in IDU communities, wherever they are in the world, in the absence of adequate precautionary measures taken by users and where there are no effective harm reduction policies and programmes in place.

IDUs make up the largest share of HIV infections throughout the nations of the former Soviet Union as well as many Asian countries, including China, Indonesia and Malaysia (UNAIDS, 2007b). In these countries and most others, HIV prevalence is often several times higher among IDUs (especially in specific urban areas) than the general population. For example, in Karachi, Pakistan’s commercial capital, a report-
ed 30 per cent of IDUs are infected with HIV (IRIN/PlusNews, 2007a). Yet overall HIV prevalence in the country is low – less than 0.2 per cent (UNAIDS 2007b).

Despite the widespread transmission of HIV through injecting drug use, only 8 per cent of users worldwide had access to HIV prevention services in 2005 (Global HIV Prevention Working Group, 2007).

Experience in many parts of the world shows that rates of HIV transmission plunge sharply when IDUs have safe, consistent and easy access to safer injecting materials and substitution treatment programmes (Open Society Institute, 2006). Yet in some parts of the world with the highest numbers of IDUs, including Russia, policy-makers continue to limit the availability of clean syringes and needles and forbid the use of methadone as a substitution therapy for people who are opiate-dependent (see Box 2.3).

Stigma and discrimination related to both drug use and HIV are the main reason for policy-makers’ opposition. In all but a handful of nations, injecting drugs is illegal.

Public attitudes toward drug users are rarely anything but hostile, based not only on legal considerations but just as often (if not more so) on moral judgements and real and perceived assumptions regarding crime and delinquency. IDUs are therefore isolated and shunned, and tend to limit contact with important social and health services.

The following two accounts by IDUs in different countries highlight the deep-seated and extensive discrimination they often face:

“The treatment [is] not like what they [healthcare workers] give to normal people, there’s a difference. Like touching you… they feel reluctant to touch. When the doctor tells them to draw blood… ah… they will think twice. They will ask us whether you can draw your own blood or not. If they touched also, immediately they go and wash their hands. [It] is happening everyday. You can go to the ward and see.”

(Zulkifli et al., 2007)

“I still have many problems with the police. A few weeks ago I was stopped on the street for no reason and then taken to the station. The police said they wanted to check if I was using drugs and that detaining me was the only way to do it. They kept me there for 24 hours before letting me go. Also, they didn’t register my detention officially, so there was no record of my arrest. My girlfriend called the station to try to find me, but no one had any information to give her. I didn’t have my ARVs [anti-retroviral drugs] with me and missed a dose.”

(Hoover, 2007)
Box 2.3 Discrimination in action: at-risk drug users in Russia and Ukraine

Government policy-makers and health officials often contribute directly to the stigma aimed at vulnerable populations. In few places has this been more apparent than in Russia and Ukraine, home to two of the world’s fastest growing HIV epidemics over the past decade.

In both countries as well as most others across the former Soviet Union, HIV has largely been concentrated among injecting drug users. UNAIDS estimates that 10 per cent of all new HIV infections globally are among IDUs, a percentage that rises to 30 per cent when Africa — where nearly all infections are attributed to heterosexual intercourse — is excluded. The agency has noted as well that more than 100 countries have reported HIV infection among drug injectors, and that HIV prevalence among IDUs exceeds 5 per cent in some 40 of those nations.

Already on the margins of society in most countries, IDUs receive little or no sympathy from the general population. Harassment against those individuals is common everywhere, but it is particularly pronounced in Russia and Ukraine because the sheer numbers are so large.

Government at all levels in both countries has generally failed (or more accurately, refused) to offer even basic services for these marginalized people despite escalating criticism by multilateral agencies (including the UN and World Bank) and international civil society. The type and scale of discrimination and abuse against IDUs in Russia and Ukraine vary greatly, from petty ignorance and corruption to calculated denial of potentially life-saving treatment.

In Lviv, Ukraine, for example, 30-year-old Andrei acknowledged having a difficult relationship with his parents, with whom he still lives, because they object to his drug use. Yet he cannot afford to move out and live on his own because it is impossible for him to find a job.

