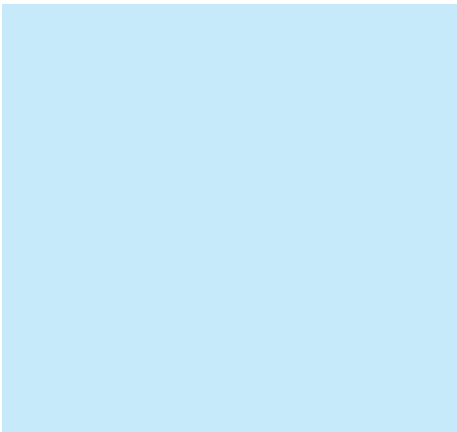


# The essential role of civil society 09



## Chapter 09



### THE ESSENTIAL ROLE OF CIVIL SOCIETY

Almost universally, the first response to the AIDS epidemic came from HIV-positive individuals, their families and communities, by organizing themselves to care for those in need.

In most countries, these early civil society initiatives are the foundations on which the national response has been built, and it is civil society which remains at the forefront of prevention, care and support programmes, particularly among the most vulnerable and hard-to-reach populations. Over the years, civil society has also helped to guide scientific research and has played a key role in challenging drug patents and bringing down the cost of AIDS medication.

#### What is civil society?

Essentially “civil society” is made up of ordinary citizens who organize themselves outside of government and the public service to deal with specific issues and concerns that normal governmental process cannot address by itself. Societies function more effectively when the State and its citizens engage openly on how policies are formulated and implemented.

In the context of AIDS, many different individuals and organizations participate

actively in the epidemic response outside of government structures. At one end of the spectrum they include the woman at village level planting a vegetable garden to feed a family of orphaned children; the nurse who hands out information leaflets on AIDS and tuberculosis to fellow churchgoers on Sundays; and the young people in anti-AIDS clubs who distribute condoms to the bars and barber shops in their neighbourhoods.

At the other end of the spectrum, civil society includes development nongovernmental organizations, faith-based organizations, women’s groups, farmers’ groups and other special-interest associations, business enterprises and labour unions, private foundations and the media. The most active members of civil society are often those with personal experience of the epidemic, either as people living with HIV or members of marginalized and vulnerable populations, such as sex workers, men who have sex with men and injecting drug users. They are present at every level of the response, in associations and networks of HIV-positive

people, specialist community organizations or as regular members of other AIDS-related organizations.

### A look back at history

Civil society groups have engaged in advocacy to press for a range of policy objectives, including better access to health care and more cheaply priced drugs. For example, in 1987 the AIDS Coalition to Unleash Power was launched by gay and lesbian activists in New York. Through public protests the members drew attention to their claim that excessive profits earned by pharmaceutical companies on AIDS medications limited access to treatment and slowed the process of drug approval, thus placing lives unnecessarily at risk. The Coalition also campaigned for public education on the epidemic and an end to AIDS-related discrimination. This early activism helped create the foundation for more affordable treatment initiatives.

Also in 1987, the AIDS Support Organisation was founded in Uganda by 16 volunteers who had been personally affected by AIDS. Most were HIV-posi-

tive themselves and all had lost family members to the epidemic and experienced first hand the stigma of AIDS. They were the forerunners of the principle of “living positively with AIDS” and have since grown into one of the most extensive grass-roots organizations in the world. Today, their programme of comprehensive community-based care and support is a model for AIDS service organizations worldwide.

In the early years of the epidemic, gay communities in the United States, Latin America and Europe were among the hardest hit by the new disease. They mobilized to demand action from their governments and from the scientific and public health authorities. Acting courageously in the face of discrimination and human rights violations which saw many HIV-positive people summarily dismissed by their employers, turned away from schools, or refused treatment by health-care workers, these organizations were the first to give a voice and a face to the epidemic. The San Francisco AIDS Foundation, the AIDS Project Los Angeles, the Gay Men’s Health Crisis in New York and the London-based Terrence Higgins Trust—all launched in



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**"WE CONDEMN ATTEMPTS TO LABEL US AS 'VICTIMS'... "**

From very early on in the epidemic, AIDS activists have demanded recognition as equal partners in the response to the epidemic. In 1984, a United States-based group called the National Association of People with AIDS—the first network of its kind in the world—issued a statement known as the “Denver Principles” in which it claimed the right for HIV-positive people “to be included in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge.” The statement also said: “We condemn attempts to label us as ‘victims’, a term which implies defeat, and we are only occasionally ‘patients’, a term which implies passivity, helplessness, and dependence upon the care of others. We are ‘People With AIDS’.\* Thus the people at the heart of the epidemic set the basic terms of debate in a way which has had a profound effect on perceptions and attitudes ever since.

\*Note, the term ‘people with AIDS’ has been the subject of much debate and change. Currently, UNAIDS uses the term ‘people living with HIV’, which includes the range of HIV-positive people from those with no symptoms to those with advanced HIV infection and AIDS.

1982—combined provision of care and support for HIV-infected people with HIV prevention strategies such as activities aimed at educating and advising on safer sex. In Brazil, gay activists successfully advocated the adoption of the first government AIDS programme in 1983 in Sao Paulo State (Berkman et al., 2005).

