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<td>Serology</td>
<td>HIV ANTIBODY</td>
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DR. KHIN ZAW LATT
M.B.,B.S.,M.Med.Sc(Microbiology)
M.C.P (Pathol.)
NATIONAL HEALTH LABORATORY
SAMA - 1986

Virologist
The challenge of HIV and AIDS

In 1993, the first *World Disasters Report* characterized the AIDS pandemic as a chronic, expanding disaster. At that time, an estimated 12.9 million people were living with HIV, 2.6 million people had developed AIDS-related illnesses and of those, 90 per cent had died (International Federation, 1993).

Some 15 years later, at the end of 2007, it was estimated that around 33 million people were living with HIV (see Figure 1.1). Although the latest revised data on HIV and AIDS (UNAIDS, 2007) show that new infections seem to have peaked in the late 1990s and global prevalence rates have apparently levelled since 2001, AIDS is the fifth major cause of death in middle-income countries, the third in low-income countries (WHO, 2007) and the leading cause in sub-Saharan Africa. More than 25 years since the first cases of AIDS were reported, there is no cure, no vaccine and not much optimism that these will be found in the near future, if at all.

In some countries, prevalence rates appear to have begun to drop, but in others – notably Indonesia and Viet Nam, and several countries in Central Asia and Eastern Europe – they are on the increase. In a number of Western European countries, the number of new HIV diagnoses attributed to unsafe sex between men nearly doubled between 1999 and 2006 (UNAIDS, 2007). To use a well-worn phrase, there is no room for complacency.

This year’s *World Disasters Report* is the first to focus on one disease. Why? Because for a number of countries (all at present in sub-Saharan Africa) and for a significant number of groups of people where the epidemic is concentrated, the HIV epidemic is undoubtedly a disaster. Government services are overwhelmed by the need for support and treatment, stigma still prevents access for many, even where services exist, and communities are decimated by its effects. In 2000, the Pan African National Red Cross and Red Crescent Societies Conference, strongly supported by National Societies from other regions, adopted the Ouagadougou Declaration stating that National Societies in Africa commit to “responding to the HIV/AIDS pandemic as an unprecedented humanitarian and development disaster in Africa, by massively scaling up their response in terms of advocacy, prevention, care and mitigation”.

A number of researchers have argued (see Chapters 2 and 6) that in southern Africa, HIV and AIDS have created a vast humanitarian emergency. This report analyses how the effects of HIV and AIDS on specific countries and key (at-risk) groups of people justify defining the epidemic as a disaster. Indeed, the future impact of HIV and
AIDS may be far more serious than we can imagine, as economists from the World Bank and the International Monetary Fund (IMF) point out:

“…in contrast with other epidemics, AIDS is overwhelmingly a fatal disease of young adults. Not only does AIDS cause unspeakable human suffering, but it also makes it difficult for these young men and women to provide for the education of their children, not to mention offer them the love and care they need to complement their formal schooling. The result is possibly a whole generation of under-educated and hence underproductive youth, who in adulthood will find it difficult to provide for their children’s education, and so on. In this way an otherwise growing economy could, when hit with an enduring and sufficiently severe AIDS epidemic, spiral downward into a low-level subsistence economy in three or four generations. This threat of a progressive collapse of the economy is particularly insidious because the effects will not be felt immediately. Thus estimates of the economic impact of AIDS that look only at the short- to medium-term effects of reductions in labor supply are dangerously misleading. They risk lulling policymakers, especially those concerned with short-term economic fluctuations, into a sense of complacency.”

(Bell, Shantayanan and Gersbach, 2004)
The key point is that the HIV pandemic is a disaster whose scale and extent could have been prevented. But ignorance, stigma, political inaction, indifference and denial have all contributed to the deaths of millions of people. Interestingly, the 1993 World Disasters Report commented on the reluctance of some health advisers to call AIDS a ‘health disaster’, partly because “disaster terminology may... give the impression that catastrophe is inevitable. Nothing could be further from the truth: like almost every disaster, HIV/AIDS is preventable.” Some 15 years later, the publication of this report shows how much more needs to be done to halt the spread of the epidemics.

Box 1.1 quotes the experiences – the personal disasters – of a number of people living with HIV, in different countries and at different stages of the epidemic.

**Box 1.1 Experiences of living with HIV**

**Larry Kramer, US activist and founder of Act Up, New York, 1983**

“Our continued existence as gay men upon the face of this earth is at stake. Unless we fight for our lives, we shall die. In all the history of homosexuality we have never before been so close to death and extinction. Many of us are dying or already dead.

There are now 1,112 cases of serious Acquired Immune Deficiency Syndrome. When we first became worried there were only 41. In only 28 days, from January 13th to February 9th (1983) there were 164 new cases – and 73 more dead... Of all serious AIDS cases, 47.3% are in the New York area.

These are the serious cases of AIDS, which means Kaposi’s sarcoma, Pneumocystis carinii pneumonia, and other deadly infections. These numbers do not include the thousands of us walking around with what is also being called AIDS: various forms of swollen lymph glands and fatigues that doctors don’t know what to label or what they might portend.

I have talked with the leading doctors treating us. One said to me, ‘If I knew in 1981 what I know now, I would never have become involved with this disease.’... A third said to me, ‘I’m very depressed. A doctor’s job is to make patients well. And I can’t. Too many of my patients die.’”

(Kramer, 1983)

**Suzana Murni, Echidna, Uganda, 1999**

“To be informed is empowering. It has enabled me to manage living with the virus. I know how to take care of myself. I know my body. I understand it. I know where to seek support if I need it. I feel courageous to ask questions. Even to protest. I know what are the choices for me. And I am capable of making careful considerations before making any decisions. All these wouldn’t have happened, or might take an awfully long time to happen, if I hadn’t been informed.”

(Healthlink, 1999)

**Miriam Mbwana, Nkhotakota, Malawi, 2001**

“In my life I have had 11 children, eight girls and three boys. Seven have passed away. The first, Lawrence, died in 1993 and one of my children has died every year since. Another six of my grandchildren have died. AIDS has carried my family away like a flood.
I look after 16 of my children’s children. My granddaughter Madrin is in hospital with her son John, and they are both very weak. She has lost three children already. My daughter Mary is now very ill. We are very close. She is my best friend.

What have we done to deserve this? My father used to say, ‘When death is there, pass by on the other side.’ But it’s not possible now. Death is everywhere.”

(Mendel, 2002)

Dessa Chidhedza, Lilongwe, Malawi

Her story is not unusual. She was 23 when her husband died. She suspected he had died of AIDS and went for a test; she found she was HIV positive. She has had many infections and is too weak and frail to work. “I have no hope of ARVs [anti-retroviral drugs],” she says. She lives in her mother’s house, with her mother and 13 other family members (11 children). Two of her own three children have been sent to her cousin in Blantyre, 360 km away, since she fell ill and lost her job as a cashier in a shop. Money is tight and food is scarce. Only a single small supper pot bubbles on a tiny fire as Dessa’s brothers sit in the shade hammering out a discordant song as they reshape an old metal hub cap in hopes of bringing in some money. Dessa says, “I’m not sure how long I can go on because my immune system is declining.”