“Society sees me as useless,” he said during an interview in April 2007. “I stopped using for a year or so and tried to get a job. But whenever people found out I used drugs, they refused to give me a job. I got depressed and started using again” (Hoover, 2007).

Andrei said he has been diagnosed with hepatitis C. He added, however, that he had not been tested for HIV even though he freely acknowledged having shared needles in the past. “It’s not necessary to get tested for HIV,” he said. “There’s nothing I can do if I have it.” Andrei’s situation and attitude are far from unique in Ukraine. Although he and most other IDUs in Lviv have regular access to clean needles and syringes, as of June 2007 ART had yet to be made available (with limited exceptions) in the public sector.

His disinclination to be tested for HIV is hardly surprising. If no treatment options exist, what is the point of knowing? An HIV diagnosis would only add stress. Without a test, it is possible to maintain hope in such an environment.

As noted in the following two examples, IDUs face other kinds of discrimination across all sectors of society:

“I’ve had many problems with the police over the years. Recently, for example, I was detained and brought to a police station, where some police officers tried to put drugs in my pocket. I resisted and was beaten. This wasn’t the first time they tried to set me up, and I acted the way I always do. My feeling is that it’s better to be beaten than to be put in prison for a year.
After they beat me, I went home and stayed there for a week until I felt better. I didn’t report the beating because there would only be more problems if I did.”

(‘Ruslan’, a 33-year-old IDU from Odessa, Ukraine)

“One friend had a problem with his kidneys so he called an ambulance. It came, but the drivers refused to take him when they found out he used drugs. It’s even worse sometimes if there’s an overdose. At one apartment, someone overdosed so they called the ambulance. They came and demanded 1,400 roubles [US$ 55] for naloxone to treat the guy. The users didn’t have any money, so the ambulance left without treating him. He ended up dying.”

(‘Sergei’, a 32-year-old IDU from Tomsk, Russia)

Such accounts are not uncommon. It is therefore unsurprising that individuals most at risk from contracting and transmitting HIV are unable or unwilling to obtain vital services and information.

Although the AIDS epidemics are not yet remotely at sub-Saharan African levels, in Ukraine and Russia they are now the largest in Europe. Even the most conservative estimates from UNAIDS indicate that absolute numbers of HIV cases have reached around 1 million in Russia (UNAIDS, 2007c) and more than 400,000 in Ukraine (UNAIDS, 2007c). The situation is especially tragic because the epidemic arrived relatively late in that part of the world, after it was clear from evidence elsewhere that certain measures such as harm reduction programmes, implemented comprehensively and compassionately, could halt HIV in its tracks.

Glimmers of hope instigated by civil society

There have been some hopeful signs recently. In particular, civil society in both Russia and Ukraine has played a crucial role in improving service delivery to IDUs and other vulnerable groups and, by extension, helping reduce HIV-related stigma and discrimination. Such organizations’ ability to have a demonstrable impact is remarkable given the fact that many engage in technically illegal behaviour and are chronically short of money. The latter problem is particularly acute in Russia, where foreign non-governmental organizations (NGOs) are viewed with suspicion by the government and are largely barred from any type of engagement (including funding local groups). A weak civil society tradition also means that authorities at all levels continue to view even local NGOs as law-breaking irritants at best, if not adversaries to be confronted and shut down.

Even so, courageous and dedicated individuals in NGOs continue to devise and implement innovative ways to reach as many people in need as possible. In St Petersburg in Russia, for example, the health and human rights of the city’s more than 100,000 drug users have been the primary focus of the NGO Humanitarian Action since it was founded in the mid-1990s. The group formed an important partnership with healthcare providers at St Petersburg’s largest infectious-disease complex and initiated a mobile outreach initiative to provide harm reduction and medical services to IDUs and sex workers. In 2006, more than 4,000 clients paid a total of nearly 14,000 visits to the outreach units.

