The humanitarian interface: using the HIV lens

The word 'interface' usually conjures up the image of a human interacting with a machine. In disaster management and responses to complex emergencies, however, the reality is one of many interfaces: e.g., those between humans, administrative systems, governmental and non-governmental organizations (NGOs), and a variety of local, national and international actors.

Relationships between and within these different groups are complicated by the unique nature of each disaster, the conditions and magnitude of which are always different. Is the event accompanied by mass migration? Are road access and communications heavily compromised? What was the state of the medical, security and administrative systems when the disaster began?

Affected populations have different levels of resilience, and local or national governments have varying capacities to respond – as well as willingness to ask for help. Moreover, different responding organizations arrive with very different skill sets, resource levels and various and often contradictory political or ideological agendas.

In the past two decades, HIV has thrown a number of perplexing factors into the complex mix and relations between disaster and development. Some of these factors can be addressed by relatively straightforward adjustments that responders have always had to make in the field when conditions change and needs become clear. For example, the importance of nutrition in maintaining the health of HIV-positive people requires a re-thinking of ration sizes and types of food when providing emergency food aid in situations with high numbers of people living with HIV (PLHIV) (Harvey, 2004a).

Beyond such operational questions, however, the impact of the epidemic on entire societies in sub-Saharan Africa has resulted in more fundamental reflections on disaster responses. For example, a recent analysis of responses to the epidemic in Swaziland argued that with the advent of HIV, disasters should no longer be viewed as linear – with a discrete beginning, middle and end – but as long-term events requiring a different paradigm for responses:

> "Traditional humanitarian thinking focuses on the short-term, and is often aimed at returning affected populations to 'normality'. HIV/AIDS in Swaziland has been characterized by a slow onset of

Photo opposite page: The US navy delivers bottled water to the Nicaraguan village of Krukira, after it was hit by Hurricane Felix in 2007. Krukira is one of the locations where a Netherlands Red Cross project is integrating climate change impacts into Nicaraguan Red Cross disaster preparedness efforts.

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impacts that have failed to command an emergency response. With insufficient resource allocation and a lack of capacity, slow onset events can become emergencies. This characterisation is supported by the lack of an agreed definition of a 'disaster' or an 'emergency'. The nature of these terms is changing. The case of Swaziland emphasizes that emergencies can be long-term, complex, widespread events that evolve over years."

(Whiteside and Whalley, 2007)

The humanitarian organizations: taking HIV on board

The humanitarian organizations involved in disaster response do not always share common interests and approaches. There is a wide range of groups and structures involved in one or more aspects of humanitarian work. These include the agencies of the United Nations (UN); governmental ministries or agencies; international, national and local NGOs; faith-based organizations; foundations and bilateral donors; and a wide variety of contractors run on business or non-profit models.

These entities have different opinions about what is a continuum, with disaster relief-oriented organizations at one end (i.e., those concerned with responding to specific, acute and random events) and development-oriented organizations at the other (those focused with longer-term objectives of reinforcing or building capacities in target societies). Some of the larger organizations cover both ends of the continuum, recognizing that some aspects of relief and development are very much interrelated.

As well as having different mandates and interests, organizations also have highly varied levels of expertise. This is particularly true in relation to HIV. Some organizations have made great efforts to integrate HIV in their operations, while others have little knowledge or experience to rely on when dealing with emergencies in which HIV is a significant factor.

Oxfam has reflected carefully on how best to integrate HIV and AIDS in its operations; a recent manual is called *Humanitarian Programmes and HIV and AIDS: A Practical Approach to Mainstreaming* (Walden et al., 2007) (see Box 3.1). The manual proposes that an 'HIV lens' should be used in all stages of the programme cycle, but also states that basic data on HIV prevalence are an essential input to decision-making. The conceptual approach used by Oxfam is taken from a previous document, published jointly with ActionAid and Save the Children UK, which makes the following distinctions between specific programming, on the one hand, and mainstreaming approaches on the other:

■ The term HIV and AIDS programming refers to HIV prevention and treatment, care and support for PLHIV, or HIV and AIDS-focused interventions that are

integrated within broader health and related programming. The goal of HIV and AIDS programming relates specifically to HIV and AIDS.

■ The term 'mainstreaming' HIV and AIDS refers to "adapting development and humanitarian programmes to ensure they address the underlying causes of vulnerability to HIV infection and the consequences of HIV/AIDS". The focus of such programmes, however, remains the original goal (in the case of Oxfam providing water, sanitation and hygiene promotion as well as livelihoods, for example) (Holden, 2004).

Box 3.1 Mainstreaming HIV and AIDS: the Oxfam experience

What impact will our programme have on the HIV and AIDS scenario in the communities with which we work, and how can HIV and AIDS affect our programme? Answers to these two basic questions help Oxfam to mainstream HIV and AIDS into all aspects of their humanitarian work.

One recent incident illustrates how simple and yet effective mainstreaming HIV can be. Last year Oxfam was working in two regions of eastern Uganda that were badly affected by floods. These are also regions with high HIV prevalence. Oxfam workers found that people were in urgent need of jerrycans for collecting water. In discussion with the community, they also discovered that there had been problems in the past with an initiative when the government had distributed free jerrycans to people living with HIV. The problem was the colour: the free ones were white and those sold in the shops were yellow. This meant that a person using a white jerrycan was identifiable as someone infected or affected by HIV, and this reinforced stigma.

In planning their humanitarian response, Oxfam staff discussed the issue and decided that the solution was to distribute white jerrycans to everyone, in the hope that it would break down the stigma.

So far 60,000 white jerrycans have been distributed. One of the beneficiaries told Oxfam: "I am extremely thankful as I can now carry my jerrycan to the communal water point. Previously I could not bring them outside my house even while cleaning them. I had always thought that the white jerrycans had been specially designed for people living with HIV and AIDS." This is a good illustration of the importance of mainstreaming HIV. "It shows how things can go horribly wrong if one doesn't take care," says Oxfam adviser Jesee Kinyangui. "It was such a simple solution. People really appreciate that."

This example shows that having good information about HIV is essential for mainstreaming. This means hard data, such as HIV prevalence, as well as understanding the community's experience, their attitudes and values.

Mainstreaming HIV has become a way of life for Oxfam, and examples can be found in many programmes. In camps for internally displaced people in northern Uganda, water and sanitation programmes have been adapted for families affected by HIV. Water pumps that are easy to use have been installed for families headed by a child and those weakened by illness. The community has also agreed that families with chronically ill members do not have to

pay for water. Housing programmes in the area have also been adapted to reduce girls' vulnerability to rape and HIV. Oxfam and other NGOs have ensured that single-sex housing shelters with well-lit latrines are provided for girls who seek shelter overnight.

There are many examples where mainstreaming has ensured that the emergency response does not exacerbate vulnerability to HIV. For example, during the Zambia food emergency, Oxfam was bringing in food from distant suppliers by truck, and this meant that the drivers had to sleep in guest houses overnight. Oxfam provided condoms and information about HIV and the drivers themselves became distributors and educators.

In Zimbabwe, Oxfam works with other NGOs to assist vulnerable and displaced people in urban communities in a programme that prioritizes families affected by HIV. Here, food baskets are provided through a system of food vouchers that targets the most vulnerable. Toendepi Masodzi is a beneficiary of this programme. An HIV-positive artist, Masodzi used to make a living by selling the metal bird sculptures that were so popular in the gardens of Zimbabwean farmers. After the land invasions, his market dwindled and he found it increasingly difficult to feed his family. His own health suffered. Since receiving the food basket, which contains peanut butter and beans, his health has improved.

The programme also helps people living with HIV to meet their extra nutritional needs by planting 'low-output' gardens. These include a variety of vegetables that require less labour and fewer agricultural inputs than the crops usually grown. People are also encouraged to grow herbs with known benefits for opportunistic diseases of HIV. These gardens are also suited to the physical abilities of older people, many of whom are car-

ing for orphaned grandchildren. One such person is Mbuya Sabawu, a 67-year-old grandmother who must feed 11 grandchildren. "In the past," she said "we never used to grow so many vegetables. Now if we get hungry we can go into the garden and find enough to prepare a meal."