(Boseley, 2003)

Mercy Makhalemele, South Africa, 2000

“I was married and HIV infected in marriage. My husband died in 1994 and a year later I lost my daughter Victoria at the age of two and a half years. These were two years of trauma for me and the experience and pain have still not gone away. Still by my side is my 11-year-old son Thabany which means ‘rejoice’.

My daughter was put on AZT [azidothymidine] after her diagnosis. I was not told about side-effects, so I could not recognize them. This to me is unacceptable. Nor did anyone tell me at the time that I could infect my baby through breastfeeding. For various reasons my doctor recommended that I take the child off AZT and her condition did at first improve. But then my child developed a bad cough and I thought it was bronchitis. She was not breathing well, so my helper said I must take her to hospital. I refused, as she had already spent so much time in hospital. In the end, I was persuaded and she was admitted. The next day they called me very early in the morning. My daughter had passed away that night – she had not been able to breathe.

Women will move mountains to have a healthy baby. I myself have fought hard for women’s access to treatment. I went on hunger strike for a week. Yet I know that treatment alone will not do but treating women with respect will help.”

(Tapper, 2000)

Edwin Cameron, 2005

“...powerfully irrational responses to AIDS overshadow the epidemic even today. For stigma – a social brand that marks disgrace, humiliation and rejection – remains the most ineluctable, indefinable, intractable problem in the epidemic. Stigma is perhaps the greatest dread of those who live with AIDS and HIV – greater to many even than the fear of a disfiguring, agonising and protracted death.

Stigma manifests itself in hatred, discrimination, rejection, exclusion. Workers are sacked. Spouses are shut out. Friends are abandoned. Services, help and support are refused.

The external manifestations find an ally within the minds of many people with HIV or AIDS. Stigma’s irrational force springs not
The challenge to the humanitarian community

Another major – and clearly linked – focus of the report is on the challenge of the HIV epidemic to the humanitarian community. The epidemic adds a hugely complicating dimension to the community’s work, whether it be reducing poverty, providing basic healthcare and welfare on a day-to-day basis or dealing with the aftermath of man-made and natural disasters such as conflicts, famines, droughts and earthquakes. Humanitarian organizations work with the most vulnerable people in the

only from the prejudiced, bigoted, fearful reactions others have to AIDS – it lies in the fears and self-loathing, the self-undermining and ultimately self-destroying inner sense of self-blame that all too many people with AIDS or HIV experience themselves.”

(Cameron, 2005)

Xu, Anhui Province, China

Xu, 55, lives with his wife and two children. He tested positive in 2004. Xu worked as a doctor but needed money to support his family. Feeling he had few options, he went to an unregistered blood collecting station and became infected with HIV. At the beginning, he did not want to tell his children about his positive status. He worried that it would negatively affect their ability to study, work and live.

Once they became aware of his health condition, his children were understanding and supportive of their father and whatever the future held. One of his goals is to save enough money so that his daughter, now in her final year in high school, can finish her education.

“Although I have HIV, I never give up my responsibility as a father. Providing for my family is one of the responsibilities that I take very seriously. Because of my HIV status this has become even more important for me. I never give up my hope for the future of my family. Now I depend on medicine to prolong my life along with my medical knowledge and my optimistic attitude. One effective method of maintaining my health is to take antiretroviral medicine continuously, and the other is to get rid of the mental burden. And part of that is the wonderful support I have received from my children. Just like I support them, sharing my HIV status with them has eased a lot of pressure for me.

I have their love and understanding. My only approach is to fight against this disease to my last breath. After I was open about my status, the greatest challenge was discrimination. Although my family members and some of my friends expressed understanding and sympathy towards my situation, most people look at me oddly. I know that it is discrimination. Although I live with HIV and am discriminated against by other people, I can endure the pressure and challenge in my positive life. I believe that I have enough capacity to meet any challenge, to earn my own living and to play the role of a father as before. If I want to fight against the disease, I must depend on myself. I think one of the most useful ways to prevent the spread of HIV is through education to the public and it would also to [sic] reduce discrimination. The government and relevant departments should provide cheaper or free testing. This act could reduce our burden in many ways.”

(IPPF and GNP+, 2005)
world. The aim is to improve the lives of these people; it is this vulnerability, whether caused by poverty, inequality (including gender) or environmental factors, that often places them at risk of HIV infection. The effects of disasters (whether acute or long-term, man-made or natural) are among the very factors that drive the epidemic – dislocation and disruption of people’s lives, sexual exploitation and violence against women and children but also men, the disruption of health services including provision of anti-retroviral treatment (ART), psychosocial support and blood screening. Migration too is a growing challenge across the globe, as people travel in their millions to find work and escape poverty. Migrants and mobile workers may face an increased risk of HIV as they travel, and when they arrive (see Chapter 4).

History: the response to HIV and AIDS

The first reported occurrence of what is now known as AIDS was published in June 1981. In the United States’ Centers for Disease Control and Prevention’s (CDC) weekly Mortality and Morbidity Report, doctors in Los Angeles wrote about five previously healthy, young, gay men who had contracted pneumocystis carinii pneumonia, a rare and fatal disease only seen before in people whose immune systems were severely damaged. Dr Michael Gottlieb explained that little could be done for these early patients: “They were very wasted… They looked like concentration [camp] survivors” (PBS TV, 2006).

Doctors in other American and European cities read the CDC’s report and realized they were seeing very similar symptoms in some of their patients too. By 1983, there were reports of cases from several African countries including Zaire (now the Democratic Republic of the Congo) and Uganda. Indeed, it is now known that HIV existed in Africa since the late 1950s. By 1985, cases had been detected in every region of the world.

Experts first called the new condition GRID (Gay-related Immune Deficiency), because it seemed restricted to gay men. This meant that another familiar aspect of the disease’s history – the reluctance of politicians to take action even when thousands of previously healthy young people were dying – was present from the start. Politicians feared spending large amounts of money from the national health budget on a group of people whom many of their citizens strongly disapproved of. Some saw this new disease as God’s punishment.

When it became clear that women, and later children, were also experiencing the same symptoms and dying, scientists renamed it AIDS (acquired immunodeficiency syndrome), but the stigma and discrimination have remained.

Politicians were not the only guilty ones. In 1983, for instance, the editor of Britain’s prestigious scientific journal Nature, John Maddox, wrote: “There is now a serious
danger that alarm about the disease physicians call acquired immune deficiency syndrome... will get out of hand.” He denounced the “pathetic promiscuity of homosexuals” and then wrote that “mercifully, the disease – whatever its causation – is neither especially infectious... nor certain in its effects” (Maddox, 1983).

There was nothing pathetic about the energy of American gay activists who, realizing that their government was unwilling to act, set up AIDS service organizations, such as the Gay Men's Health Crisis, founded in New York in 1981. These organizations provided – and many still do – a range of services, including education, awareness raising, advocacy, care and support for people living with HIV. Similar organizations followed in Europe, Canada and Australia, and eventually the developing world. In all the most affected countries, activists – mainly but not exclusively men and women living with HIV – have been at the forefront of pushing for a stronger response to the epidemic, for programmes of prevention, care, support and treatment for all, and combating stigma and discrimination.