Civil society groups have been particularly effective in drawing attention to populations and communities that are often left out of policy debates and deliberations. For example, in 1988 a professor of medicine at the University of Casablanca in Morocco recognized that it was difficult for a government AIDS programme to work with people whose behaviour was condemned by legal and social systems, such as sex workers and drug users. To meet their needs, she founded the Association marocaine de lutte contre le SIDA, the first nongovernmental AIDS organization in the Maghreb. In 1989 in Slovenia, a group of

drug users started Stigma, a self-help organization, to attend to the needs of drug users and keep them informed about AIDS. The Ljubljana branch of Stigma set up a needle-exchange programme, a measure that has proven effective at reducing HIV transmission in drug-using populations. That same year, the Pakistan AIDS Prevention Society was formed by a group of people, including teachers and trade unionists, who saw the need for broad-based community action. In addition, organizations like the Treatment Action Campaign in South Africa have provided a voice to people in need of treatment worldwide as well as within national borders.

In the 1990s, when the epidemic emerged in countries with little tradition of civil society, such as the former Soviet countries of Central Asia, international agency support for HIV prevention emphasized working through nongovernmental organizations, based on the success

of this approach in other parts of the world. As well as creating new nongovernmental organizations where none had previously existed, this helped to change official attitudes towards vulnerable populations and to spread both the concept and practice of democratic governance and grass-roots political participation (Atlani-Duault, 2005).

#### THE POWER OF NETWORKS

In 1990, the Fourth International Conference for People Living with HIV/AIDS was held in Madrid, Spain, attended by 500 people from 43 countries. This marked the first truly international conference to unite a broad range of HIV-positive people from different countries and provided an occasion for raising awareness and sharing experiences. It also prepared the ground for action beyond national boundaries. In 1992, the Global Network of People Living with HIV/AIDS was officially launched, the same year that the International Community of Women with HIV/AIDS was set up.

In addition to the emergence of global networks, similar trends have also had a huge impact at national level. In 1997, the Indian Network for People living

with HIV was formed by 12 people from various states. Today it has more than 20 000 members, making it one of the largest networks of HIV-positive people in the world.

The Egyptian nongovernmental organization Network against AIDS was established in December 2003 with a membership of 19 nongovernmental organizations, many of which had never worked on HIV but were committed to learning more. This network conducts training for member nongovernmental organizations and provides a space for people living with HIV in the absence of an established independent association for them in Egypt. Although still faced with many challenges, in the short years since its inception the network has created a voice for nongovernmental organizations in the AIDS response and now participates fully in the national HIV coordinating forum.

Thanks to the combined efforts of organizations and networks, the basic principle of ensuring meaningful involvement of civil society, and particularly of people living with HIV, is now being written into the policies and strategies of many



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**UNITED NATIONS GENERAL ASSEMBLY  
SPECIAL SESSION ON HIV/AIDS 2001: A  
TRIUMPH AND AN OPPORTUNITY**

The UN General Assembly Special Session on HIV/AIDS (UNGASS) in June 2001 was a momentous event and a tribute to the zeal and advocacy of civil society campaigns which have helped keep AIDS high on the political agenda. The Declaration of Commitment signed by 189 heads of state at the close of proceedings prescribed a key role for civil society, in partnership with government, in meeting a set of time-bound goals in response to the epidemic, and in monitoring governments' compliance with these obligations. The 2001 Session not only demonstrated the tensions that often exist between governments and civil society groups but also generated some heated debate about appropriate representation and the need to ensure that the provisions for civil society in general, particularly in its role as a voice for people living with HIV, were not just acts of tokenism. Articulating these tensions helped set the stage for a genuine commitment to working in partnership towards shared goals.

The Declaration set deadline targets to be assessed in 2003, 2005 and 2010. The UN General Assembly's review of progress for the year 2005 therefore constitutes an important milestone and one which has focused the attention and energies of many members of civil society.

One example is the development of a civil society consortium of nongovernmental organizations organized in 2005

to support civil society-led monitoring, advocacy and reporting around the implementation of the UNGASS Declaration of Commitment. The consortium includes the nongovernmental organizations Fundar, Gestos and Panos (based in Mexico, Brazil and the United Kingdom respectively), the Public Health Watch/Open Society Institute, the International Council for AIDS Service Organizations, the World AIDS Campaign, and the Latin American and Caribbean Council of AIDS Service Organizations. The consortium built on earlier work by the International Council for AIDS Service Organizations which was the first organization to support this kind of civil society-led monitoring and advocacy.

In 2004, they published a report presenting the findings and recommendations from community-based research in Kenya, the Philippines, Ukraine and Venezuela, representing four pilot regions affected by the HIV epidemic (ICASO, 2004a). The research focused on five areas of commitment under the Declaration: access to treatment, women's empowerment, human rights of people living with HIV, allocation of resources, and the involvement of civil society. A major finding was that government adoption of the Declaration of Commitment has had no evident impact on the vulnerability of girls and women to HIV, and that this remains one of the most neglected areas in the global response. Reports from the International Council and the consortium of nongovernmental organizations indicate that collaboration between government and civil society is often more akin to tokenism than to real commitment, which translates into a lack of meaningful civil society involvement in policy-making.



### Scaling up and sustaining the response

To tackle the long-term challenges of AIDS, countries need to think beyond short-term planning and election cycles and envisage a sustained and wide-reaching response. Civil society is uniquely placed to help ensure a longer term perspective.

In December 2004, nongovernmental organizations from around the world came together to agree on a code of practice to help guide their response to the epidemic. They created the nongovernmental organization HIV/AIDS Code of Practice. Aspirational in nature, it provides a set of principles of good practice for advocacy and AIDS programming, to which nongovernmental organizations can commit themselves and be held accountable. The code advocates a human rights-based approach to AIDS work which promotes the meaningful involvement of people living with HIV and seeks to address the causes of vulnerability through programmes based on evidence.