The experience of this programme showed that many people could not afford the very basic items needed for the care of their sick family members. The programme was then adapted to supply 'primary caregiver kits' along with the food baskets. These contain items like soap, cotton wool, antiseptic, bandages, vitamins and iron tablets. The kits are replenished monthly and people are given training in home-based care. One beneficiary, 68-year-old Gogo Sibanda, was found caring for two chronically ill family members in their 30s. "My son, I did not know all this you are teaching us," she told the programme officer, "especially the fact that one can get the disease through nursing the sick if no proper care is taken."

For Oxfam, mainstreaming begins at home. That is because Oxfam staffers working in high-prevalence areas are often as vulnerable to HIV as the beneficiaries of their programmes. This applies as much to international workers as to locals. "When staff members speak, you realize they have something in common with displaced people," says Oxfam's health team coordinator, Marion O'Reilly. "They talk about what it feels like to be struggling without networks and families. It is well known that aid workers can be a risk to communities and to themselves."

Oxfam has long been committed to ensuring that HIV is mainstreamed into their own management practices, for example by considering whether staff members need time to care for sick relatives or attend funerals. Inter-

nal mainstreaming, as it is known, involves ensuring that policy and practice reduce the organization's own vulnerability to HIV. It may result in HIV and AIDS workplace policies, or awareness-raising work with new staff on HIV prevention or treatment needs. Some country offices choose one person to be the HIV focal point for staff welfare. His or her job includes ensuring that condoms are available at the office and that staff members know where they can find local HIV services. The focal point must also brief new staff members about HIV mainstreaming and what it entails. This practice of internal mainstreaming provides a solid basis for mainstreaming HIV into all development and humanitarian work. ∎

Some of the UN agencies with particular responsibilities for disaster response have long been active in attempting to mainstream HIV in their operations. For example, the Food and Agriculture Organization (FAO), along with its related agency the World Food Programme (WFP), has for many years formally included policies to "integrate an AIDS dimension in its emergency assistance... This is first and foremost relevant for rural areas in sub-Saharan Africa, where there are frequent emergencies, and where rural livelihood vulnerability merges with high HIV prevalence" (FAO, 2001). The FAO worked systematically to find the cost-effective measures to achieve this integration, with considerable internal discussion about both its comparative advantages (vis-à-vis other organizations) and its mandated mission. Several organizational focuses for building or increasing internal expertise have emerged; these include rural reconstruction, HIV as a factor in rural women's vulnerabilities in disasters (as well as their capacities to respond to the epidemic) and nutritional aspects of care for PLHIV. For its part, the Office of the United Nations High Commissioner for Refugees (UNHCR) has included HIV in its strategic planning for several years now, regularly producing documents like *UNHCR's strategic plan for HIV/AIDS and refugees, 2002-2004* (UNHCR, 2004).

Government organizations, too, have increasingly accepted the importance of mainstreaming HIV in all their operations, including those specifically related to disasters. The Deutsche Gesellschaft für Technische Zusammenarbeit (GTZ, or German Technical Cooperation) has been doing so for more than a decade. The GTZ strategy has both internal and external focuses: the internal one aims to provide a comprehensive HIV workplace programme for all staff around the world, while the external focus makes it a priority for GTZ country teams in sub-Saharan Africa to engage with all opportunities to respond to HIV and AIDS in their work (Adams, 2007). These opportunities may arise, for example, through GTZ teams' ongoing relationship with the UN Development Programme (UNDP), the UN system's HIV/AIDS Theme Groups and the national structures of the Global Fund to Fight AIDS, Tuberculosis and Malaria.

Some major NGOs have recognized and dealt successfully with the difficulties of integrating HIV considerations into established ways of working. The International

Federation of Red Cross and Red Crescent Societies (International Federation) began a process in 2000 to engage with HIV issues in a more comprehensive manner by instituting a Global HIV Programme. One of the initiatives undertaken within this process was to set up a partnership with the Global Network of People living with HIV/AIDS (GNP+). The initiative had a somewhat rocky start, in part because it challenged internal culture and established ways of working, but also because of worries about how National Societies might react (Knight, 2003). However, the two partners persevered, and the partnership has become a close one. A 2005 report noted that:

> "…after 4 years of implementing the Federation's renewed Global HIV/AIDS Programme, National Society HIV/AIDS work is growing from strength to strength. It is evident that National Societies are engaging with the Federation's Global Programme three-pillar structure as a foundation and see stigma and discrimination reduction as a crucial pre-requisite for an effective HIV/AIDS response.
>
> Increasingly National Societies realise the importance of the principle of greater involvement of people living with HIV/AIDS (GIPA) in HIV/AIDS and stigma reduction work and 2004 has seen a significant interest in partnerships with people living with HIV/AIDS (PLWHA). Many National Societies who 4 years ago could not envision working with or employing PLWHA are starting to talk about engaging PLWHA and several even employed PLWHA in their National Society during 2004."
>
> (International Federation, 2005)

Box 3.2 The Red Cross Red Crescent Global Alliance on HIV: "Rising to the challenge"

The International Federation has the world's largest voluntary network with millions of members and volunteers among 186 National Red Cross Red Crescent Societies living in communities in every corner of the globe. Mobilizing the power of this humanity to make the difference is at the heart of the International Federation's approach to HIV.

In 2006 the Red Cross Red Crescent Global Alliance on HIV was formed to boost in-country HIV programming, in support of national HIV and AIDS programmes, to reduce vulnerability to HIV and its impact. The

Global Alliance is about scaling up to do more and better through strengthening and making better use of the combined capabilities of the Red Cross Red Crescent Movement. It also brings in regional networks and other funding and operating partners, to support community-level action. The HIV Global Alliance methodology is based on:

- simplifying what is done
- harmonizing how it is done
- scaling up what can be done well.

The HIV Global Alliance aims by 2010 to double Red Cross Red Crescent programming

International Federation
of Red Cross and Red Crescent Societies

in targeted communities. This means dealing with 10–20 per cent of client load in some countries. This is being done through three programmatic outputs:

- **Preventing further HIV infection** by focusing on: peer education, community mobilization; information, education and communication (IEC) for targeted vulnerable groups; voluntary counselling and testing (VCT); preventing mother-to-child transmission (PMTCT); and promoting skills for personal protection, including condom use.
- **Expanding HIV care, treatment and support** by focusing on: assisting children and orphans made vulnerable by HIV; providing treatment, support and care (home- or community-based and through health institutions) for PLHIV; and providing livelihood and food support for the most vulnerable.
- **Reducing HIV stigma and discrimination** by focusing on developing community support groups and networks of PLHIV, and partnerships with PLHIV organizations; ensuring that HIV in workplace policy and programmes for all staff and volunteers are in place in National Societies; tackling gender inequalities and sexual and gender-based violence; and peer education, community mobilization and population-based IEC.

These are bolstered by a fourth enabling output:

- **Strengthening National Red Cross Red Crescent Societies** capacities to deliver and sustain scaled-up HIV programmes by focusing on improving governance, accountability and leadership of National Societies for discharging planned commitments; improving volunteer and staff support and management; strengthening programme cycle management; and widening partnerships and expanding resource mobilization.

The HIV Global Alliance's programming principles are that interventions must:

- **Be evidence-based** – informed by locally prevalent patterns of HIV risk, vulnerability and impact, and driven by a demonstrable understanding of what is effective in a particular context.
- **Be mainstreamed**, wherever feasible – not only within structures and programmes of the Red Cross Red Crescent, but importantly, they should be integrated into and seek to strengthen community and institutional systems for health, education, social care and livelihood promotion. Thus HIV activities should be carried out jointly with maternal and reproductive health, tuberculosis, safe blood and other related interventions.
- **Seek out the most vulnerable and build resilience** by prioritizing reaching and empowering the people that are most in need. Particular emphasis is on involving PLHIV and their families. Crucially, in the face of an increasingly feminized epidemic, addressing gender inequalities – and sexual and gender-based violence – is also a priority feature.