The AIDS story is one of fairly rapid progress in certain areas of scientific research; the human immunodeficiency virus (HIV) was isolated as the cause of the new disease in 1984, quickly followed by the development of a blood test to detect the virus and confirmation that condoms prevent transmission. But in other areas, progress came at a snail’s pace, notably in the response from political leaders across the globe.
During the early years of the AIDS epidemic, this incurable and inevitably fatal new disease was not treated as a major priority for the humanitarian community. In the early 1980s, the World Health Organization (WHO), the United Nations (UN) body with a mandate for maintaining global health, had only one person working on sexually transmitted infections (Berridge, 1996). In 1988, the then Director-General of WHO, Halfdan Mahler, admitted that denial had been a major cause of WHO’s delayed response to AIDS. He said: “I know that many people at first refused to believe that a crisis was upon us. I know because I was one of them” (Mahler, 1988).

An Oxfam report explains: “Until now HIV/AIDS has not had a high profile in Oxfam’s programming for a variety of reasons: it is difficult to measure; it is difficult to prevent; it was seen as a medical issue; it was not seen as an emergency issue” (Oxfam, 2006).

The experience of the Red Cross Red Crescent is somewhat different. The Norwegian Red Cross Society was the first to become involved in AIDS information and prevention work internationally in 1985. It may have been the first non-governmental organization (NGO) to start to work internationally on a bilateral basis on AIDS-related issues (Gnaedinger, 2007). Calle Almedal of the Norwegian Red Cross Society initiated the work after visiting African countries, such as Kenya and Uganda, where hospital wards were filling up with AIDS patients and funerals were becoming a far too regular occurrence.

Red Cross Red Crescent volunteers, often based in affected communities, were well placed to provide education and care and support for people sick and dying from AIDS. A major task, however, for many National Societies and other humanitarian organizations would be to overcome stigma against people living with HIV.

Almedal recalled that when the Norwegian Red Cross Society began working on HIV in Africa, the only people already involved in HIV and AIDS work (apart from members of the local community and health workers) were from the Roman Catholic church. “Nuns in particular were talking to people about what caused HIV infection, and listening to them. They understood the reality of people’s lives. Some gave out condoms. Catholic hospitals and primary healthcare clinics were in too many cases the only ones caring for those people sick and dying from AIDS. But the same was true elsewhere; in New York at the beginning of the pandemic, hospitals refused to take in people with AIDS and funeral parlours refused to bury them. St Vincent’s Catholic Hospital in Manhattan was for some time the shining exception.” These nuns and priests in Africa and elsewhere understood that if communities were to be spared the ravages of HIV, they had to understand how it was transmitted, and then be given the means – both information and condoms – to prevent transmission. Faith-based organizations still provide a major part of the prevention, care, support and treatment services for people living with HIV and AIDS (see Box 6.3).
Much of the support for people living with HIV and AIDS in developing countries was provided by small organizations within communities, organizations that depended on unpaid volunteers. The AIDS Service Organization (TASO) was set up in Uganda by Noerine Kaleeba whose husband had died of AIDS. Initially, TASO had 15 volunteers, 12 of whom were living with HIV. Its work in providing counselling, information, medical and nursing care has been copied by other organizations in many countries. “[TASO] aimed at impressing upon people in the community, especially at the grassroots, that the person who has HIV infection or AIDS is not dangerous. They need our compassion, our concerted effort to be supportive… The emphasis is on positive living” (Kaleeba, 1991).

The Norwegian Red Cross Society worked with African National Societies, initially only the Rwandan Red Cross and Kenya Red Cross Society, developing health information materials and distributing them nationwide. Messages about HIV were also broadcast on local radio. It was also through the collaboration with the Rwandan Red Cross that the first group of people living with HIV was established in Africa.

The importance of such organizations is now recognized across the AIDS world, though their involvement in developing policies and programmes is not as wholeheartedly promoted in many countries as it should be.

There was also collaborative work on HIV between some National Societies and International Planned Parenthood Federation (IPPF), the World Council of Churches and, as part of the youth work programme, the World Organization of the Scout Movement. In 1987, the General Assembly, the supreme governing board of the International Federation of Red Cross and Red Crescent Societies (International Federation), passed a resolution calling on all National Societies to respond to the challenge of AIDS (very much prompted by the work of the Norwegian Red Cross Society). That same year, WHO launched its Special Programme on AIDS, to be renamed the Global Programme on AIDS a year later.

The epidemiological data of the period are not clear; although AIDS was declared a global challenge by WHO, in 1988 there had been only a total of 75,392 cases of AIDS officially reported to WHO from 130 countries in the world. However, many cases were unreported and at the start of 1988, WHO made a conservative estimate of 5 million people infected with HIV (Gnaedinger, 2007).

By 1990, at least 100 National Societies were actively working in prevention and care. In Thailand, for example, The Thai Red Cross Society was at the forefront of work on HIV and AIDS. The epidemic was the key international programme of the Australian Red Cross, which supported projects in a number of Asian countries. Since the early 1990s, HIV had spread substantially in Asia, especially in some South-East Asian countries, and in several Latin American nations.
By the mid-1990s, however, the International Federation had lost much of its original momentum on AIDS work. It had reduced its activities and support to HIV programming, and there had not been enough sharing and dissemination of experiences, monitoring and evaluation of programmes or sufficient encouragement to National Societies to develop and scale up their work (Knight, 2004). In 2000 there would be a revival in the International Federation’s commitment to fight HIV and AIDS, and as this report shows (see Boxes 3.3 and 3.5), National Societies are actively involved in the whole range of prevention, care, support and treatment (International Federation, 2005).

The early- to mid-1990s was also a period when resources worldwide for HIV and AIDS had begun to fall (they had never been enormous), partly as a result of a reduction in overseas development assistance (ODA) globally and also due to the end of the Cold War. As HIV was reaching near disaster proportions in many African countries, Africa was losing its political relevance to the industrialized world.

It was decided to disband the WHO’s Global Programme on AIDS and set up a new UN body, UNAIDS (the Joint United Nations Programme on HIV/AIDS), to coordinate the work of various UN agencies on AIDS. As the new organization opened its doors for business, an estimated 20 million people were living with HIV around the world (the majority in the developing world) and nearly 4 million had died.

A report to the UN Economic and Social Council (ECOSOC) in 1995 (UN ECOSOC, 1995), which described aspects of the new UN programme, stressed the continuing challenges of the epidemic. It wrote about “its urgency and magnitude… its complex socio-economic and cultural roots… the denial and complacency still surrounding HIV and the hidden or taboo behaviours through which it spreads… the discrimination and human rights violations faced by the people affected”. However, until the late 1990s, the response to AIDS, whether from affected countries or donors, did not meet these challenges. Combined with stigma, the fact that there is about a period of eight to ten years between infection and the development of clinical AIDS may have lulled many politicians into inaction and reinforced denialism.