Humanitarian Action remains the largest (in terms of both staff and clients served) and arguably the most influential harm reduction provider in Russia. Its reputation has ensured
that many of its strategies and methods have been adapted for use elsewhere in the country, even where drug use trends and levels of harassment differ greatly. In Tomsk for example, the NGO Center Anti-AIDS’s outreach efforts focus primarily on scheduled visits to ‘cooking flats’ where groups of IDUs gather to prepare and inject hanka, a relatively inexpensive homemade opiate especially popular in that Siberian city.

In Balakovo, meanwhile, the Saratov branch of No to Alcoholism and Drug Addiction (NAN) offers a wide range of health-promotion and social-welfare services aimed at improving the lives of vulnerable individuals. Although many of its services are not directly related to harm reduction among IDUs, they all tend to focus on drug use prevention and helping end drug dependence. For example, the organization’s extensive outreach work among sex workers is buttressed by a referral scheme to doctors and counsellors carefully chosen and screened to offer confidential and anonymous care at no cost. The group also seeks to reduce HIV-related stigma and discrimination by conducting training sessions for police officers and teachers throughout the city.

The efforts of these NGOs are bearing some fruit. At least partly in response to civil society advocacy, a few key government policy-makers in Russia and Ukraine are responding more aggressively and appropriately to their countries’ devastating HIV epidemics. Since 2005, they have allocated far more substantial resources for treatment and prevention not only for HIV but also for other key conditions closely related to HIV in the region (notably tuberculosis (TB) and sexually transmitted infections).

With the prominent exception of Moscow – where needle and syringe exchange is still not permitted – authorities in a growing number of Russian cities and towns have recognized that more pragmatic and comprehensive health-promotion assistance for IDUs is vital to prevent further degradation in public health in general.

Overall, however, far too little has been done. Although policy-makers’ recent steps are important, for the most part they have not directly addressed the most crucial factors behind the local epidemics. Far too few IDUs have access to safer injecting materials such as clean needles. Although now available in Ukraine (albeit at levels yet to meet demand), substitution treatment for drug users remains illegal in Russia. Drug users therefore lack realistic options to help treat their addiction. As observed recently by the director of Humanitarian Action’s case management programme: “A lot of people have died because methadone is illegal and they are unable to stop injecting drugs through other means.”

Such persistent obstacles result directly from lingering social attitudes that have proved impervious to change. As observed by Vitaly Djuma, the head of the Russian Harm Reduction Network:

“A lot of people, especially those [at the federal level] in Moscow, still think harm reduction ‘comes from elsewhere’ and thus is not only irrelevant but immoral. In their view, drug use is ‘anti-Russian’, as is homosexuality. Therefore, harm reduction must also be anti-Russian. Their attitude is: ‘Helping people engage in immoral behaviour is also immoral.’”
Men who have sex with men

In many wealthier nations, including the United States and in Europe, HIV was first identified among MSM and they remain by far the most at-risk and affected individuals in those regions. A recent review of evidence from 39 low- and middle-income countries from all regions found that, on average, the HIV prevalence rate among MSM is 12.8 times the rate among the whole adult population. In countries with very low rates of HIV prevalence, the difference is often extreme. For example, in Mexico, the rate among MSM is 109 times the rate among all adults. In countries with high rates of HIV prevalence, the difference is still very considerable. For example, in Kenya, the rate among MSM is 6.9 times the rate among all adults. This trend is found in all regions of the world except Eastern Europe and Central Asia, where injecting drug users account for most cases of HIV (Baral et al., 2007).

MSM are at high risk of contracting HIV for a number of reasons, but perhaps the most significant are stigma, discrimination and isolation. Sex between members of the same gender is taboo in many cultures. Seventy-nine member states of the UN have laws criminalizing sex between men and, even where it is legal, sex between men is often strictly taboo. A recent study found that, because of criminalization and taboo, MSM are ‘off the map’ in most of sub-Saharan Africa, so that little effort is made to cover them with serological or behavioural surveillance or address their unique needs for HIV prevention, treatment, care and support (Johnson, 2007).