More than 160 nongovernmental organizations have signed up to this code so far.

Protecting existing human resources across all sectors involved in the AIDS response is a high priority and includes safeguarding the health of people living with HIV. These people are often the backbone of the national response. Access to treatment and care, including antiretroviral therapy and treatment for concomitant tuberculosis, is essential, as are measures to minimize stress and exhaustion. In Brazil, universal provision of treatment and prevention services has played a major role in averting sickness and death among nongovernmental organization staff and volunteers and maintaining their effectiveness in responding to the epidemic (Halmshaw and Hawkins, 2004).

In South Africa, the Health Economics and HIV/AIDS Research Division of the University of Natal have developed tools for helping nongovernmental organizations and community-based organizations to plan for and respond to AIDS in the workplace. This was spurred on by a research project carried out in the worst affected province, KwaZulu-Natal, and which underlined the urgency of mitigating the impact of AIDS on civil society organizations (Manning, 2002).

The International AIDS Alliance produced a toolkit to help nongovernmental organizations evaluate and build their capacity to respond to the epidemic (International AIDS Alliance, 2004). Field-tested by more than 50 nongovernmental and community-based organizations in Ecuador, Cambodia and India, the toolkit focuses on five areas of capacity: organizational strength, technical understanding of HIV, participation of

## **NONGOVERNMENTAL ORGANIZATION HIV/AIDS CODE OF PRACTICE: PROGRAMMING PRINCIPLES\***

### **Cross-cutting issues**

- Our HIV/AIDS programmes are integrated to reach and meet the diverse needs of people living with HIV and affected communities.
- Our HIV/AIDS programmes raise awareness and build the capacity of communities to respond to HIV/AIDS.
- We advocate for an enabling environment that protects and promotes the rights of people living with HIV and affected communities and supports effective HIV/AIDS programmes.

### **Voluntary Counselling and Testing (VCT)**

- We provide and/or advocate for voluntary counselling and testing services that are accessible and confidential.

### **HIV prevention**

- We provide and/or advocate for comprehensive HIV prevention programmes to meet the variety of needs of individuals and communities.
- Our HIV prevention programmes enable individuals to develop the skills to protect themselves and/or others from HIV infection.
- Our HIV prevention programmes ensure that individuals have access to and information about the use of commodities to prevent HIV infection.
- We provide and/or advocate for comprehensive harm reduction programmes for people who inject drugs.

### **Treatment, care and support**

- We provide and/or advocate for comprehensive treatment, care and support programmes.
- We enable people living with HIV and affected communities to meet their treatment, care and support needs.

### **Addressing stigma and discrimination**

- We enable people living with HIV and affected communities to understand their rights and respond to discrimination and its consequences.
- We monitor and respond to systemic discrimination.
- We enable communities to understand and address HIV/AIDS-related stigma.
- We foster partnerships with human rights institutions, legal services and unions to promote and protect the human rights of people living with HIV and affected communities.

**Source: Nongovernmental organization HIV/AIDS Code of Practice Project, 2004.**

\*The Code was developed jointly by ActionAid International, CARE USA, the Global Health Council, the Global Network of People Living with HIV/AIDS (GNP+), Grupo Pela Vidda, the Hong Kong AIDS Foundation, the International Council of AIDS Service Organizations (ICASO), the International Federation of Red Cross and Red Crescent Societies, the International Harm Reduction Association, the International HIV/AIDS Alliance and the World Council of Churches.



people living with HIV and other affected groups, partnerships, and coordination and effective advocacy. By early 2006, the toolkit had been used by 165 of the Alliance's partner organizations in more than eight countries.

#### AT THE FOREFRONT OF HEALTH-CARE PROVISION

Early in the epidemic, as public hospitals became overwhelmed by the burden of HIV, civil society organizations also took on responsibility for health care. They were the pioneers of counselling, both for and by infected and affected people, and of home-based care for the sick. And as medicines—including, eventually, antiretroviral drugs—were developed to treat HIV, civil society organizations were at the forefront of efforts to bring down the cost of treatment, to demonstrate that antiretroviral therapy is feasible in resource-poor settings and to urge national governments to commit themselves to providing treatment. Furthermore, in many countries where a combined epidemic of HIV and tuberculosis is present, it is often civil society that drives efforts to ensure integrated programmes address the crisis created by the two diseases.

A joint survey, conducted in 2004 by the Paris-based treatment rights group, Sidaction, and UNAIDS and WHO, found that nongovernmental organizations are still the main providers of health care in many African countries, where the burden of HIV is heaviest. The survey covered 274 community-based organizations working with HIV-positive people in 45 countries, with a total of 210 400 clients between them. Antiretroviral therapy was carried out by 182 organizations, of which 68 were prescribing drugs themselves, while 133 were giving medical follow-up and 156 psychosocial follow-up for people on therapy. A total of 159 organizations were providing education and information on antiretroviral therapy and on the symptoms and management of side-effects. In addition, 141 organizations reported that they were providing direct treatment for opportunistic infections, including tuberculosis (Sidaction et al., 2005).

Community-based organizations in Burkina Faso preceded the government and international donors in importing generic antiretroviral drugs; and community groups serve as the primary source for HIV treatment in Burundi. In



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Uganda, the AIDS Support Organisation used its experience providing antiretroviral drugs to its own employees to develop its community-based treatment programme, which began in 2004 with 3000 clients and currently serves over 7000. In Haiti, Partners in Health and The Haitian Study Group on Kaposi's Sarcoma and Opportunistic Infections were the first organizations in the country to offer antiretroviral therapy, and nongovernmental organizations still care for the majority of people on antiretroviral drugs. In Cambodia, 70% of nongovernmental organizations engaged in the response to HIV focus on health care and treatment.