Nevertheless, the evidence of a disaster was clear. WHO’s 1999 World Health Report stated that AIDS was the number one cause of death in Africa (WHO, 1999). As The New York Times journalist Larry Altman wrote: “If political and religious leaders had responded with effective public health programmes much earlier, they might have prevented hundreds of thousands, if not millions, of deaths. Some leaders simply denied the scientific evidence that HIV was being transmitted in their countries. Others mistakenly believed they had more pressing problems to address” (Altman, 1999).

Over the past decade, there has been a sea-change in the attitude of many political and other leaders, and of donors, towards HIV. Uganda’s president, Yoweri Museveni,
publicly acknowledged the threat of HIV, and instituted prevention programmes in
the mid-1980s, earlier than any other leaders. It took much longer for others to speak
out. But on World AIDS Day, 1 December 1998, President Nelson Mandela of South
Africa spoke for the first time about AIDS. South Africa was experiencing one of the
fastest-growing epidemics in sub-Saharan Africa. Mandela spoke of “breaking the
calence”. Others followed suit.

The issue of AIDS was ratcheted up to a global level in January 2000, when the UN
Security Council discussed AIDS in Africa as a major human security concern as well
as an obstacle to development. It was the first time a health issue had ever been debat-
ed in the Security Council. This was followed in June 2001 by the UN General
Assembly Special Session on AIDS at which, after much wrangling during late-night
meetings, all the heads of state signed a Declaration of Commitment that contained
time-bound targets on HIV prevention, resource mobilization and other aspects of
the global AIDS response. It was a clear global mandate that made governments
accountable (UNAIDS, 2001).

The combination of a considerable increase in political commitment and a huge hike
in funding (from US$ 300 million in 1996 to US$ 10 billion in 2007) has inevitably
strengthened the response to HIV in all the most affected countries. There are signs of
optimism in that the latest data (UNAIDS, 2007) show a levelling-off of new infec-
tions, and even a reduction in a small number of countries (including Cameroon,
Haiti, Kenya, Malawi, Rwanda, Togo, United Republic of Tanzania, Zambia and Zim-
babwe), suggesting a change in sexual behaviour among young people. But many chal-
lenges remain, notably in meeting the need for prevention and treatment (see below)
and also in providing care and support for groups that are too often overlooked.

In the most affected countries, older people provide the bulk of care for their sick
and dying adult children and for their orphaned grandchildren. They too are at risk of
HIV infection (see Box 1.2). At a different stage of their lives are children who are
HIV positive and have reached adolescence. They, like all HIV-positive people, have
a right to a fulfilling sex life but may need support and advice to achieve this – like
many adolescents worldwide. Projects such as the Brazilian programme described in
Box 1.3 try to meet this important need.

Box 1.2 The toll of HIV and AIDS on older people

Older women and men are the backbone of AIDS care. United Nations Children’s Fund
UNICEF) data show that between 40 and 60 per cent of orphaned children in severely HIV-
affected countries are cared for by their grandparents. These figures are increasing.
For example, in Namibia, the percentage of orphans living with grandparents increased
from 44 per cent in 1992 to 61 per cent in 2000. Households run by older women are twice as likely to include orphans as those headed by older men. However, older male heads of households take in more orphans than do younger men. In southern Africa, for example, 24 per cent of older male-headed households take in orphans compared to an average of 12 per cent for all male-headed households (Monasch and Boerma, 2004).

In addition to the enormous responsibilities that older people must shoulder at a time of their lives when they themselves could reasonably expect to be cared for, the risk of infection among older age groups remains unrecognized and the spread of infection goes undetected and unreported. Assumptions are made that older people are not susceptible to infection, because they are assumed to be sexually inactive. This neglect of older people’s sexuality is reflected in the aggregated international data on HIV prevalence.

During a humanitarian crisis, loss of assets or displacement pushes coping mechanisms to the limit, increasing the burden of care faced by older people. Furthermore, in conflict settings such as Darfur, for example, older women describe leaving the safety of camps in search of firewood in order to protect younger women from sexual violence and rape, but putting themselves at risk (Feinstein International Famine Centre, 2005).

**Caring for people living with HIV and AIDS**

Many adults return to their parental home when they are sick, particularly in the terminal stages of an illness. For people of any age, caring for terminally ill family members is difficult, but the additional burden of supporting grieving grandchildren increases the stress. Stigma surrounding AIDS may result in older carers facing social exclusion. In extreme cases, superstition and fear can even lead to accusations of witchcraft and sorcery resulting in ostracism, physical violence and even death.

Yet carers have little time to deal with their own feelings and to care for themselves. An older woman from Cambodia describes the emotional impact of caring for her grandchildren after the death of her adult child: “Every morning I wake up thinking about how I will have money for my grandchildren... I can’t sleep because I think about it so much.” Another carer describes the risks to her own health through caring for her daughter living with HIV: “Sometimes I would fall down myself when trying to pick my daughter up and move her” (HelpAge International, 2007). Older female caregivers may have concerns of their own: reduced energy and stamina, or even serious health problems, including pain and disabilities.

The financial, and emotional, costs of HIV must also be shouldered by older people; the epidemic affects their economic roles, forcing them to become the main breadwinners for their families. The average household income for households run by older people in some communities affected by HIV and AIDS in Kenya is a third of the minimum required household expenditure. A WHO study on AIDS and older people in Zimbabwe found that nearly two-thirds of caregivers identified financial difficulties as the main barrier to caregiving (WHO, 2002).

In Tamil Nadu, India, older people caring for orphaned children reported selling property or pledging it with moneylenders at interest rates ranging from 36 per cent to 210 per cent.

Vanida, a 52-year-old woman carer in northern Thailand, explained how her assets were depleted: “The hospital expenses were getting higher and higher until we ran out of money. We finally had to sell the land that we
had bought for our child” (HelpAge International, 2005).

Even if anti-retroviral treatment (ART) is provided free of charge, there are additional costs that an older carer must assume: food for the patient, medical treatments, transport to clinics and caring for grandchildren’s needs (food, school fees and other related expenses). The more caring responsibilities that older people have, the less time they have to spend earning income and farming land. Finding work is challenging: jobs that they are able to obtain are often low paid.

In war-torn northern Uganda, over half the children are estimated to live with grandparents. In Lira district where 80 per cent of the population have returned home following the cessation of hostilities, 80 per cent of those who remain are older people looking after numerous children. In one extreme case, a grandfather had 40 children in his care.

The lack of any educational provision in areas that these children have returned to, as well as the uncertainties of reduced access to food, clean water and shelter, was regularly stated as a major disincentive to return (Inter-Agency Standing Committee and HelpAge International, 2008).

**Older people’s susceptibility to HIV infection**
The 2005 UNAIDS/WHO global epidemic update published statistics on people aged 50 and over in two countries, Botswana and Uganda, revealing high rates of HIV infection for this age group. In Botswana, 21 per cent of people in their early 50s are HIV-positive, compared to 25 per cent of people aged 15–49. In Uganda, 7 per cent of men aged 50 to 59 are living with HIV; this is the same as the national adult rate. The rate for women in their 50s is 5 per cent. To those for whom older people are ‘off the radar screen’, the results are surprising. The report describes the level in Botswana as “unexpectedly high”.