The comparative advantage of the Red Cross Red Crescent is the capacity to undertake direct action at community and family level while also having access to policy-makers and building sustainable systems for service delivery. A strong emphasis is placed on tracking results with the aim of doubling outreach to at least 137 million beneficiaries worldwide by 2010. ■

The 2005 General Assembly of the Red Cross Red Crescent resolved to make HIV a corporate priority within its Global Agenda. A high-level position of Special Representative was created and, on World AIDS Day, 1 December 2006, the International Federation launched its Global Alliance on HIV (Box 3.2) aimed at doubling its programming by 2010. The majority of National Red Cross Red Crescent Societies around the world are scaling up HIV programmes covering prevention, treatment, care and support, and countering stigma and discrimination (see Boxes 3.3 and 3.5).

Box 3.3 Russian Red Cross support for HIV-positive women in Siberia

Over the past decade, the Russian Federation has experienced one of the fastest-growing HIV epidemics in the world. In 2007, UNAIDS estimated that approximately 1 million Russian adults (aged 15 to 49) were living with HIV. Injecting drug use remains the main mode of HIV transmission in the Russian Federation, although HIV is also transmitted by increasing numbers of male injecting drug users (IDUs) to their sexual partners.

The East Siberian region of Irkutsk has the fourth highest caseload of HIV in the Russian Federation.

Fuelled by needle sharing among IDUs, the HIV epidemic expanded fast in Irkutsk. Only two cases of HIV had been reported in 1998; a year later, 2,631 cases had been reported.

Currently, there are 21,500 registered HIV cases in Irkutsk. The pattern of the epidemic is also rapidly changing, with sexually transmitted HIV cases making up a growing share of new diagnoses, and over 40 per cent of new HIV cases found among women, particularly among young women (aged 19 to 25). Another alarming trend has been the rising number of children born to HIV-positive mothers, and the growing risks of mother-to-child transmission (MTCT) of HIV.

When the Irkutsk branch of The Russian Red Cross Society began working on HIV in Irkutsk City in 1999, few non-governmental or civil society organizations were active in the response, the local government refused to acknowledge that HIV was a problem, limited health services or anti-retroviral drugs were available for PLHIV, funding for HIV and AIDS was negligible, and there was virtually no public discussion about the epidemic. Since then, the climate has changed, largely due to the persistent efforts of members of the Irkutsk branch, and their demonstration that high-quality care and support services can be provided and can make a difference.

The foundation for the Irkutsk branch's HIV and AIDS programmes was built on existing community outreach, care and support services that targeted the most vulnerable populations in Irkutsk. For the first two years, HIV interventions focused on basic IEC campaigns and peer-to-peer outreach, especially with IDUs. As the HIV epidemic matured and the problems confronted by community members became more complex, the Irkutsk branch, under the direction of Anna Zagainova, at the time Director of The Russian Red Cross Society's Eastern Siberian Zone, actively sought collaboration and partnerships with the Ministry of Health and other ministries, the Federal AIDS Centre, healthcare workers and state agencies concerned with social issues of its

citizens. The dedicated staff at the Irkutsk branch went out of their way to learn from doctors, epidemiologists and other health experts who were tasked with monitoring the health status of the HIV-positive population in Irkutsk.

However, it was not until February 2003, with grants from the Anne Ray Charitable Trust and in partnership with the American Red Cross, that the Irkutsk branch was able to design and implement comprehensive community-based care and support programmes aimed at expanding access to HIV-positive pregnant women and new mothers to interventions to prevent MTCT, and to provide care and support to people living with HIV.

The Irkutsk branch's care and support initiative integrates PMTCT into family-focused care through a visiting nurse programme; provides high-quality and free psychological and social counselling through trained social workers, lawyers, peer support groups and hotlines; supports treatment protocols for HIV-positive pregnant women in coordination with the Federal AIDS Centre and other healthcare providers, and develops training materials and curricula for caregivers of PLHIV and children of HIV-positive mothers, and healthcare professionals. Through the project, the Irkutsk branch has, since 2003, provided psychological, legal and social assistance and PMTCT support to more than 18,000 people affected by HIV and AIDS in Irkutsk City.

One of the unique aspects of the care and support programme are services offered by visiting nurses who make home visits to children born to HIV-positive women. As part of the visit, nurses assess a child's health, development and living conditions, counsel the mother and provide food parcels and vitamins. Any problems in a child's physical and/or psychological development are tracked, and referrals to the Irkutsk branch counselling or medical services are made. Providing these services has required implementing and promoting a referral system among the regional AIDS Centre, other government agencies and NGOs, and medical and social services in Irktusk. During 2006, the Irkutsk branch visiting nurses made 2,320 home visits to children under the age of 2, and 373 children and 52 pregnant women received food parcels and nutritional supplements on a monthly basis that same year.

The care and support services provided have evolved over time, based on the suggestions of clients, medical providers and others working in HIV programmes. The Irkutsk branch learned early on that PLHIV were a critical group to partner with; as such, they are both primary clients and primary actors in their programmes. A significant number of the branch's paid staff and volunteer workforce are openly HIV positive and have a keen interest in making a difference in their community.

The stigma and discrimination associated with HIV and AIDS still present a major hurdle for all programmes that focus on prevention, treatment or care of people living with HIV in Irkutsk. HIV-positive women seeking care for themselves and their children continue to feel stigma from health workers, relatives and friends, but the situation is improving.

Eugenia, who became HIV positive after a sexual encounter with a boyfriend at the age of 19, is pregnant and works as a peer counsellor at the Irkutsk branch, where she met her husband, who is also HIV positive and works at the same branch.

Both talk openly about the harsh treatment they continue to face in the healthcare system, but they find refuge and purpose in the supportive environment of the branch, and Eugenia is thriving under the care of the

professional staff there. "I worry every day about delivering a healthy baby, but with the support I receive from the branch counsellors and the infectious disease doctor, I am able to maintain a level of optimism that all will be well!"

Another client was equally enthusiastic about the services: "If I had not visited the Irkutsk branch, I would have probably had an abortion. No one at the local polyclinic told me that an HIV-positive person could give birth to a healthy child. Now I am very happy that I have had a baby and I am also proud of that."

The Irkutsk branch is now focusing on developing the capacity of other Russian Red Cross branches to design, implement and monitor their own HIV prevention, care and support programmes, in partnership with the American Red Cross, and with funding from the Anne Ray Charitable Trust. ∎

Unlike organizations with a broad humanitarian 'portfolio', many NGOs have a mandate or organizational ethos that is tightly focused on specific aspects of disasters. Médecins sans Frontières (MSF) is one of the best-known of the organizations that provides 'front-line' medical services in disaster situations. Since MSF designs its services to include care of all common major health problems, HIV programming is a solid part of those services. For over a decade, the organization has built up substantial expertise in treating PLHIV, and has pioneered the provision of anti-retroviral treatment (ART) in difficult situations. However, MSF is careful to dismiss expectations that it will initiate large-scale programmes, stating firmly: "The responsibility for scaling up comprehensive HIV/AIDS treatment programmes rests with governments which have a responsibility to provide adequate health care to their people" (Calmy, 2004).

Other NGOs such as the International HIV/AIDS Alliance very much focus on working with community-based organizations; their work includes support programmes for ART provision (see Box 3.4).

Faith-based organizations, too, have been involved in HIV responses for as long as the epidemic has been apparent, particularly in clinical and community-based care services. Faith-based organizations differ widely, ranging from small groups with a single programmatic focus to fully-fledged international organizations responsible for dozens of projects. In recent years, some have become more politically outspoken, taking on a role as advocates for development policy changes in areas that relate to HIV. One of these is the UK-based Tearfund, a Christian organization that currently works in 70 countries. Of Tearfund's 450 partner organizations around the world, about 120 are working on HIV-related activities. Within the UK, it has actively lobbied the responsible government ministry, the Department for International Development (DFID), to increase funding to local-level AIDS initiatives, whether Christian or not (Tearfund, 2004).

Box 3.4 Positive partnerships for treatment support in Zambia

The Zambian government's national implementation plan for scaling up ART states: "Communities can make major contributions to ARV [anti-retroviral] treatment programmes." Thus one of the key principles of the government's plan to scale up ART effectively is to promote partnerships between government, private sector, civil society and communities.