Even in societies without such laws, widespread social stigma often prevents MSM from obtaining important HIV education, information and treatment services. One consequence is increased risky behaviour. In Pakistan, according to a news report from November 2007, “Less than 25 percent of MSWs [male sex workers] reportedly used a condom for anal sex with their last client, and even fewer used any form of lubrication aside from saliva” (IRIN/PlusNews, 2007a).

According to amfAR, infection rates among MSM are “as high as 14 percent in Phnom Penh [Cambodia’s capital]; 16 percent in Andhra Pradesh, India; and 28 percent in Bangkok, Thailand… dramatic increases in some areas [of Asia] have been seen” in recent years and this trend is particularly alarming given that MSM activity “in the region is diverse, often completely hidden, and beyond the reach of current prevention efforts” (amfAR, 2006).

The impact and sources of stigma and discrimination

Both the extent and the type of stigma faced by key groups at high risk vary. Wherever they live, however, members of such groups are in the main more likely than the general population to face legal, economic, political and social neglect at best, opprobrium and abuse at worse – regardless of their HIV status or risk-related behaviour.
HIV, and the fear of HIV, have compounded those attitudes (Human Rights Watch, 2007).

Discriminatory attitudes and judgemental decision-making vis-à-vis certain at-risk groups are not limited to low- and middle-income nations. Donors and wealthy countries often impose barriers on aid and other forms of assistance based on domestic moral agendas. Even today, the country with the world’s largest economy, the United States, bars the use of federal funding for domestic needle exchange programmes for IDUs. That ban persists in the face of overwhelming evidence that such programmes drastically reduce HIV transmission risk among injecting drug users (Open Society Institute, 2007).

Official guidelines of the US government’s President’s Emergency Plan for AIDS Relief (PEPFAR), undeniably one of the most important global health initiatives ever undertaken, place restrictions on funding for groups working with sex workers and mandate that one-third of programme funds allocated for HIV prevention must be spent on activities promoting or encouraging abstinence. This promotion of abstinence programmes through PEPFAR and other initiatives continues despite any evidence of their effectiveness as population-based HIV prevention strategies. The US government is essentially telling recipient governments and organizations that its moral guidelines and assumptions must take precedence over local stakeholders’ ability to identify appropriate responses on their own, based on their unique local knowledge. The ban on domestic needle exchange funding and PEPFAR guidelines also appear to signal official US discrimination against certain groups because of their behaviour and lifestyles.

**Stigmatization of HIV-positive people in general**

HIV-related stigma is not just confined to groups at higher risk, however. All people living with HIV meet with suspicion, contempt and distrust (see Box 2.4). They even meet stigma in countries with relatively high education and income levels, where HIV awareness efforts often have been extensive and regular, and/or where legal provisions not only bar discrimination based on HIV status, but are actually followed.

The findings of a recent multi-country survey “highlight the prejudice, fear and stigma that surrounds AIDS”, according to news reports from November 2007 (Brown, 2007). The survey, conducted by the MAC AIDS Fund, involved a total of 4,510 interviews in Brazil, China, France, India, Mexico, Russia, South Africa, the United Kingdom and the United States. A summary of the results noted: “Overall, almost half of respondents said they felt uncomfortable walking next to an HIV-positive person, 52 percent did not want to live in the same house, and 79 percent did not want to date someone harbouring the virus.” Perhaps unsurprisingly, such stigma tends to be particularly extensive and pervasive in countries, including those covered by the
Box 2.4 A survey on people’s knowledge, attitude, practice and behaviour regarding HIV and AIDS in KwaZulu Natal province

In 2007, the South Africa Red Cross Society (SARC), with British Red Cross (BRC) support, undertook a survey on people’s knowledge, attitude, practice and behaviour regarding HIV and AIDS in KwaZulu Natal (KZN) province where BRC supports HIV programming.

The population of KZN province (10 million people) accounts for 21 per cent of South Africa’s total population. Many people live in rural areas, some of which are remote and difficult to reach. KZN has the lowest life expectancies (42 years for women, 45 for men) and the highest prevalence of HIV in South Africa.