Wherever women have limited control over protective measures, where men and women have multiple partners and intergenerational relationships, and where practices of wife inheritance occur, older women and men are as much at risk as younger people. Older women may be biologically more susceptible to HIV infection because of the thinning of their vaginal walls with menopause; this can increase the risk of tearing and therefore transmission (American Association of Retired Persons, 1996). Where there is poor blood safety and screening, older people are at the same risk as others of HIV infection through contaminated blood products in procedures such as transfusions.

Medical staff can mistake HIV-related symptoms for conditions associated with ageing. Discriminatory attitudes extend to withholding testing and treatment for older people who may be suspected of being HIV-positive. In extreme cases, the value of the life of the elderly may be denied because they are perceived to be near its end. Older patients and younger clinicians may be equally disinclined to raise sexuality and sexually transmitted infections with each other.

Data gathered at individual sites and two mission hospitals in Zambia and Namibia also show that older people are HIV positive, and are coming forward for voluntary counselling and testing (VCT) and treatment. In Zambia, at Monze Mission Hospital, of the 605 HIV-positive people registered in the ART programme, 13.6 per cent were over 50. At Rehoboth Mission Hospital in Namibia, 12.6 per cent of the 530 HIV-positive women and men registered for ART were over 50. The percentage of HIV-positive women and men in the
upper age brackets has been sufficiently significant for the programmes to now collect data up to 60 years, and to consider disaggregating it to 70. As the UNAIDS/WHO update reports, the emerging trend of rising infection rates among older generations in some countries may point to “an important gap in prevention efforts”.

**Conclusion**

To understand the critical role that older people are playing as carers is also to understand the massive impact of HIV on them. The challenge for service providers is to look beyond the most visibly affected groups to find the older men and women caring for the sick, grieving for lost children or resuming a parenting role for orphans and grandchildren.

During times of humanitarian crisis, older people caring for those affected by HIV must be included within vulnerability analysis and needs assessments; it is vital to recognize the protection issues they face that can increase their own vulnerability to infection.

**Practical ways to support older carers and people living with HIV or AIDS**

- Consult and involve older people in the design, implementation and review of HIV interventions, policies and services
- Target HIV and AIDS information and training to older people. Access to information and training are essential to ensure that older carers are able to protect themselves and those in their care from HIV infection
- Disaggregate data on HIV by age and sex to ensure an appropriate and informed response
- Support older carers economically. Income-generating schemes, regular cash payments (through state grants or community social funds) and social protection measures such as social pensions can ease the financial burden
- Recognize the importance of psychosocial support. Older people are under tremendous psychological pressures. Home-based care programmes need to listen to older carers, address their fears and anxieties, as well as provide health information and care support
- Assist older carers practically to claim their entitlements and use existing resources. Lack of awareness, combined with costly, time-consuming and complicated procedures, prevents older carers from accessing entitlements
- Vulnerable children should be entitled to free education. Older carers repeatedly stress concern about education for children in their care and frequently prioritize school fees over their own needs
- Those with protection responsibilities during humanitarian crises, especially child protection agencies, must recognize both the protection needs of older people and the role they are playing in protecting others.

**Treatment**

When the first effective ‘highly active anti-retroviral treatment’ was announced at the International AIDS Conference in 1996 in Vancouver, it gave hope to many people living with HIV. ART could delay the onset of AIDS for many years, but it was not a cure; it was very expensive (then about US$ 20,000 per year per person in the United States) and therefore beyond the reach of the majority of people who needed it. But by
Box 1.3 Thinking about the future: there is more to life than HIV for HIV-positive young people

As anti-retroviral drugs become more available, there will be increasing numbers of HIV-positive young people who need support. Brazil is one of the few countries in Latin America where there are already significant numbers of young people who have been living with HIV since childhood.

In March 2007, the International HIV/AIDS Alliance joined the NGO, Saber Viver, to work on a year-long project with adolescents in Brazil, many of whom have been living with HIV since childhood. Through the project, called ‘Thinking about the future’, the 13- to 18-year-olds have been writing about their experiences in a bilingual magazine called Saber Viver Jovem (Youth Savoir Faire), which has been distributed in Portuguese and English in Brazil and other countries where the Alliance works.

‘Thinking about the future’ has been working with some 20 HIV-positive teenagers in two different locations – Rio de Janeiro and Niterói (a city located 60 km from Brasilia). The project, led by Saber Viver in collaboration with another NGO, Pela Vidda, has focused on how young people deal with the challenges of living with HIV, and builds on the Alliance’s already significant role in HIV work with adolescents.

The project has created safe, inclusive and empowering spaces for young people to talk openly. For example, 24 arts and literature workshops have encouraged the young people to find out more about each other and about how they cope with the challenges of living with HIV as adolescents.

It has also helped those involved to explore issues such as young people’s rights, participation, poverty, disclosure, gender and sexual and reproductive health rights. Discussions also cover planning for the future, social interaction with families, schools, institutions, health services and NGOs and stigma and discrimination, including self-discrimination.

The results so far have shown that adolescents want to talk to other young people, and some of them want to be involved in HIV prevention work as well. But the young people have also been experiencing HIV differently, depending on where they live. Most of the young people in the Niterói workshops were born with HIV. In Rio de Janeiro, by contrast, some acquired HIV through unprotected sex and violence. The Rio de Janeiro group rarely brought the subject of HIV up in the workshops, whereas in Niterói, HIV issues were routinely considered, possibly because HIV has always been part of the lives of these young people.

One of the most important messages from the young people, which is reflected in the content of the magazine, is that there is more to life than HIV. Indeed, a key part of the project has been to create a space for them to talk about themselves and their lives, as well as about HIV.

Breaking down barriers

“Before we came to the first workshop that Saber Viver organized, the first question that came to us was: will this be another one of these lectures where adults keep reminding us what we should or shouldn’t do? However, the workshop started and we found out this wasn’t true at all,” says an editorial in Saber Viver Jovem. “We talked about everything, taking our stories as examples: how terrible it is to take our medication every single day, the difficulties of facing discrimination, how we miss our families or sometimes hate them, our plans
for the future, and things we are ashamed of telling others... We hope this magazine will help many youngsters living with HIV like us to realize that we are like all the other young people in the world. The difference lies just in the fact that we have to take medication every day.”

Adriana Gomez, coordinator of Saber Viver and a journalist by trade, says the project has been a huge challenge, but has had great results. “To add more value to the work we were doing, the editorial process of the magazine used participatory workshops to get direct involvement of young people. The result was very positive for Saber Viver and for the young people. They are now motivated to participate in other groups and help to build up similar processes. For example, they want to work on new publications with other young people living with HIV.

“For me as a journalist, this project was also a way to work with different generations, and to see other ways of doing my work so we can build up HIV prevention strategies that work and that respect the sexual and reproductive rights of young people. For this, it is crucial that there is direct participation of the group in the whole process.”