The International HIV/AIDS Alliance's Antiretroviral Treatment Community Education and Referral (ACER) project in Zambia is providing an important example of an effective community-driven and -led ART programme. The overall aim of the ACER project is to improve health-seeking behaviour, prevention, equity of access and adherence to ART for people living with HIV. It does this through community education and referral, with the participation of PLHIV and other community stakeholders.

The ACER project links existing community organizations and support networks – traditional healers, home carers, positive people's groups and church groups – with government health services. The project employs people openly living with HIV to promote uptake of treatment, to support treatment adherence and to promote prevention efforts in community and clinic settings.

A key feature of the project is the two-way referral system between community support services and healthcare providers, developed around the concept of a treatment journey. Following training on ART and on HIV prevention, the communities involved enable the project to address gaps in the care and support of PLHIV. Developing a referral system recognized by and appropriate for the community has resulted in excellent cooperation

between traditional healers, positive people's networks, home-based care providers, healthcare workers and other community support providers, as they now understand each other's services better.

PLHIV have been very directly involved at all stages of the design and implementation of ACER. The positive people's support group system has been used by all organizations within ACER, enabling people to share information and personal experiences as part of the process of supporting one another. The support groups are an important strategy in promoting adherence through sharing and encouragement among positive people, in addition to providing them with a collective voice.

As well as referring people to appropriate services, ACER partners have also provided treatment literacy education to the community; this has reduced stigma among people on treatment, their families and communities.

The ACER project's community referral system has maximized community resources, has shortened and facilitated the treatment journey, and provides continuity of HIV and ART support within the community.

The ACER project currently employs four treatment support workers and two treatment mobilizers. All have been living openly with HIV for a number of years. The treatment support workers help people visiting the clinics by listening and offering advice on issues related to ART. They have strong relationships with community organizations and health services, to which they refer clients for further care, support and prevention. The treatment mobilizers' work involves raising awareness of HIV and ARV treatment, increasing treatment literacy and linking communities with the treatment

support workers in health clinics. They coordinate community education and referral activities, reaching over 80,000 people with intensive ongoing activities.

Eric Mweemba Nachibanga is one of the treatment support workers in the ACER project. Eric grew up in the copper belt of Zambia, in a town called Ndola, but currently lives in Lusaka, the capital city.

In 1992 he tested HIV positive and for a while he lived in denial of his status and led a double life. "Then I decided to come out of my shell, and went down to a local clinic to talk about my HIV status," he says.

He came into contact with the Zambian Network of People Living with HIV (ZNPLH) which, along with his local clinic, helped him to answer lots of questions about how to continue living with HIV. This ignited his 'activist spirit' and before long he was speaking publicly, encouraging others to talk openly about their HIV status.

"Through my volunteer work with ZNPLH I worked alongside other NGOs and HIV programmes. This work led to my involvement with the International HIV/AIDS Alliance as a local consultant at first and later to my current role within the ACER treatment support programme.

"My week is split into two. I spend Mondays, Wednesdays and Fridays at the clinic in University Teaching hospital in Lusaka, the rest of the time I can be found at the Ngombe Urban health clinic. This approach is used so that as many people in the urban and the rural locations can easily gain access to the treatment that is available.

"I usually have two or three counselling sessions in the mornings. The questions can be wide-ranging from 'Can I still have sex with my partner?' to 'Do I have to take drugs straight away?' In Zambia there is a lot of confusion about drug treatment. People don't realize that if they have a good diet and look after themselves they will not need the ART straight away.

"In the afternoons we focus on our outreach work with local faith and community leaders. We try to dispel some of the very dangerous myths that surround HIV and AIDS. We recently had to work on dispelling the myth that you are able to cleanse yourself of the virus by sleeping with a virgin. Through our work with the community leaders we hope to help people to come forward for testing and treatment without worrying about the alienation that they fear.

"One particular day, I attended to two clients. The first was a 30-year-old woman, divorced due to her status and illness. She has a sick 1½-year-old baby and two other children. This is what she had to share with me on stigma from the family: 'I'm facing a great burden of problems with my mother. I feel my mother has been treating me like I am not her daughter. I feel this could lead me to death as I can see it coming. I am responding well to the treatment I am taking – I am on Triomune 30 – but the problem is with my mother who blames me from time to time. Mother's actions will lead me to taking my own life and child's life. She treats me like a doormat where everyone leaves the dirt from the shoes. My father is very supportive to me and my children. I did not want to get this HIV. I didn't parade myself before men other than the man of her choice, who I got married to and later divorced because of the illness he brought into the house. This man has made me suffer this stigma from my own family. I am given food and separate dishes with my youngest child away from the rest of the family on marked dishes and utensils. I feel like exploding inside myself from the stigma I suffer. If only I could have

someone like you to talk to my family, especially my mother. I see my days to be numbered. Please help me before it is too late.'

"I was very touched by this revelation. I made a follow-up visit and shared with the family information on how to support her and on modes of HIV transmission. Today, my client has been accepted by the family with apologies from the mother. On the same day, another client shared this about her treatment journey: 'These drugs are really working wonders. Some of us had come to the brink of death, facing bouts of severe diarrhoea and vomiting before ART. I used to soil my pants with loose watery stool before I could even reach the toilet. I did not have strength to spread my bed nor bath myself. But today things have changed for the better. My stomach used to protrude like an anthill and I did not want to eat at all. I used to have a pretty face, but despite being young I started looking like an old woman or a monkey. As you look at yourself in the mirror while naked, you can easily get scared of yourself and start thinking "What next?" I weighed as little as a chicken. This morning I can boast that I am weighing more than 40kg from a weight of 27kg. I know God is a miracle performer. For this reason, I have a duty to help those who are in denial to accept their status and encourage others to go for voluntary counselling and testing.'

"These people are now living happily, leading positive lives with support from family members," concludes Eric. "They have also become active members of the treatment support group and the ZNPLH Lusaka chapter."

While maintaining adequate funding is perhaps the biggest ongoing challenge for the ACER project, the success of the treatment support workers has itself brought about another challenge. Over time, appreciative and overworked medical staff in the clinics have become quite dependent on the work of the treatment support workers, who have been willing to take on extra duties such as supervising trainee counsellors and keeping counselling registers up to date. In the long term, it will be necessary to see how counselling services from non-nursing staff can become an integrated part of clinics' ART services without depending on ACER. It is also important to make sure that the potential pressure and stress arising from this dependency does not undermine the health of the treatment support workers, as they themselves are living with HIV.

A wider challenge for the project is the hidden cost of ART which continues to hinder access. While the government has now made ART free, thanks to advocacy work by the Alliance and others, many of the tests necessary for the continuation of treatment are not free. For people living in rural areas, who have to travel long distances to reach their nearest clinic, transport costs can still be very high. The ACER programme has collaborated with community advocacy initiatives to pressure the government into covering all the costs of treatment, but this is not yet a reality. ∎

Donor organizations, too, are also taking HIV very seriously, and not just in the high-prevalence countries. For example, the Bill & Melinda Gates Foundation is currently working closely with the Chinese government, the International Federation and both the Red Cross Society of China and the American Red Cross on implementing a long-term programme of prevention activities in large cities, targeting

high-risk groups, particularly men who have sex with men (MSM) (International Federation, 2007). As a strategy, the Foundation will work not only with the Chinese authorities but also with a number of local organizations which have proven outreach capacities. These will be provided with small capacity-building grants, which may lead to larger, more long-term funding for HIV prevention programmes. This initiative comes at the same time as the International Federation has been scaling up its own collaboration with the Red Cross Society of China, moving from relief to recovery activities (specifically on the construction of houses that have been destroyed by the floods and typhoons) and on improving disaster preparedness.

Box 3.5 Responding to the HIV and AIDS emergency in Iran

There were no HIV and AIDS cases reported in the Islamic Republic of Iran until 1987 when Ali, a 6-year-old boy from a poor family, was diagnosed as HIV positive. His doctors were very surprised because they believed Iran had a very low risk of HIV prevalence. But Ali suffered from haemophilia and had needed a blood transfusion. After thorough investigations, the doctors found that the blood used for the transfusion, imported from abroad and untested for HIV, had caused the infection. Another 60 people were also infected with HIV, most of them children under the age of 15.