Civil society groups play a central role in advocating for greater treatment access and they also promote greater accountability by monitoring treatment-related activities of governments, donors and nongovernmental organizations. Extensive networks have been forged in many countries to support easier access to antiretroviral drugs. For example, the Kenya Coalition on Access to Essential Medicines—whose network includes people living with HIV, the Kenya Medical Association, international nongovernmental

organizations and a broad range of civil society groups—promotes coordinated action to scale up treatment.

Besides threatening the lives and well-being of people living with HIV and violating their human rights, stigma and discrimination inhibit every aspect of the response to AIDS. They adversely affect people's willingness to heed prevention messages, come forward for HIV testing, or seek treatment for HIV-related health problems, and are root causes of denial and slowness to act by governments (Ogden and Nyblade, 2005). These issues are discussed extensively elsewhere in this report. However, it should be remembered that civil society has always played a leading role in combating stigma and discrimination, and its efforts continue today in most parts of the world. In addition to heading the fight to tackle these issues, civil society has provided much needed support for the rights of marginalized groups to access AIDS-related services and information.

In the south of Kazakhstan, the nongovernmental organization "Senim" which means "trust" in Kazakh, gives support to commercial sex workers in distributing

condoms, organizing referrals to sexual health services, as well as setting up a syringe exchange system for drug users. Senim speaks for the rights of the sex workers and advocates against the violence they are often subjected to. Over the last four years the incidence of sexually transmitted infections among this community decreased from 64% to 40% and HIV prevalence has remained stable at 1.6%, with 60% of sex workers reporting condom use with clients.

In Ethiopia, the Integrated Service for AIDS Prevention and Support Organization has helped minimize the risk of HIV infection among commercial sex workers. Sex workers in Ethiopia are a neglected and marginalized group and have been difficult to reach through HIV interventions that have tended to target the population in general. The

Organization has worked to raise awareness and change behaviour and living conditions through creating opportunities and choices for various populations. More than 1000 women have been reached through these activities and more than 200 of them have left sex work to run small businesses.

### Old partners, new partnerships

Enhancing and sustaining the involvement of civil society groups in multisectoral national responses is essential if countries are to get ahead of their epidemics. Strength in unity is ever more widely recognized and organizations of all kinds are seeking opportunities to set up new partnerships and alliances, and to revitalize existing ones.

### PREPARING THE GROUND FOR ANTIRETROVIRAL THERAPY

Successful antiretroviral therapy requires much more than simply making services available. Those who could benefit need to know they are HIV-positive, which means being prepared and able to go for testing. People need to understand what antiretroviral treatment is, how the drugs work and what lifelong medication means to themselves and to their family members, who may well be required to make sacrifices to accommodate the demands of treatment. In addition, the general public needs to be aware of and knowledgeable about the issues and to create a supportive environment for treatment.

Such activities—widely known as treatment “preparedness” or “literacy”—have been undertaken almost exclusively by nongovernmental groups. Besides campaigning for HIV treatment services and stimulating public debate, they have developed and implemented treatment literacy programmes in all regions and provided ongoing psychosocial support to individuals and communities through a myriad of grassroots mechanisms. Since November 2004 their efforts have been given additional support by the Collaborative Fund, a partnership between the International Treatment Preparedness Coalition, a global coalition of community-based treatment advocates and educators, and the Tides Foundation, a United States-based charity with long experience in administering small grants to community-based organizations. The leadership positions in the Fund are held by people living with HIV who, through their associations and networks, set the funding priorities.

### A DIFFERENT PERSPECTIVE: TAPPING CIVIL SOCIETY EXPERTISE

As well as its work in AIDS-related service provision and advocacy, civil society constitutes a vast reservoir of information and independent expertise. This was illustrated vividly in 2004 when the UNAIDS Inter-Agency Task Team under the leadership of UNESCO commissioned the first ever Education Sector Global HIV/AIDS Readiness Report (IATT, 2006). This involved a self-assessment questionnaire mailed to ministries of education in 117 countries and answered by 71 (the summary findings are discussed in 'Reducing the impact' chapter). A parallel study, conducted by the nongovernmental organization Global Campaign for Education, was based on workshops bringing together civil society education networks, teachers' unions and representatives from ministries of education in 18 countries heavily burdened by AIDS (Boler and Jellema, 2005).

The two studies provided very different assessments of how well ministries of education and schools are responding to AIDS. The report by the Global Campaign for Education entitled "Deadly Inertia," is considerably more critical of the situation than is the Inter-Agency Task Team's report. For instance, it points out that coherent AIDS strategies are actually being implemented in only two of the 18 countries and that little action has been taken to address the educational needs of orphans and vulnerable children. Both these informative studies draw attention to the AIDS-related challenges facing the education sector (see 'Impact' chapter).

In addition to adding qualitative data to the Global Readiness Report, the Global Campaign for Education project aimed to stimulate dialogue between civil society and governments and encourage civil society participation in shaping national AIDS and education policies.

The research for these studies generated important spin-offs. In Bolivia, for example, the agencies taking part in the Campaign's workshops decided to act immediately and submitted a proposal to government for the immediate inclusion of AIDS education in the national curriculum.

### ORGANIZATIONS OF PEOPLE LIVING WITH HIV: TIME FOR CHANGE?

As a general rule, organizations of people living with HIV are initially created to provide mutual support and care, and evolve gradually to play wider and more varied roles in the epidemic response as their capacity and collective voice strengthen. Today, in addition to the thousands of people living with HIV who continue to provide support and care services at the grass-roots level, there are

networks of HIV-positive people working at national, regional and global levels.