Fábio Henrique de Moraes Souza is 20 years old and lives in Rio de Janeiro. He found out he was HIV positive four years ago. “When the doctor saw the swollen glands in my neck, she commented in front of everybody that I must be HIV positive,” he says. “I hadn’t been aware of it. That happened in the building where my mother lives, and the neighbours started to gossip. I made up my mind to take an HIV test, and the results were positive. When my mother found out, she said I was not the son she had asked God for, because I had this illness and I was a homosexual. She said a lot of bullshit in a moment of anger, but I got hurt.”

Hopes and fears
Asked what thoughts they always come back to in their lives, the youngsters involved have clear insights into their hopes and fears. “I always think about... the time when I got infected,” says Carla who is 16. “I had a very nice life until I met a boyfriend who had HIV and did not know. We had a romance, but did not protect ourselves. I got infected with HIV and since then my life has completely changed. I have to take medication. I had never thought that I would go through this: so young and dependent on medication. But with the support of my doctors who are very helpful, and the adverts on TV, I have realized that HIV does not mean death.”

Marta, 17, talks about the life she feels she has lost: “When I close my eyes, I see the life I want to have: being sure that I will see my kids grow up and have a joyful and healthy life. There is something I haven’t achieved: I am not happy. I experience moments of happiness, but they are few. I have a big load of responsibility in my life. I have to divide myself into so many parts that I don’t know which of them I really am. I have to be mother, daughter, friend, lover, wife. But most of the time, I would like to be just a girl. I would like to be fragile, like a normal girl. I have to be all shoulders for other people, when sometimes I am the one who needs a shoulder for support.”

Friendship
At one of the programme’s workshops, a group of teenagers and adolescents discussed the topic of friendship. “Is it hard to talk about HIV to friends who are not positive?” one of them asks the group.

“I have never told any of my friends. I am ashamed,” says Tamires. “I think they won’t come close to me anymore. They will be dis-
gusted. There are times I want to tell them, but I don’t know how, I just can’t do it.”

Another voice adds: “I have a friend who I talk to about everything. I want to tell him, but I keep thinking: what if we have a quarrel? What if he becomes spiteful and then tells everybody.”

Suellen Chaves Alcântara, a 19-year-old from Niterói, who was born with HIV, says: “I am an HIV-positive adolescent. I wish people with HIV had a better quality of life and more choice of medication. I am 19 and I have been taking medication against HIV for 12 years. I have had to change my medication many times, maybe seven or eight times. What is available for me here no longer works for me. My doctor told me my body gets used to the medication. My viral load is very high; I have a high temperature and get the flu quite easily. I decided to be part of a study for a new medicine called Maraviroc.”

**Sero-discordance**
The magazine candidly approaches the issue of sero-discordance, interviewing Elizana (15) and William (20), who have been dating for three years. They had been dating for more than two years when William found out he was HIV positive. “Are you afraid of transmitting the virus to her?” asks Suellen, the 19-year-old interviewer.

“Yes. I don’t want her to go through what many other people are suffering,” replies William. “My greatest concern is the medication. I am not taking it yet, but I know the day will come, and I don’t want that to happen to her.”

**Medication – a love–hate relationship**

I hate my treatment:
- “when I have to take the pills before I go out with friends”
- “when it feels like my body starts burning from within after I have taken them”
- “when it ‘explodes inside of me’ like a bomb”
- “because of the strict schedule”
- “because of the side effects it can have”

But, I love my treatment when:
- “I get the test results with a viral load below the limit of detection”
- “my health condition improves”
- “I think that, some time ago, people didn’t even have the opportunity to go through treatment, because there was no medication”
- “I make plans for the future: working, studying, having a family”

The magazine also looks at the story of Maison, a young man who found out that he had Type 1 diabetes when he was 12 years old, describing the difficult routine of his treatment. The story highlights the similarities between Type 1 diabetes and HIV as manageable conditions. “This is a disease for which, like HIV, there is no cure, but there are ways to treat it,” says Saber Viver Jovem.

**Workplace rights**
The implications of HIV as a long-term manageable condition are explored in an article on workplace rights. “People living with HIV have the right to work in whatever profession they choose,” says the editorial.

“Our young reporter Bianca Machado complains that she can’t work as a stewardess or join the navy. She must have heard about cases of dismissals, or refusals to hire people with HIV. But this belongs to the past.

“After all, people with HIV can now assert their rights. Since 1990, every Brazilian under 18 years of age is protected by a law called the Statute on Children and Adolescents.”
2007, through the combined efforts of activists in developing and developed countries and of humanitarian agencies (NGOs and the UN), the price of ART had dropped hugely. Most importantly, it has been shown that ART can be effectively prescribed in facilities where resources are very limited. In December 2006, in low- and middle-income countries, an estimated 7.1 million people were in need of ART, and of these, a reported 2 million had access to the treatment (UNICEF/WHO/UNAIDS, 2007).

However, treatment has to be sustained, until or if a cure is found. When people stop taking ART – and disasters such as conflict and natural events (see Chapters 5 and 6) often cause disruption of supplies – they may develop resistance to the drugs they were taking. The ‘second-line’ drugs that are then needed remain too costly in many countries (UNAIDS, 2006). There is also a concern that the funding needed to provide ART in low-income countries may not continue indefinitely.

Is ‘universal access’ just a pipedream, another of a long line of improbable global targets? Already there has been considerable criticism of the fact that so much money goes to AIDS compared with other public health needs such as safe water and drugs for preventable fatal illnesses, such as diarrhoea and respiratory diseases. It is also argued that the focus on treatment has sidelined work on HIV prevention. But it is not a question of either/or, treatment or prevention, HIV or clean water. All are inter-connected and extra resources are required across the board to prevent people dying.

The prevention gap

Prevention was, and still is, key to combating the virus, and by the late 1980s almost as much was known about ways to prevent HIV transmission as is known today (see Box 1.4). Although the evidence that male circumcision protects against infection only appeared in 2007, scientists and others had suspected this was the case for many years. But for much of the 1990s, it was not thought particularly cost-effective to devote resources to HIV prevention in the absence of a vaccine (Behrman, 2004).
Box 1.4 Major components of a comprehensive HIV prevention programme

Every country – even different parts of countries – has ‘its own HIV epidemic’ so prevention programmes must be tailored according to the features of the epidemic.

At all stages of prevention, local communities and people living with HIV must be involved; ‘outsiders’ imposed by donors and government authorities can make a contribution, particularly as regards early recognition of the need for action, but only local people have the detailed knowledge of their community that is necessary to drive and sustain behaviour change.