Approximately 40 per cent of people attending antenatal clinics in KZN in 2005 were HIV positive, and 19.7 per cent of young people aged between 2 and 18 have lost one or both parents to HIV – the highest rate in the country. The current TB epidemic is driven largely by HIV; the cure rate for TB in KZN in 2004 was 36.4 per cent compared to the national average of 54.1 per cent.

The survey
The survey was carried out in September 2007 in the districts of South Coast, Zululand, Pietermaritzburg and Umzimkulu. Its aim was to collect, compile and analyse baseline information so the programme could be planned, designed and developed effectively, and supported by monitoring and evaluation.

The survey included young people and adults in the community. To observe the difference the work of SARC was making, at least one village not covered by the Red Cross was selected in each district. Community leaders, households and individuals were interviewed. The process can be repeated to monitor trends over time and between different sites.

Summary of findings
Interviews with community leaders
Some 61 community leaders and resource people (such as counsellors, church leaders, traditional leaders, and youth and women’s group members) were interviewed in 14 villages in four districts.

While all community interviewees acknowledged HIV and AIDS as a problem in their community, 26 per cent of the communities reported no activities in place to address HIV and AIDS; in Umzimkulu, no mechanisms were in place.

Stigma and discrimination were a concern in 57 per cent of the villages surveyed. Of those, while 36 per cent did not have the means and the information to address it, the same proportion are encouraging and educating the community to talk about stigma and discrimination. Some 9 per cent of communities have established support groups, have a disciplinary committee or report discrimination to the police.

Young people (aged 15–19)
In some areas, understanding of HIV was very poor. Condom use and knowledge about female condoms varied between districts. Stigma and discrimination were high – a factor linked to knowledge and understanding. Many taking advantage of voluntary counselling and testing (VCT) services do not return for results. Crucially, the age range of sexual activity among those interviewed was from 10–19 years. Most prevention activities currently target only the latter half of this bracket.
Adults
Overall, uptake of condoms was very low; 30 per cent of those with multiple partners in Umzimkulu reported very high rates of unsafe sex. The Red Cross will need to ensure that it is providing appropriate information, education and communication (IEC) services and advocating effectively for services. Knowledge of HIV prevention, including mother-to-child transmission (MTCT) during pregnancy, was also low. Again, effective life-skills training and IEC are crucial to increase knowledge.

Key findings
Young people aged 15–19 in school
- While 99 per cent lived with family members, 27 per cent were living with relatives other than their parents
- 78 per cent were at secondary school; on average they had ten years of schooling
- 55 and 40 per cent of young men and women respectively were sexually active in the 12 months prior to the survey
- The range of ages at first sexual encounter was between 10 and 19 years, with an average age of 15.5 years
- In South Coast, 83 per cent of the women and 67 per cent of the men were involved in several concurrent sexual relationships
- Young men tended to have partners of the same age while females had slightly older partners
- 3 per cent of the sexually active males reported having paid for sex in the last 12 months, while 2 per cent reported being paid for sex

Young people aged 15–19 out of school
- 64 per cent of the 138 young men and 137 young women interviewed lived with their parents and 12 per cent with grandparents;
- 8 per cent were head of their households
- 82 per cent of young men had finished primary school and almost four years of secondary education
- 75 per cent of young women completed primary school and over three years of secondary education
- 81 per cent of the young men and 58 per cent of the young women reported having had sexual intercourse
- The range of ages at first sexual encounter was between 10 to 19 years old with an average age of 15.7 for males and 16.1 for females

Reproductive age (20–49 years old) male and female
- Of 373 people interviewed, 183 were male and 190 female. The median age of adults was 28 years for females and 27 for males
- 57 per cent of males and 47 per cent of females were living with their parents
- Over 85 per cent of all males and females interviewed reported having had sexual intercourse in the last year
- 54 per cent of men and 33 per cent of women had had sex with more than one partner in the last 12 months – with only one in three using condoms
- Lowest condom use with non-regular partner was found in Umzimkulu – 88 per cent of the respondents were having unsafe sex. Reasons given for unsafe or risky sex vary between sexes
- 4.6 per cent reported having paid for sex in the last 12 months; 1.5 per cent reported being paid for sex

The communities interviewed were aware of HIV and AIDS, stigma and discrimination and gender-based violence; however they do
not feel empowered or informed enough to respond within their communities.