The primary purpose of networking is to represent the interests of HIV-positive people in the wider arena and give them a voice wherever policies and decisions are being made that affect their lives. But today these networks are at a crossroads. Although the principle of involving HIV-positive individuals in all aspects of the response is widely accepted and they have

won seats at many tables, the question now facing them is how to make effective use of the opportunities they have won. To look for answers, a group of people living with HIV from around the world have been discussing future strategies. A series of brainstorm ‘think tank’ meetings in 2005 were supported by UNAIDS and partners in Johannesburg and Nairobi (UNAIDS, 2005c, 2005d).

After a process of self-examination, the participants agreed that there was a pressing need to professionalize informal structures to enable them to function effectively and participate independently in high-powered organizations and forums. Discussions also revealed a tendency for networks to lose touch with the grass roots as they engage with the wider world and the need for clear mandates, accountability and proper lines of communication. Participants in the discussions also emphasized the need for mechanisms to help new people and new ideas to advance within their organizations and networks so that they remain relevant to younger generations of HIV-positive people. A more recent development is the diminishing commitment to action on AIDS-related issues—especially

among people on antiretroviral treatment, for whom sheer survival is no longer such a preoccupation and wider opportunities have opened up (Rawstorne and Prestage, 2005).

One of the many important issues identified by the think tanks was the tendency to allow donor priorities to influence the agenda set up for people living with HIV. Another matter of concern was the lack of real commitment to the principle of Greater Involvement of People Living with HIV/AIDS (GIPA) by donors and other organizations working on AIDS, including nongovernmental organizations, governments and the UN. Thus, the response to the epidemic continues to grow at national, regional and global levels but often without the meaningful participation of people living with HIV.

### Women’s groups

Of the 40 million people living with the virus in the world today, more than 17 million are women and the gender gap continues to narrow. In 2004, The Global Coalition on Women and AIDS was launched under the auspices of



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**BREAKING NEW GROUND**

The All-Ukrainian Network of People Living with HIV is a unique example of the effective mobilization and self-organization of people living with HIV in the Commonwealth of Independent States of the former Soviet Union. Over the last six years the Network has reached and united people living with HIV in 34 Ukrainian cities. It has established itself firmly as both an ardent advocate for the rights of people living with HIV and as a strategic service provider for its constituency. The Network is an excellent example of how civil society organizations can address issues of sustainability at different levels. For instance, the Network invests consistently into its own organizational development, by identifying, recruiting, training and retaining leaders from the community. As a result, the Network can boast a large nucleus of managers who lead the organization on a number of fronts.

In 2005 the All-Ukrainian Network founded the Union of People Living with HIV in eastern and central Europe involving organizations of HIV-positive people from 10 countries of the former Soviet Union. This Union serves as a valuable reference for the 24 countries in the eastern European and central Asian regions which have experienced serious difficulty in obtaining funds to create and maintain their own organizations. They now have at least one functional organization of people living with HIV. These groups are mainly small and located in major cities with weak outreach to HIV-positive people further afield. However, they constitute a hopeful development in a region unfamiliar with the practices of civil society.

In September 2005, the Russian Orthodox Church launched an HIV prevention and care programme in the Russian Federation. The programme seeks to train clergy and church volunteers in counselling and nursing care of HIV-positive people, establish telephone helplines, and develop prevention programmes for young people that address the issues of drug use and HIV. It has the potential to bring together church communities across the countries of the former Soviet Union and benefit from their considerable network of social centres, Sunday schools and youth clubs.

UNAIDS to highlight the effects of the epidemic on women and girls and to stimulate practical and efficient action to address their needs. The Coalition constitutes an informal global alliance of a wide range of partners from civil society groups, networks of people living with HIV, governments and UN agencies. It has three interrelated spheres of action: evidence and policy development, high level advocacy and country-level action.

By providing 'catalytic' funds of up to US\$ 50 000 to UN Theme Groups in

countries affected by HIV, the Coalition strengthens the gender component in national AIDS strategies and fosters the inclusion of women's groups in civil society forums. In 2004–2005, seven countries in Asia and Africa and two regions, Mekong and the Middle East, received support (UNAIDS, 2006). In Kenya, for instance, the funds were used to map women's organizations as a resource for the National AIDS Coordinating Committee. In Viet Nam, UNAIDS partnered with the Women's Union, which has 13 million members

countrywide, to develop an HIV strategy. In the Middle East, a regional meeting in Jordan in June 2005 focused on promoting women's human rights, capacity-building for women's organizations and raising awareness of gender, risk and vulnerability to HIV.

Research shows that ensuring women are adequately represented in policy and planning forums is a difficult strategy to implement. For example, the International Center for Research on Women found that women's organizations had not involved themselves in a systematic way in the discussions leading to the establishment of the Global Fund to Fight AIDS, Tuberculosis and Malaria, and that there remains a lack of expertise on gender issues among the civil society representatives on the Fund's board (Cornman and Duvvury, 2005). Furthermore, case studies from countries show that gender concerns are rarely reflected in the programmes that receive funding. Programmes that do address women's needs tend to focus primarily on mother-to-child transmission. The general picture is one of limited participation of women's groups in national AIDS planning forums. A recent UNAIDS assessment carried out

in 79 countries showed that 90% of the national AIDS frameworks received little or no input from women's organizations, although participation was improving in 50% of the countries reviewed (see 'National responses' chapter).