Over the years Iran has witnessed a sharp rise in HIV prevalence, especially among IDUs and young people. It is currently estimated that there are 270,000 IDUs in Iran.

According to September 2007's statistics from the Iranian Ministry of Heath, the total number of HIV-positive people (both registered and unregistered) is estimated at 60,000–70,000 in the country. Men accounted for 94.4 per cent and women 5.6 per cent of the total number of cases reported from 1986 to 2006.

The Ministry of Health and the World Health Organization consider Iran to be now in a concentrated epidemic stage since the normal population prevalence rate is less than 0.1 per cent and the high risk prevalence rate (among key groups) is more than 5 per cent.

Like many countries in the Middle East and North Africa region, the level of HIV infection among prisoners is significantly higher than among the general population. In its December 2005 *Epidemic Update*, UNAIDS cited incarceration as the biggest risk factor for HIV infection in Iran and other countries in the region. A sharp increase of HIV infection among IDUs has been reported in a number of prisons in recent years. The wives of prisoners are also at risk of infection.

Leila, a 20-year-old woman who had been tested HIV positive at a VCT centre, told her story, weeping: "My husband has ruined my life and family and deprived me of my hope for the future." A few years ago her husband served a two-year jail sentence following a car accident. Leila became pregnant one year after his release from the prison. However, during her pregnancy test the doctors discovered that she was infected with HIV. After testing her husband and after further investigation, they discovered that he had been infected with HIV as a result of sharing syringes in the prison. Despite treatment during her pregnancy to prevent transmission, her baby was HIV positive.

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HIV infection is spreading among young people. Iran has a population of nearly 70 million, 50 per cent of whom are under the age of 25. Recent studies show that the mode of transmission is changing from IDUs to unsafe sexual behaviour because the general public, especially young people aged between 14 and 25, do not know about the risks of HIV transmission and methods of prevention. There is a lack of educational material and discussion about HIV in schools. Many people, as in other countries, are reluctant to seek treatment or counselling services for fear of stigma and discrimination.

The Iranian government and the Red Crescent Society of the Islamic Republic of Iran (IRCS) regard the current HIV situation in the country as an emergency because it could reach the dangerous level of generalized epidemic if the right measures on prevention and treatment are not taken.

The IRCS formed a 'committee of the campaign against behavioural disorder', which is responsible for policy-making, planning and directing the society's HIV and AIDS-related activities and which aims to increase their impact. In the light of its mandate and specific roles in the country, the Iranian Red Crescent is focusing its activities on four areas in the fight against the spread of HIV and AIDS. It provides IEC to young people, volunteers and the general public and has arranged for its trainers from 30 provincial branches to be trained by specialized university professors. The trainers then return to their local branches and teach target groups of vulnerable people. Some 2.2 million people have been trained so far.

The Iranian Red Crescent has established 32 VCT centres throughout the country, where it provides about 40,000 to 45,000 people with HIV counselling and testing services every year. If the test result is positive, the patients are referred for treatment and care to Ministry of Health clinics which deal with cases of HIV, sexually transmitted infections (STIs) and addiction and provide, free of charge, methadone maintenance therapy.

Through its VCT centres, the National Society has been involved in harm reduction by encouraging condom use and syringe exchange, and through the implementation of a joint harm reduction project in cooperation with other partners. The Italian Red Cross and the IRCS have agreed to set up and run three mobile units in Tehran as a pilot harm reduction project. Based on the experience and outcome of this pilot phase, both sides are expected to expand these activities to other parts of the country.

Meanwhile, with the support of the Empress Shôken Fund, the IRCS's women's affairs department is implementing a project aimed at helping the wives of HIV-positive men to have a better understanding of the ways and means of prevention and self-protection from HIV and AIDS infection.

A series of training workshops conducted as part of this project was welcomed by many women. Zahra, a 23-year-old woman who attended one of these workshops, said she learned very useful and important things there. "I felt huge relief when I came to know the ways and means of protection from HIV infection at the workshops," she said. "My husband has just been released from prison and stays at home with my family. Although we heard that he had been infected with HIV at the prison, we did not know how we have to protect ourselves from possible infection by him. Had there been no training by the IRCS, my three children and myself would have been infected with HIV."

As a lead agency in disaster response in the country, the IRCS also pays attention to HIV and AIDS intervention during emergencies. As disasters and complex emergencies increase the incidence of HIV infection, the Red Crescent trains the midwives and nurses who will provide disaster survivors with reproductive health services in the first hours after a disaster.

"HIV/AIDS has more complex implications than a health problem," said Dr Seyed Ahmad Mousavi, Under-Secretary General for Health, Treatment and Rehabilitation of the Red Crescent Society of the Islamic Republic of Iran. "Therefore, it is crucial that all parties concerned in the country make joint efforts and play their part to the full. We believe prevention is better than cure and the National Society has a clear role to play in this regard. With more than 2 million volunteers and a nationwide network of branches, the Red Crescent is in a better position than any other organization in the country to make a real difference in containing the spread of HIV/AIDS." ∎

Relief, development, HIV: competing or disconnected?

Over the years, the tasks associated with disaster responses have multiplied. Originally concerned with restoring what were considered 'basics' (in the first instance, food and shelter) and providing emergency healthcare, the mandate has extended to areas traditionally seen to be part of the 'development' agenda. The Inter-Agency Standing Committee (IASC) of the UN and non-humanitarian partners have delivered several sets of guidelines that cover some of these areas. In 1999, it issued guidelines on gender considerations in emergency responses, flagging several areas where gender-related rights needed additional attention in crisis situations, including access to healthcare of quality and participation of women in programme planning and decision-making (IASC, 1999). More recently, it published a guideline document on human rights and natural disasters (IASC, 2006).

HIV can thus be seen as one of these areas of concern that, having formerly been outside the traditional concerns of emergency responses, has now gained a much more visible profile, through both the 'push' of advocacy and the 'pull' of increased funding. All this has not happened without debate, some of it related to an ongoing controversy about whether HIV captures more than its fair share of healthcare resources, but rather more about the question of the time frames used to characterize terms like 'disaster' or 'emergency'. Paul Harvey, of the Overseas Development Institute, has eloquently described the problem. After noting that humanitarian (i.e., relief) aid must be understood as only part of a much larger international response to the impact of the HIV and AIDS pandemic, Harvey emphasizes the importance of recognizing that relief systems have limits to what they can accomplish:

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> "The overall response to HIV/AIDS needs to take place over decades, and requires a rethinking of relief modalities, development modalities and of the links between humanitarian aid and development… A response across entire countries and regions over a period of decades is obviously ill-suited to the ways in which humanitarian aid is currently delivered, based as it is on short-term time horizons and funding cycles. The core business of humanitarian relief should remain focused on saving lives and alleviating suffering in response to acute crises."
>
> (Harvey, 2004b)

Part of the problem, too, may stem from the policies and rhetoric of the UN system. The first UN guidelines on HIV in emergencies were published jointly by the World Health Organization, UNHCR and the newly created UNAIDS in 1996, and focused on how to prevent transmission of the virus. The guidelines went largely unimplemented for the rest of the decade, partly because of competing organizational priorities but also because of the low priority accorded to them by humanitarian organizations (IASC, 2007). Moreover, the focus of the guidelines was almost entirely medical, which put them out of step with the prevailing doctrine of 'multisectoral' responses rather than 'medicalized' ones.

The orientation changed, however, with the 2001 UN General Assembly Special Session on HIV/AIDS (UNGASS), which unanimously adopted a wide-ranging Declaration of Commitment on HIV/AIDS. Among other things, the Declaration called on *all* member states to create national emergency strategies incorporating "HIV/AIDS awareness, prevention, care and treatment elements" (UN, 2001). The reason, stated the Declaration, was the "populations destabilized by armed conflict, humanitarian emergencies and natural disasters, including refugees, internally displaced persons and in particular, women and children, are at increased risk of exposure to HIV infection" (UN, 2001). Such a statement, however stirring, is clearly not of any practical use to most member states. HIV and AIDS are not important health issues in *all* conflicts, emergencies or natural disasters, as other chapters in this report explain, and some countries would be wasting valuable resources if they observed the Declaration to the letter.

Neglect or rational prioritization?