Comprehensive knowledge about HIV and AIDS remains low in the four districts surveyed across all adult and youth target populations. Adults and youths expressed difficulties in accessing information and services. Incorrect beliefs about HIV are still prevalent among adults and youth populations. This leads to fear and increasing stigma and discrimination.

The survey has highlighted a number of opportunities where increased support can be provided more efficiently. Through sharing and using the valuable information gained, the Red Cross and other stakeholders can plan, deliver and monitor more effective interventions.

MAC AIDS Fund survey, where HIV is concentrated among specific groups. HIV-related stigma may persist in countries with generalized epidemics, such as those in sub-Saharan Africa, but its virulence and impact are often muted in such environments because so many people are living with the disease themselves and have known at least one person who has died of AIDS.

The survey does reinforce the views of long-time advocates such as the Executive Director of UNAIDS, Peter Piot, who regularly states that stigma and discrimination, along with gender inequality, are the major barriers to comprehensive, compassionate and effective provision of HIV care in nearly every country in the world (Piot, 2006). Stories abound of social ostracism, even within families and otherwise close-knit communities. Even if widely available, uptake of HIV testing has lagged behind in many parts of the world because people are afraid of being identified with the virus in any way. As a result, individuals are often only diagnosed with HIV when they are very ill and near death. By then, their immune systems may be so ravaged that ART offers limited benefit, if any.

**Is HIV an ‘emergency’ as well as a ‘disaster’?**

Is HIV also an ‘emergency’ in the contexts where it is a disaster? And does it matter even if defined as such? The short answers are ‘yes’ and ‘yes’.

Definitions of the two terms differ of course, but there is a remarkable symmetry between them. A recent report about the HIV and AIDS crisis in Swaziland concluded, following a literature review, that emergencies and disasters “are defined in a myriad of ways [sic]”, adding, “While there is no shared definition of what constitutes an ‘emergency’, there is broad agreement reflecting concern with reducing suffering and preserving human dignity.” The authors continued: “An emergency can be thought of as an event affecting a group of people, causing a social, infrastructural or health impact which places the population under an excessive amount of stress and exceeds their coping capacity” (Whiteside and Whalley, 2007).
Such a view mirrors the definition of disaster put forth by the UN’s Disaster Management Training Programme (DMTP) (OCHA, 1996). This is important because it offers the possibility of reframing and re-conceptualizing the HIV epidemic, both globally and locally. Academic and stakeholder definitions aside, disasters are frequently perceived as localized events with specific area, time and impact parameters. An emergency, meanwhile, by its very name appears to be unbounded and threatening. It demands action, even by those not directly affected.

One reason global, regional and national responses have for the most part been only fitfully successful is that HIV is rarely referred to as an emergency in any context. Yet as succinctly observed recently in *The New York Times*, “Despite the revised estimates, the epidemic remains one of the great scourges of mankind” (McNeil, 2007). For far too many people, however, ‘mankind’ in terms of HIV appears to have a limited instead of expansive implication. That limitation in perception is perhaps the biggest emergency of them all. It is also the one that must be addressed first before sufficient responses can be implemented elsewhere in response to the epidemic.

*This chapter was written by Jeff Hoover who is a freelance researcher, editor and writer based in New York, USA and Cape Town, South Africa. He also contributed Box 2.3. Box 2.1 was written by Jean-Luc Martinage, International Federation. Box 2.2 was written by Gurvinder Singh, Prevention of Sexual Exploitation & Abuse (PSEXA) Officer, Canadian Red Cross. Box 2.4 was written by Alyson Lewis, HIV and AIDS Adviser Africa, British Red Cross and Elena Ruiz Roman, independent consultant.*

**Sources and further information**