Preventing sexual transmission
- Programmes to change behaviour – to increase condom use, delay initiation of sexual behaviour in young people, reduce the number of partners
- Condom promotion
- Access to voluntary HIV counselling and testing
- Diagnosis and treatment of sexually transmitted infections (STIs)
- Adult male circumcision

Preventing blood-borne transmission
- Provision of clean injection equipment to injecting drug users
- Methadone or other substitution therapy for drug dependence
- Blood safety (including routine screening of donated blood)
- Infection control in healthcare settings (including injection safety, universal precautions and anti-retroviral prophylaxis following potential HIV exposure)

Preventing mother-to-child transmission
- Primary HIV prevention for women of child-bearing age
- Anti-retroviral treatment
- Prevention of unintended pregnancy in HIV-positive women
- Breast feeding alternatives
- Caesarean delivery (in the case of high maternal viral load)

Social strategies and supportive policies
- HIV awareness campaigns (including mass media)
- Measures to confront and mitigate HIV-related stigma and discrimination
- Gender equality and women’s empowerment initiatives (including universal education for girls, international efforts to eradicate human trafficking, child marriage and harmful traditional practices)
- Visible political leadership
- Engagement of a broad range of sectors in HIV awareness and prevention measures: i.e., a multisectoral response to the epidemic
- Legal reform to create an environment supportive of HIV prevention (such as laws decriminalizing sex work, homosexuality and needle possession, laws recognizing and protecting women’s inheritance, enactment and enforcement of laws against sexual violence – aimed at women and men)

As early as 1986 the United States Surgeon-General released a report arguing for parents and schools to have a “frank and open conversation” with adolescents and pre-adolescents about AIDS because of their vulnerability when exploring their own sexuality and perhaps experimenting with drugs (PBS TV, 2006). In 1997 UNAIDS published a comprehensive literature review of sexual health education across a range of cultures; this showed that good HIV education among adolescents does not lead to increased sexual activity but on the contrary delays the age of first sexual intercourse. It also confirmed that when the same adolescents become sexually active, they tend to avoid risky sexual behaviour (UNAIDS, 1997).

Like the strong evidence on the effectiveness of harm reduction approaches with injecting drug users, the reality is counterintuitive so it is not surprising that many parents worldwide continue to believe that sex education for children promotes sexual activity. Today a majority of young people in high-prevalence countries still do not have accurate and comprehensive knowledge of HIV (UNICEF/WHO/UNAIDS, 2007).

“We should be winning in HIV prevention. There are effective means to prevent every mode of transmission; political commitment on HIV has never been stronger; and financing for HIV programmes in low- and middle-income countries increased six fold between 2001 and 2006. However... the effort to reduce HIV incidence is faltering” (GHPWG, 2007). Yet again, a group of leading public health experts, other researchers and advocates, and people affected by HIV, produced a report showing the missed opportunities to prevent HIV. Most people at risk of HIV infection have little or no access to basic prevention tools (UNICEF/WHO/UNAIDS, 2007; UN 2007).

There are a number of reasons, some of which are dealt with in this report (see Chapter 7), why the money does not always reach the people who need it, and is not used effectively. Although political commitment has increased, political leaders are not necessarily consistent in supporting the range of services that must be provided to reduce HIV incidence; for example, compared with the efforts of senior political leaders in some of the most heavily affected countries to support efforts to bring AIDS treatment to scale, “fewer have spent political capital in energetically expanding HIV prevention” (GHPWG, 2007).

Even when governments take prevention seriously, they often aim at the wrong targets. There is still a considerable reluctance to engage with a major challenge; namely, that in many regions, particularly Asia and Latin America, the epidemics are driven by the behaviour of injecting drug users, men who have sex with men, and sex workers and their clients. These are not the groups of people politicians usually choose to mix with, nor to be seen to fund. These groups – with much higher rates of HIV than the population as a whole – face stigma, rejection and often criminalization. But if
Programmes for HIV prevention, care and treatment are not provided, and politicians do not engage in combating stigma, rates among these at-risk groups will increase.

In 2005, only 8 per cent of injecting drug users worldwide had access to HIV prevention services (UNICEF/WHO/UNAIDS, 2007). Prevention services for men who have sex with men currently reach only 9 per cent of that group (UNAIDS, 2006) and fewer than 20 per cent of sex workers globally had access to HIV prevention services in 2005 (UN, 2007).

Financial and human resources are being wasted in some of these countries on mass educational and awareness-raising programmes for young people, most of whom are not particularly at risk of HIV infection. When dealing with natural or man-made disasters (see Chapters 5 and 6), humanitarian organizations need to take into account the particular features, including prevalence patterns, of the country’s HIV epidemic. Matching the response to a country’s epidemic is key to effective prevention. Prisoners are another major key group at risk of infection (see Box 1.5).

**Box 1.5 Prisons are high-risk environments for HIV transmission**

Prisoners have been identified as one of the four most vulnerable and at-risk populations for HIV transmission and infection. They tend to have a higher prevalence of HIV infection, not only because they engage in behaviour that puts them at higher risk of becoming infected, but also because the prison environment can be bad for health (Gatherer et al., 2005). Prisons can be considered a net driver of the HIV epidemic in many countries.

Living conditions in most of the world’s prisons are unhealthy. Overcrowding, violence, a lack of light, fresh air and clean water, poor food and infection-spreading activities such as injecting drug use, rape and tattooing are common issues. Rates of tuberculosis (TB), HIV and hepatitis infection in prisons are much higher than amongst the general population (Coyle, 2007). HIV prevalence among prison populations varies considerably across settings, although several countries have reported rates in the range of 10 to 25 per cent and evidence of the rapid spread of HIV infection has been observed within specific detention settings.

Two important population streams contribute to the complexity of the situation: new inmates who may be uninfected and inmates who are already HIV positive flow in and out of prisons on a regular basis and thus increase the risk of infection.

**Guiding principles for HIV work in prisons**

The lack of HIV education, harm reduction measures and voluntary and confidential testing for HIV infection, adequate pre- and post-test counselling and treatment for HIV-infected prisoners, as well as mandatory HIV testing and segregation of HIV-positive prisoners, are all factors that undermine the public health response to HIV and AIDS, are contrary to human rights and compromise the human dignity of the person (International Federation, 2003).
The Declaration on Prison Health as part of Public Health, which was adopted at the WHO International Meeting on Prisons and Health in Moscow in October 2003, recommended that penitentiary health be an integral part of the public health system of any country; in other words, that prison and public healthcare be closely linked. With regard to HIV, one of the recommendations is: “Public and penitentiary health systems are recommended to work together to ensure that harm reduction becomes the guiding principle of policy on preventing the transmission of HIV and hepatitis in penitentiary systems” (WHO, 2003).

**Examples of National Society HIV-related work with prisoners**

In addressing HIV-related challenges in prisons, National Societies can help follow through from inside prisons to community prevention and harm reduction programmes, ensuring drug substitution, anti-retroviral treatment and, in relation to TB, ensuring the completion of directly observed treatment, short-course (DOTS) therapy, thereby helping to control the rate of infection in the wider population. The health-related work of National Societies includes HIV, TB and psychosocial support work and covers different and sometimes overlapping time frames: pre-, post- and during detention periods.

The Italian Red Cross’s Villa Maraini Therapeutic Community runs a centre for alternative detention outside Rome which provides an alternative to traditional prison settings and enables certain prisoners with substance abuse problems to carry out their sentences at the centre. The Italian Red Cross’s HIV prison-related services include a range of activities: the provision of psychosocial support, harm reduction programmes, providing an entry point for drug users and supporting their reintegration into the communities.