UNAIDS, the UN programme mandated to "lead, strengthen and support an expanded response to HIV and AIDS" (UN, 2005), has identified a different source of controversy: the different orientations of three streams in the international structures created to provide assistance coordination and cooperation. The following acronym-laden paragraph also illustrates the challenges of coordinating the coordinators:

"[T]he development system has planning frameworks such as PRSPs, I-PRSPs, UNDAFs, and CCAs; the humanitarian system has CAPs and transitional recovery frameworks and appeals; and the HIV/AIDS system has the UBW [Unified Budget and Workplan] and the recently agreed GTT [Global Task Team] approach. All the systems seek internal coherence, coordination, and harmonization while some efforts have also been made on linkages among the systems. At the country level, the Resident/Humanitarian Coordinator system is mandated to provide the necessary linkages. At the same time, there are also UN Theme Groups for HIV/AIDS along with other coordination groups in countries where there is Global Fund programming (i.e. Country Coordinating Mechanisms). These multiple arrangements can be challenging to sustain effectively. The development, humanitarian and HIV/AIDS systems all have one shortcoming in common: beyond token acknowledgements, they largely neglect the HIV/AIDS-related needs of people of humanitarian concern…"

(UNAIDS, 2006)

This 'neglect' is apparent from a quick scan of some key international documents. For instance, the Hyogo Framework for Action – named after the Japanese city where the International Conference on Disaster Reduction was held in 2005 – is currently the world's 'blueprint' for disaster risk reduction (UNISDR, 2005).

Signed by 168 nations, it is an attempt to improve countries' preparedness for disasters, aiming to substantially reduce disaster losses by 2015 and (significantly) to bridge gaps between disaster management, risk reduction and sustainable human development. The 25-page *Framework* mentions HIV only once, at the end of a long list of "increasing vulnerabilities" (namely "changing demographic, technological and socio-economic conditions, unplanned urbanization, development within high-risk zones, under-development, environmental degradation, climate variability, climate change, geological hazards, competition for scarce resources, and the impact of epidemics such as HIV/AIDS") (UNISDR, 2005).

A similar sense of HIV's low overall priority in disaster management can be seen in statements by government bodies. For example, DFID's major policy statement *Saving lives, relieving suffering, protecting dignity: DFID's Humanitarian Policy* does not specifically mention HIV (except on the back cover, in relation to DFID's major areas of work). Instead, the document emphasizes that "humanitarian assistance must be balanced, and needs to address the variety of people's basic requirements, and be appropriate to their context" (DFID, 2006). It places considerable emphasis on the vulnerabilities of the poorest people, and in reducing such vulnerabilities, particularly through building social security systems.

Photo opposite page: An Iranian prisoner consults with a physician on drug use and AIDS at a clinic inside in a special ward of Qesel-Hesar prison about 480 kilometres west of Tehran.

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'Wheres' and 'whens'

Two of the key questions regarding the HIV-related responses needed in disasters are: where has the disaster occurred; and at what stage is the disaster? The first question is largely about HIV prevalence and the type of epidemic in the disaster area; the second is about what responses are appropriate and cost-effective at any given stage of the specific disaster.

Currently, it is only responses to crises occurring in sub-Saharan Africa, Central America and the Caribbean, and a few Asian countries that will have to deal with the high prevalence which characterized a 'generalized' epidemic. In other parts of the world, the epidemic is considered to be 'concentrated' when it occurs in less than 1 per cent of the general population but more than 5 per cent of any key population at higher risk such as injecting drug users (IDUs), MSM and sex workers – migrants and prisoners are also frequently included in the list (see Chapters 2 and 4). The challenges of providing treatment and prevention services are very different in these two types of epidemic. In a generalized epidemic, for example, coverage of prevention programming should be wide, targeting all age groups and both males and females. By contrast, coverage in a concentrated epidemic must be carefully targeted at the groups at greatest risk if it is to be cost-effective.

Moreover, from a fund-raising or public relations point of view – an important consideration in disaster relief – it is much easier to raise resources for a generalized epidemic affecting men, women and children than to do so for the marginalized populations in concentrated epidemics. Few politicians or donors will argue with appeals to fund ART for preventing mother-to-child transmission (PMTCT) of HIV, or home support for families affected by HIV and AIDS. In contrast, finding funds to work with IDUs or prevent HIV transmission among sex workers or MSMs is notoriously difficult (UNAIDS, 2004).

This is doubly true in emergencies – one need only imagine the difficulty of asking for money to establish a needle-and-syringe exchange for IDUs as part of an earthquake disaster appeal, or announcing an outreach programme for men who have sex with displaced men in *any* African setting.

The question of 'when' revolves around the stage of disaster. It is also a question about 'who' since different organizations have their own special expertise and priorities, and the responsibilities of host governments also come into play. (Note that the following apply most closely to disasters characterized by sudden crises; for conflict situations and slow-onset disasters, see Chapters 5 and 6 respectively.)

Acute stage. HIV is unfortunately not among the top priorities for humanitarian efforts in the early stages of any disaster. Nor are most of the early responders likely to send personnel with the specialized skills needed to deal with HIV and AIDS. However, some HIV-related interventions are certainly priorities, notably ensuring safe blood supplies (universal precautions and screening), and security for women and children. These should be maintained in the following stages. Where possible, HIV-positive people in need of anti-retrovirals should be identified and attempts made to supply medications if they are in danger of running out of them.

Post-emergency/stabilization phase. In a stage where humanitarian concerns are shifting towards re-establishing (and in some cases creating) health systems – and where prevalence justifies the effort on a cost-effectiveness basis – responders should be working on integrated HIV interventions within broad health concerns related to reproductive and sexual health (antenatal clinics, condoms, sexually transmitted diseases treatment) or tuberculosis (TB) control. They should also be setting up certain specialized HIV interventions, notably PMTCT services (babies keep coming, disaster or no disaster) and Post-Exposure Prophylaxis (PEP). Treatment should be restored to patients already on established anti-retroviral regimens bearing in mind the dangers of drug resistance if treatment is interrupted (Spiegel et al., 2005).

Long-term programming phase. In the long-term follow-up to a disaster, humanitarian organizations and both source and host governments often need to consider questions of repatriation or, if that is not possible in the forseeable future, local inte-

gration and resettlement. This is the stage at which the principle of mainstreaming is most applicable, since it is where the 'humanitarian' stream interfaces most fully with the 'development' stream, and where multisectoral collaboration with government HIV structures (and health systems more generally) are most likely to bear fruit.

The question of prescribing ART for those in need at this stage – in addition to the task of identifying not only who is HIV-positive but who would benefit from ART– begs a number of hard questions.

The UNHCR's recent *Antiretroviral Medication Policy for Refugees* outlines some of the issues that need to be taken into account for refugees (note that refugees are only part of the wider group that are of concern to humanitarian aid organizations):

> "The number of refugees needing ART is very small compared with the approximately 6.5 million persons worldwide who are estimated to need ART at present; of the 8.9 million refugees of concern to UNHCR, approximately 25,000-35,000 would currently need ART. Therefore, it would be much more efficient for host countries to provide ART to refugees through national health facilities, in conjunction with those organisations already working with refugees, than for another entity to do so on its own."
>
> (UNHCR, 2007)

On a case-by-case basis, UNHCR or NGOs that have earmarked funds for at least one year may decide to pay for long-term ART while continuing to advocate for the inclusion of refugees in the host country's ART programme. Paul Spiegel's essay 'HIV/AIDS among conflict-affected and displaced populations: dispelling myths and taking action' illustrates some of the specific challenges facing humanitarian organizations concerned with providing treatment to PLHIV by examining the similarities and differences in delivering TB treatment and ART (Spiegel, 2004). The latter tasks involve more complex diagnosis and patient follow-up; treatment is lifelong and more expensive.

In addition to health providers, other sectors such as agricultural extension, economic development and education may have useful roles to play providing HIV and AIDS-related programming to cover the long-term needs of affected populations. Community-based approaches, particularly those involving HIV-positive people and their representative organizations, are particularly recommended. Recognition of this can be seen, for example, in the conceptual work being carried out by UN Educational, Scientific and Cultural Organization (UNESCO) in collaboration with UNHCR (see their *Educational Responses to HIV and AIDS for Refugees and Internally Displaced Persons: Discussion Paper for Decision-Makers* (UNHCR and UNESCO, 2007), among others).