#### FAITH-BASED ORGANIZATIONS

Churches and other faith-based organizations, especially in developing countries, were among the first to deliver treatment, care and support to people living with HIV and dying of AIDS, and to address the needs of orphaned children. They remain at the forefront of service delivery in many places. The Christian Health Associations in Africa, for example, working in collaboration with ministries of health, provide around 40% of national health care in Lesotho, 45% in Zimbabwe, 48% in Tanzania, 47% in Liberia, 40% in Kenya and 30% in Zambia (Dimmock, 2006). Worldwide, WHO estimates that one in five organizations engaged in AIDS programming is faith-based (WHO, 2004). However, there is undoubtedly still untapped potential within faith-based communities to contribute to the AIDS response—not least in working with their extensive membership structures to challenge



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stigma and discrimination, and expand coverage of education, care and support services. UNAIDS helps to identify gaps in the response for subsequent action by faith-based groups. It also seeks to broker partnerships with other AIDS-focused organizations and collaborates with the larger, international faith-based development organizations, such as World Vision, Christian Aid, and Norwegian and Danish Church Aid. UNAIDS has signed a formal memorandum of understanding with Caritas Internationalis to work jointly to stimulate HIV activities in 180 countries through its worldwide network of member organizations. UNAIDS also collaborates with Positive Muslims based in Cape Town and has a special relationship with the African Network of Religious Leaders Infected or Affected by HIV (see box).

Since the epidemic poses moral and ethical dilemmas that can be divisive and confusing, it is important to encourage open debate within and between religious communities about responding to AIDS. In December 2004, for example, a colloquium for religious leaders from Africa was organized in Cairo by UNDP in partnership with Family Health International.

Held under the auspices of the League of Arab States, it brought together Muslim and Christian leaders from 19 countries who drafted and signed the Cairo Declaration committing themselves to urgent action in response to the epidemic. The Declaration, which has since been signed by a further 300 religious leaders, emphasizes the need “to abolish all forms of discrimination ... and stigmatization of people living with HIV.... .”

#### **PRIVATE ENTERPRISE AND WORKERS’ ORGANIZATIONS**

Businesses are ideally placed to contribute to the epidemic response. They have the capacity to reach millions of workers through workplace AIDS programmes, and also the communities from which they draw their employees and customers. The 2006 report on business and AIDS from the World Economic Forum says that an increasing number of companies have AIDS policies in place or plans to introduce them, although the potential remains for a greater contribution to the epidemic response (Bloom et al., 2006).

Many smaller companies, however, lack the resources to measure the potential impact of HIV on their business, let alone



respond. For this reason they are the focus of the ILO Workplace AIDS Education Programme with the United States Department of Labor, now operational in 289 enterprises in 22 countries. Focal points are identified and peer educators are trained in enterprises as diverse as small mines in India and Russia, garages in Ghana and hotels in Cambodia. Strategies for HIV prevention and health care are developed with the assistance of the local trade unions and employers' organizations. Surveys of workers are carried out and a monitoring plan agreed upon. Both public sector workplaces and the informal sector are covered, ranging from the docks authorities in Indonesia to hairdressers in Jamaica (ILO, unpublished reports).

Organizations of employers have a particular role in helping motivate and support smaller, nationally owned, and less well-resourced companies. These organizations—which are supported by a global

body, the International Organization of Employers, with a membership of 142 national organizations in 137 countries—provide guidance and training, encourage the pooling of resources and partnerships between larger and smaller companies. The Barbados Employers' Confederation, for example, disseminates examples of good practice among members, provides materials and training, and has collaborated with the Ministry of Labour to draft a national code for the workplace.

Trade unions have also played an important part in the response to HIV. Many unions deal with issues such as pre-employment screening, continuity of employment for people with HIV, provision of sickness benefits and death benefits for dependents. Efforts have also focused on prevention, with the training of union officials and activists as AIDS focal points, peer educators and trainers. In this way, trade unions are helping

#### RELIGIOUS LEADERS LIVING OPENLY WITH HIV

In November 2002, a group of church men and women in the Ugandan town of Mukono decided to set up the African Network of Religious Leaders Living with or Personally Affected by HIV and AIDS. To Canon Gideon Byamugisha this was the fulfilment of a dream. The first Anglican priest to disclose his HIV status publicly, Canon Gideon had been living openly with the virus for 10 years and knew there were many other HIV-positive religious leaders living in silence and fear of discrimination who were in need of care and support. He and his colleagues at the Mukono meeting—convened partly to celebrate the tenth anniversary of his disclosure—believed that, as leaders in their various faith communities, they were uniquely well-placed to break the silence surrounding AIDS and challenge stigma and discrimination. Their Network was launched officially at the 11th International Conference for people living with HIV held in Kampala in October 2003 with the theme "The Dawn of New Positive Leadership." With funding from World Vision International, Christian Aid, SIDA and USAID, the Network started with a series of training workshops in several countries and today has more than 1000 members in most African nations and from all faith-based communities represented on the sub-continent. All members are HIV-positive themselves or caring for close relatives living with HIV.

extend access to treatment. In Uganda, the federation for agricultural, food and hotel workers has partnered with local women's groups to set up clinics on plantations where workers can receive HIV testing and family planning (UNAIDS/ILO/ICFTU, 2006). At the global level, the International Confederation of Free Trade Unions, with 236 affiliated organizations in 154 countries, has partnered with the 10 global union federations to run a Global Unions Programme on HIV/AIDS.