The main area of health in the prison-related work of the Kenya Red Cross Society is focused on HIV, with programmes being conducted in, for example, the Malindi G.K. prisons. These are mostly peer education and HIV-prevention activities. The Kenya Red Cross Society also plays an important post-detention mental policies and operational measures in prisons in order to create a safer environment and reduce the risk of transmission of HIV, tuberculosis and other diseases among detainees, prisoners and staff.” (International Federation, 2003)

**Improving access to care for prisoners and increasing resilience**

An essential part of the specific public health context of prison settings is improving access to care and building the resilience of former detainees and their families. In many cases, there is a risk that prisoners start TB treatment (and anti-retroviral treatment in some places) but stop once they are released. It is crucial to improve and ensure adequate and appropriate access to health services for former detainees when they are released back into the community, as well as psychosocial support for prisoners and their families.

For the International Federation, prisoners, former detainees and their families are people in situations of vulnerability and particularly exposed to harm such as HIV infection. The commitment of the International Red Cross and Red Crescent Movement to tackling the issue of health in prisons was reiterated in the *Agenda for Humanitarian Action* arising out of the 28th International Conference of the Red Cross and Red Crescent in 2003, which states:

“States in cooperation with the components of the Movement, are urged to imple-
role, bridging the gap and facilitating, as far as possible, the links and continuation of access to health services back in the community when detainees are released.

The Mongolian Red Cross Society started implementing its HIV-prevention project entitled ‘Let’s Go Home Healthy’ in selected men’s prisons through the Tuv and Baganuur Red Cross branches in 2004. The project involves many elements aimed at reducing the transmission of HIV, the provision of psychological support and training of peer educators. It involves activities not only in prisons but during the transition periods, also addressing the problems surrounding population flows in and out of prisons.

Conversely, as Helen Epstein and others have argued (Epstein, 2007; Hudson, 1999), some HIV experts have been reluctant until fairly recently to acknowledge a key feature of the epidemic. The HIV epidemic in many African countries has been driven by sexual networks, consisting of overlapping partnerships. These networks, it is suggested, created a kind of ‘superhighway’ for HIV, even if everyone in the network had

Donor priorities may also not be in line with a country’s priorities for prevention. As the report of the Global HIV Prevention Working Group (GHPWG) explains, the United States government’s ban on using funds for needle exchange “prevents the resources of the single largest AIDS donor from being used for a highly effective strategy to prevent HIV transmission as a result of drug use” (GHPWG, 2007). The report also explains that the independent US Government Accountability Office “concluded in 2006 that abstinence earmarks in US foreign assistance legislation often impede the ability of national programmes to tailor US-supported HIV prevention programmes to national needs.”

Another significant factor in the failure of prevention programmes is that they are too often imposed by ‘outsiders’, consultants from industrialized countries, with little involvement of local people. The attitudes of these ‘experts’ and much of the ‘AIDS industry’ are perceived as arrogant and racist. The lack of progress in the early days to halt the epidemic’s spread is partly rooted in centuries-old cultural and social attitudes that are not easy to overcome. Thus it is essential that the local experts — people living with and affected by HIV, community leaders and shakers, the country’s doctors and other experts — are involved in all HIV and AIDS policy and programming. Such local involvement, leadership and mobilization are a key component of the dynamic of empowerment that drives successful HIV responses though building community and individual resilience. Outsiders can be a support, but communities must be actively engaged rather than waiting for outsiders to come and solve the problem.

The Russian Red Cross Society is involved in HIV and TB work in certain parts of Russia. As with the Mongolian Red Cross Society, a large part of Russian Red Cross activities is aimed at reducing the transmission of HIV, through organizing information sessions in prisons and with former prisoners. It also helps to facilitate the follow-up of DOTS therapy and other health services when detainees are released back in the communities.
fewer partners than people in other countries who have engaged in serial monogamy. Epstein writes that such partnerships are now “widely acknowledged” as major drivers of the epidemic, and, she asks, if people had known this, would they have changed their sexual behaviour and would many lives have been saved?

Indeed, James D. Shelton of the Bureau for Global Health at the United States Agency for International Development (USAID) argues that “our priority must be on the key driver of generalized epidemics – concurrent partnerships” (Shelton, 2007). As he writes, this aspect of behaviour has been neglected for a number of reasons: “the culture wars between advocates of condoms and advocates of abstinence, because it smacks of moralizing, because mass behavioural change is alien to most medical professionals, and because of the competing priorities of HIV programmes”.

It is not just behaviour change that is needed. Women and children in particular are often powerless to negotiate safer sex, let alone say “no”. Sex is something to trade when you have nothing else to bargain with. As Annacius Duportal, a worker in a Haitian drop-in centre for HIV-positive women, explained: “For the poor, the whole notion of sexuality is difficult; it’s not a matter of identity as we see it in a modern, affluent Western society. Rather, in poor societies sexuality is something you use to find shelter, food and safety. It has a use; it has a value” (Renton, 2007).

Thus poverty may increase someone’s vulnerability to HIV but HIV is not a classic disease of poverty. It is too simplistic to say poverty is a driver of the epidemics. The most affected countries are among the world’s poorest nations but HIV affects all social classes within those countries. Recent evidence clearly indicates that AIDS is a disease of inequality, often associated with economic transition, rather than a disease of poverty itself (Piot et al., 2007). Moreover, in some countries (such as Zimbabwe) HIV has declined without major improvements in poverty and discrimination (“notwithstanding substantial economic and social distress”) (Shelton, 2007).

**Conclusion**

Responding to HIV and AIDS is probably one of the greatest challenges faced by the humanitarian, religious and political worlds. Epidemics vary from country to country, and responses must vary accordingly and be tailored to the reality of the epidemic. Social and legal changes are needed, as well as targeting and empowering the right people, if prevention programmes are ever to be fully effective. Such changes would contribute to the fight against stigma and discrimination, which have crippled the response worldwide. As this report describes, myths abound about those ‘other’ people that spread HIV – refugees, migrants, people escaping from conflict and poverty. What is abundantly clear is not just the need for more effective and targeted prevention and treatment, but also the need for more committed political leadership to ensure a sustained response to the epidemic and eradicate stigma.
There are many lessons for the humanitarian community in this report but a significant one is to understand, and act on, the fact that the response to HIV requires a longer-term reaction than the usual response to emergencies. There are no short-term solutions to underlying causes of vulnerability such as discrimination against marginalized groups and gender inequality, although more than 25 years since the first cases of AIDS, so much more could have been done. On a more positive note, responding to HIV is an opportunity to strengthen those aspects of humanitarian work that build resilience and empower communities rather than merely to provide assistance when disaster has overwhelmed their capacity to cope.

Chapter 1 was written by Lindsay Knight, Editor of the World Disasters Report 2008, and a writer on HIV, health and social issues. She also developed Boxes 1.1 and 1.4. Box 1.2 was written by Jo Wells, Emergency Co-ordinator – Policy, HelpAge International. Box 1.3 was written by Simon Moore, Head of Communications, International HIV/AIDS Alliance. Box 1.5 was written by Jennifer Haselgård-Rowe, Officer, Health and Prisons, International Federation.

Sources and further information