In search of consistency and balance

In recent years, much effort has been invested in systematizing practical knowledge about how to deal with HIV in disaster contexts, notably in the creation of codes and guidelines. In many cases, such codes and guidelines reflect a high degree of consensus as a result of the consultation processes that went into their creation.

One of the major advances in this regard was the 2004 revision of the *Sphere Humanitarian Charter and Minimum Standards in Disaster Relief* to include HIV prevention within responses in disasters. The 2004 revision added Standard 6 (HIV/AIDS) to the Health Services chapter within the rubric of controlling communicable diseases. It advised that people affected by disaster should have access to a "minimum package of services to prevent transmission of HIV/AIDS" and goes on to specify that during the post-emergency and rehabilitation phases "…more comprehensive surveillance, prevention, treatment, care and support services should be introduced" (Sphere Project, 2004).

The text stopped short of recommending the provision of ART in most post-disaster settings on the grounds of still-limited feasibility, but added that "this may change in the future as financial and other barriers to their use fall" (Sphere Project, 2004). (It is worth noting that one of the faith-based organizations which had participated in the Sphere Project since its beginning dissented from Standard 6 on the grounds that the minimum package included condom distribution. This illustrates one of the dangers, as well as the strengths, of consensus-based projects involving many participants.)

The Sphere Project was an important point of reference in the creation of *Renewing our Voice: Code of Good Practice for NGOs Responding to HIV/AIDS* (Cabassi and Wilson, 2004) (see Box 3.6). Like the Sphere Project, the NGO HIV/AIDS Code of Practice Project was a joint initiative of different organizations. The Code of Practice covers many aspects of HIV/AIDS responses, including emergency responses:

> "Increasingly, attention is being directed to addressing vulnerability to HIV infection and the effects of HIV/AIDS in emergency settings, including natural crises such as droughts and earthquakes, as well as situations of armed conflict. Humanitarian work in emergency settings has much in common with development work, where programmes address the water and sanitation, food security, housing and healthcare needs of people who are not displaced from their homes."
>
> (Cabassi and Wilson, 2004)

Again, the relationship of humanitarian and development work – and the issue of HIV within these two areas of endeavour – is flagged.

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Another, highly influential set of guidelines was issued by the IASC in 2007, following extensive consultations by a task force specifically set up to examine responses to HIV and AIDS in emergencies. The *Guidelines for HIV/AIDS interventions in emergency settings* covers an array of responses to address the possible impact of the epidemic in a variety of conditions. Responses range from including HIV-specific interventions (e.g., condom distribution, integrating HIV within sexual health and primary healthcare) and 'mainstreaming' strategies such as factoring HIV into planning for sanitation or water facilities. The Guidelines also discuss HIV as a factor to be considered in preparedness planning, in minimum responses for the acute phases of emergencies and in more of the comprehensive activities to be implemented in the stabilization phase.

Box 3.6 The *Code of Good Practice:* ensuring everyone is 'on the same page' in responding to HIV

The *Code of Good Practice for NGOs Responding to HIV/AIDS* was developed in response to the growing numbers and diversity of NGOs involved in the response to HIV. Drawing on lessons learned over the past 25 years, the Code outlines evidence-based principles that are necessary for effective responses to HIV. These include the meaningful involvement of PLHIV and affected communities, and the promotion of human rights and public health principles. In addition to overall organizational and programming guidance, the Code addresses sectoral responses to HIV, including HIV in emergency settings.

Like the Sphere Project, the *Code of Good Practice* is a joint initiative by a number of organizations. A broad consortium of NGOs developed the Code, including development and humanitarian agencies, AIDS specialist groups, networks of PLHIV, sexual and reproductive health initiatives and faith-based organizations. In this way, the Code is relevant to all NGOs involved in the response to HIV, thereby fostering consistency, collaboration and coherence, as well as mobilization at all levels. Unlike Sphere's minimum standards,

the *Code of Good Practice* provides aspirational guidelines on a wide range of HIV-related issues – a shared vision of good practice to which NGOs can commit and be held accountable.

To date, the *Code of Good Practice* has been endorsed by 204 organizations – many of whom, in their effort to mainstream HIV into their programming, use the Code as a guide on the key issues that underscore best practice in responding to HIV. NGO signatories see the Code as a unifying set of standards in NGO-friendly language, which helps 'get everyone on the same page' without searching through endless reports and handbooks targeted at guiding the response of NGOs.

Many NGOs, such as Concern Worldwide, use the Code's principles as a reference for their HIV policies, organizational plans and systems, and as a 'unifying guide' and framework for building partnerships with other NGOs, governments and stakeholders. One of the key principles that Concern identifies as being essential for addressing HIV in emergencies, is mainstreaming HIV. Integrating

HIV work into all areas of support as part of a comprehensive HIV strategy is possible even if an NGO is not an expert on HIV issues.

Another of the core issues outlined in the Code is the meaningful involvement of PLHIV in a variety of roles at different levels and in terms of humanitarian work. This is particularly relevant during disaster preparedness. In the experience of the Australian Red Cross, the organization's commitment to 'giving PLHIV a voice' has led to new partnerships with PLHIV networks and programmes to support the network's organizational capacity to engage in advocacy.

But while signatories agree that the theoretical nature of the *Code of Good Practice* makes it a powerful reference tool, they also acknowledge that it puts the Code at risk of being another unopened book on a shelf, never put into practice in the field. The Australian Red Cross notes that in order for the *Code of Good Practice*, or any code, to reach its full potential, everyone at all levels (NGOs, governments and donors) must commit to it and fashion their programmes and systems around this commitment. In order to step up its profile and achieve the buy-in of this diverse group of stakeholders, the project has recently relaunched its endorsement process and is actively engaging new audiences with new tools and in different languages.

NGOs have also cited the need for tools to make the Code more practical, to help them see where they stand along the lines of good practice and be supported to take tangible steps to improve their programmes. In response, the project, in partnership with signatories and other NGOs, is developing a series of self-assessment checklists that address 21 topics outlined in the *Code of Good Practice*, including a module on HIV in emergency response.

This has been developed by Tearfund, also a key NGO contributing to the revision of the IASC guidelines, therefore ensuring that this NGO response will complement the work of the UN and fully utilize its system of coordination and policies. ■

Other guidelines are more specific, dealing with more detailed aspects of HIV services in emergencies. An example is UNHCR's *Antiretroviral Medication Policy for Refugees* (UNHCR, 2007), which discusses a variety of practical options for the provision of ART. The document emphasizes the importance of preparation for the early provision of services and for continuity once treatment has been started.

Preparedness and development

The issue of preparedness, which became prominent with the publication of the 1994 Yokohama Strategy (the intellectual ancestor of the Hyogo Framework), should also be considered as it may be particularly useful for HIV responses. As a means of reducing the overall impact of disasters, the Strategy identified the need to address disaster risks in the context of sustainable development and to build resilience by strengthening national and local capabilities to manage and reduce risk (UN, 1994). The Strategy called for attention to five main areas:
- governance (organizational, legal and policy frameworks)
- risk identification, assessment, monitoring and early warning

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- knowledge management and education
- reducing underlying risk factors
- preparedness for effective response and recovery.

These areas fit with multisectoral, development-based approaches to HIV and AIDS, particularly the second and fourth components. The risk identification component should cover the need for data about prevalence and vulnerability, answering the question of who will need what services in the event of a disaster. The preparedness component should identify what will be needed during the early phases (e.g., maintaining ART supplies for those enrolled in treatment) and how to re-introduce services as quickly as possible if they have been disrupted. There is considerable evidence from the field that these goals can be achieved in conflict settings (see Chapter 5).