The Global Business Coalition on HIV/AIDS is a leading and expanding alliance of more than 200 international companies which are dedicated to responding to the AIDS epidemic. Its aim is to harness the individual and collective power of the world's top corporations to tackle AIDS at the local, national and international levels. Working to raise awareness and stimulate the business response to AIDS, it created the first international measurement system, the Best Practice AIDS Standard, a quantitative self-assessment tool that measures a company's involvement and guides business strategies for addressing the AIDS pandemic.

National private sectors are also increasing their response to AIDS. A group of leading professional entertainers in Barbados including musicians, performance poets, disc jockeys, songwriters and events planners, formed a network to promote HIV prevention within the national music industry. These champions are developing a strategic approach to the promotion of positive and safer sexual lifestyles, in a context where risk behaviour is often aggressively exploited by the entertainment business. The mobilization and transformation of an organized core

group of music industry professionals and performers creates a powerful medium, given the immense popular appeal of the music industry among the majority of youth in Barbados, and in the Caribbean region as a whole.

Considering how difficult it is to reach sexually active youth through more traditional channels, this innovative approach holds much promise. Early successes include a four-fold increase in the acceptance of voluntary counselling and testing provided by mobile services at music festivals.

### Spending money where it most helps

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**"Community initiatives must be a priority for our support, because they are the foundation for a sustainable response owned by the people who have the most to lose, the most to gain."**

*Peter Piot, 27th June 2005*

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In 2005, the amount of money spent on AIDS in low- and middle-income countries was around six times more than was spent in 2001 (see 'Financing' chapter). The dramatic increase is due in part to the tireless advocacy and activism of civil society organizations at all levels. It still falls short of what is required to get ahead of the epidemic, and a number of civil society organizations continue to work across sectors to focus on mobilizing resources and sustaining the commitment of the international community. Raising the level of funding is as important as ensuring the money is used effectively to improve people's lives and slow the course of the epidemic.

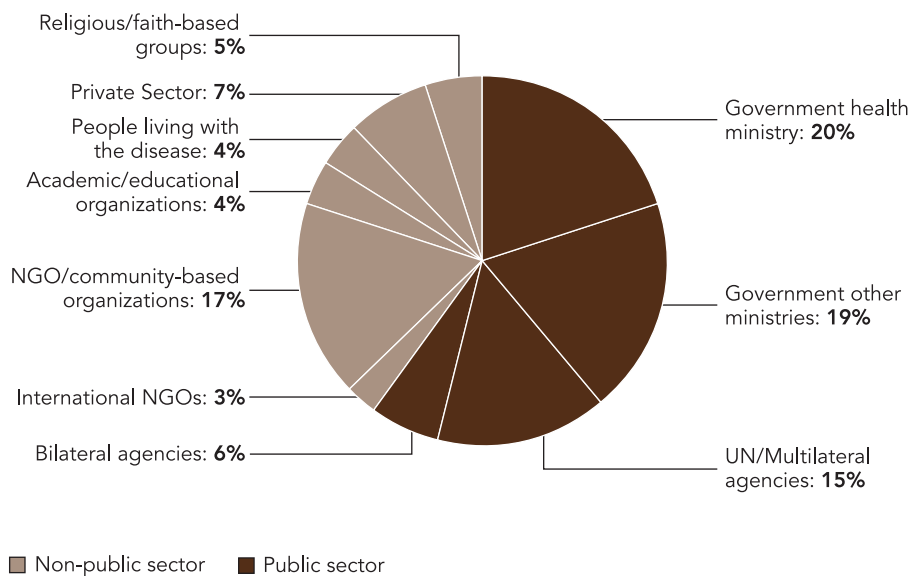
**CIVIL SOCIETY AND THE GLOBAL FUND**

Building on the experiences of other organizations working on AIDS, the Global Fund to Fight AIDS, Tuberculosis and Malaria set out to offer HIV-positive people and civil society organizations the opportunity to participate in policy and decision-making processes. Nongovernmental organizations and people living with or affected by HIV, tuberculosis or malaria constitute around 25% of the Fund’s membership and have full voting rights. The Fund’s Country Coordinating Mechanisms—responsible for developing and submitting grant proposals to the Global Fund and overseeing implementation—are required to include representatives from all sectors and interest groups (see Figure 9.1). The Global Fund Partnership Forum, which meets every two years, enables a broad range of stakeholders to provide feedback and

to recommend changes in policies and procedures.

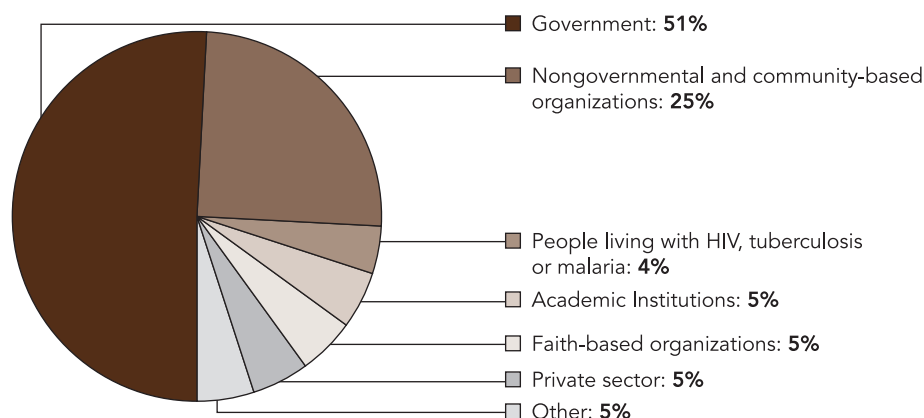
By late 2005, the Fund had committed US\$ 4.4 billion to 350 grants in 128 countries. Nearly one-third of the grants were made to nongovernmental and community-based organizations (see Figure 9.2), many working with difficult-to-reach populations who are at most risk of HIV exposure. In Kazakhstan, for example, the Global Fund is helping the national programme to build partnerships with nongovernmental organizations to provide services for injecting drug users, and sex workers and their clients, among whom the epidemic is spreading fast. In Madagascar, the Fund is directly financing the nongovernmental organization Population Services International to provide information and condom supplies with the aim of reducing sexually transmitted infections, and to increase access to