However, the work of a few brave but small-scale projects run by NGOs is no substitute for well-planned and well-implemented national programmes. There is today a great deal of funding available to governments from bilateral and multilateral donors which could be used to extend AIDS treatment and HIV prevention services to refugee and displaced populations; there is also funding available for organizations working in weak states or areas of chronic conflict. The current context also offers good opportunities for relief, development and HIV organizations to work together – preferably in harmony with the coordinating mechanisms already in place in countries – and making best use of the different actors' comparative advantages (as is encouraged by UNAIDS' 'Three Ones' principles: one agreed HIV/AIDS Action Framework that provides the basis for coordinating the work of all partners; one National AIDS Coordinating Authority; and one country-level Monitoring and Evaluation System).

The International Federation, for instance, has huge assets in its well-organized National Societies, which can call upon both highly skilled professionals and large corps of volunteers. While consigning laboratory services and clinical management to collaborating institutions demonstrating sufficient technical preparedness and competence, it is envisaged that the National Society can make a solid contribution in its areas of competence such as community mobilization, treatment literacy, promoting adherence to ART, providing nutritional support through home-based care programmes, and education of PLHIV, family members and communities on how to prevent the spread of HIV (International Federation, 2004). This approach does not reduce the need for the specialist relief services which may need to be mobilized quickly from outside countries when disaster strikes, but it will greatly aid their work when they arrive.

In the end, building national capacity for HIV programming in 'normal times' strengthens responses all along the relief/development continuum – and in both generalized epidemics and those concentrated in marginalized populations. It is a means

of both strengthening resilience and speeding up responses in the early stages of disasters (in the traditional sense) and of tackling head-on the long-term, complex disaster that HIV poses to high-prevalence countries.

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Sources and further information

Adams, S. *The GTZ Approach to Mainstreaming AIDS: a low-cost complement to other strategies for scaling up the response to AIDS in developing countries.* Berlin: Deutsche Gesellschaft für Technische Zusammenarbeit (GTZ), 2007.

Cabassi, J. and Wilson, D. *Renewing our Voice: Code of Good Practice for NGOs Responding to HIV/AIDS.* Oxford: Oxfam, NGO HIV/AIDS Code of Practice Project, 2004.

Calmy, A. *MSF and HIV/AIDS: Expanding treatment, facing new challenges.* New York: MSF-US, 2004. Available at www.doctorswithoutborders.org/publications/ar/i2004/hivaids.cfm.

Department for International Development. *Saving lives, relieving suffering, protecting dignity: DFID's Humanitarian Policy.* London: DFID, 2006. Available at www.dfid.gov.uk/pubs/files/humanitarian-policy.pdf.

Harvey, P. *HIV/AIDS and Humanitarian Action: Does HIV/AIDS imply a new variant famine and which preventive steps have been taken?* London: Overseas Development Institute, Humanitarian Policy Group, 2004a. Available at www.odi.org.uk/hpg/papers/hpgreport16.pdf.

Harvey, P. *HIV/AIDS and humanitarian action.* London: Overseas Development Institute, Humanitarian Policy Group, 2004b. Available at www.odi.org.uk/HPG/papers/hpgreport16.pdf.

Holden, S. *Mainstreaming HIV/AIDS in development and humanitarian programmes.* Oxford: Oxfam, 2004. Available at www.oxfam.org.uk/what_we_do/resources/downloads/mhivaids-20.pdf.

Inter-Agency Standing Committee. *Guidelines for HIV/AIDS interventions in emergency settings.* Geneva: IASC, 2007.

IASC. *Protecting persons affected by natural disasters: IASC Operational Guidelines on Human Rights and Natural Disasters.* Geneva: IASC, 2006.

IASC. *Mainstreaming Gender in the Humanitarian Response to Emergencies.* Working Group XXVI Meeting, Rome, 22–23 April 1999.

International Federation of Red Cross and Red Crescent Societies. *Programme Update 2007 No. 5. East Asia.* Geneva: International Federation, 2007.

International Federation. *Annual Report: UNAIDS Collaborating Centre for reducing stigma and discrimination through collaboration with GNP+ at global, regional and national levels.* Geneva: International Federation, 2005.

International Federation. *Service delivery model on access to care and antiretroviral therapy for people living with HIV/AIDS.* Geneva: International Federation, 2004.

Knight, L. *A vital partnership: the work of GNP+ and the International Federation of Red Cross and Red Crescent Societies on HIV/AIDS.* Geneva: UNAIDS, 2003. Available at http://data.unaids.org/Publications/IRC-pub06/JC961-GNP_en.pdf.

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Sphere Project. *Humanitarian charter and minimum standards in disaster response.* Oxford: Oxfam, 2004.

Spiegel, P. et al. *Strategies to support the HIV-related needs of refugees and host populations.* Geneva: UNAIDS and UNHCR, 2005.

Spiegel, P. 'HIV/AIDS among conflict-affected and displaced populations: dispelling myths and taking action' in *Disasters*, Vol. 28, issue 3, 2004.

Tearfund. *Reaching out? Donor approaches to faith-based organisations in the response to HIV/AIDS.* Teddington: Tearfund, 2004. Available at http://tilz.tearfund.org/webdocs/Website/Campaigning/Policy%20and%20research/AIDS_briefing_1_FBOs_final.pdf.

United Nations. *Combatting HIV/AIDS, malaria and other diseases.* New York: UN System Chief Executives Board, 2005. Retrieved 8 January 2008 at www.unsystemceb.org/oneun/2/p210.

UN. *Declaration of Commitment on HIV/AIDS.* UN General Assembly, 26th Special Session, 2 August 2001. Available at www.un.org/ga/aids/docs/aress262.pdf.

UN. *Yokohama Strategy and Plan of Action for a Safer World: Guidelines for Natural Disaster Prevention, Preparedness and Mitigation.* World Conference on Natural Disaster Reduction, Yokohama, Japan, 23–27 May 1994. Available at www.unisdr.org/eng/about_isdr/bd-yokohama-strat-eng.htm.

UNAIDS. *Report on the Global Epidemic.* Geneva: UNAIDS, 2007.

UNAIDS. *Programme Document for a United Nations System-Wide Work Programme on Scaling-Up HIV/AIDS Services for Populations of Humanitarian Concern.* Geneva: UNAIDS, 2006.

UNAIDS. *Report on the global HIV/AIDS epidemic, July 2004.* Geneva: UNAIDS, 2004. Available at www.unaids.org/bangkok2004/report.html.

United Nations Educational, Scientific and Cultural Organization and UNHCR. *Educational Responses to HIV and AIDS for Refugees and Internally Displaced Persons: Discussion Paper for Decision-Makers.* Geneva: UNESCO and UNHCR, 2007. Available at www2.reliefweb.int/rw/lib.nsf/db900SID/AMMF-6YEHVN/$FILE/unhcr-refugees-jan2007.pdf?OpenElement.

United Nations Food and Agriculture Organization. *Emergencies and HIV/AIDS: Exploring the role of FAO and mainstreaming HIV in the Organization's emergency response with a priority focus on Sub-Saharan Africa.* Rome: FAO, 2001. Available at www.fao.org/hivaids/publications/mainstream.pdf.

United Nations High Commissioner for Refugees, Office of the. *Antiretroviral Medication Policy for Refugees.* Geneva: UNHCR, 2007. Available at www2.reliefweb.int/rw/lib.nsf/db900SID/TBRL-74DMX9/$FILE/unhcr-ARVsandRefugees-Jan2007.pdf?OpenElement.

UNHCR. *UNHCR's strategic plan for HIV/AIDS and refugees, 2002–2004.* Geneva: UNHCR, 2004. Available at http://data.unaids.org/Topics/Security/hcrstrategicplan_19feb02_en.doc.

United Nations International Strategy for Disaster Reduction. *Hyogo Framework for Action 2005–2015: Building the Resilience of Nations and Communities to Disasters.* World Conference on Disaster Reduction, 18–22 January 2005.

Walden, V. M. et al. *Humanitarian Programmes and HIV and AIDS: A Practical Approach to Mainstreaming.* Oxford: Oxfam, 2007.

Whiteside, A. and Whalley, A. *Reviewing 'emergencies' for Swaziland: Shifting the paradigm in a new era.* Mbabane and Durban: Health Economics and HIV/AIDS Research Division and National Emergency Response Council on HIV/AIDS, 2007. Available at www.heard.org.za/research/ResearchReports/2007/Reviewing%20Emergencies%20For%20Swaziland_Report.pdf.

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