**FIGURE 9.1** Country Coordinating Mechanisms (CCMs): Entities participating in preparation of Round Four proposals  
100% = all representatives of all 78 surveyed CCMs



Source: The Global Fund to Fight AIDS, Tuberculosis and Malaria.

FIGURE 9.2 Sector of recipients



Source: The Global Fund to Fight AIDS, Tuberculosis and Malaria (2005). Rounds 2–4 only. Information not available for Round 1.

youth-friendly sexual health services (Global Fund, 2006).

#### IMPROVING EFFECTIVENESS

Evaluation of the Global Fund by a number of organizations, including the Fund itself, shows that, despite the organizational commitment to civil society involvement, performance has been uneven and challenges remain (ICASO, 2004b). For example:

- commitment to multisectoral partnership among the leadership of the Global Fund is often not reflected at country level—many governments lack experience and willingness to work with civil society organizations;
- on many Country Coordinating Mechanisms there is inadequate representation of nongovernmental organizations and vulnerable populations, including people living with HIV, injecting drug users, sex workers, men who have sex with men, and women;
- civil society representatives often do not have a mandate from their constituencies—they may be appointed by government rather than selected

through a democratic and transparent process; and

- civil society representatives often lack the education, skills, confidence and/or financial resources to participate effectively in Country Coordinating Mechanisms or other forums, or to challenge the imbalances of power.

A variety of efforts are being made to respond to these problems. As the Country Coordinating Mechanisms are the gateways to grants and a critical structure for building a truly multisectoral response, it is essential that they function properly. In Arusha in late 2004, the Global Fund's board agreed to guidelines explaining their purpose, structure and composition, with explicit instructions to ensure that civil society constituencies select their representatives, that people living with or affected by the disease be represented, and that the full range of stakeholders participate in developing proposals and overseeing grants (Global Fund, 2005a, 2005b). The Global Fund's Technical Evaluation Reference Group has developed a Country Coordinating Mechanism Performance Checklist available on the

Global Fund website. A handbook to facilitate the involvement of HIV-positive people has been produced by the Global Network of People Living with HIV/AIDS with support from USAID's POLICY Project and Deutsche Gesellschaft für Technische Zusammenarbeit (German Agency for Technical Cooperation). Recently the Global Network and the International Council of AIDS Service Organizations secured a grant from the Open Society Institute to support the developing country delegation to the Global Fund's Board.

### **Towards greater harmonization of national action**

The “Three Ones” principles (one national AIDS action framework, one national AIDS coordinating authority, and one agreed country-level monitoring and evaluation system—see ‘National responses’ chapter) are the foundations of a supportive environment for civil society activities, and simplify the administrative processes involved in the AIDS response. In particular, the national AIDS coordinating authority provides the opportunity to advocate for and move towards a truly meaningful role for civil society in all aspects of the national response, from policy-making and planning to implementation.

The success of the “Three Ones” is threatened, however, by the dramatic imbalance of power which exists between civil society, state and donors. Unless measures are taken to correct it, a new bureaucracy may emerge within which civil society has only token involvement. The outcome will be a response that reflects the agendas of the most powerful stakeholders such as

government ministries or international donors. Building the capacity of civil society groups is a key strategy for redressing this power imbalance. The International HIV/AIDS Alliance and the 2005 discussion paper “Civil Society and the ‘Three Ones’” put forward a two-way process wherein the role and contribution of civil society are explained to governments and donors and advice given on how to respond to its needs. Suggested measures include raising awareness of the function of civil society and improving skills in collaborative planning and jargon-free communication (ICASO, 2005).

Perhaps the most significant outcome of the wide-ranging discussions prompted by the “Three Ones” and other worldwide initiatives has been the recognition that civil society organizations, with their unrivalled understanding of the epidemic and people's needs, are essential components of the national response. If countries are to progress towards meeting the commitments made by their governments at the UN General Assembly Special Session on HIV/AIDS in 2001, every effort must be made to support and strengthen civil society and give it a voice that is heard.

Aware of the multiple challenges faced by civil society organizations—especially the thousands of smaller groups working in isolation at community level—the Institute for Democracy in South Africa offers training in budget analysis and resource tracking to nongovernmental organizations, academics, AIDS activists and others in their region. More recently, the training sessions have expanded to include government officials. Participants from government and civil society prepare budget analyses and draft reports together, actions which help foster understanding and cooperation between them, thus

### ADVANCING CIVIL SOCIETY THROUGH THE “THREE ONES”

Experience in two very different countries shows how the “Three Ones” can be used to advance civil society involvement in national AIDS responses.

Indonesia is the fourth most populous country in the world, with 212 million people spread across a vast geographical area and thousands of islands. It has a national AIDS strategy and a national AIDS coordinating authority but is currently going through a process of decentralization. Strategies are therefore needed to ensure that directives from its coordinating authority are not simply imposed on provincial authorities. In the spring of 2005, two civil society consultations were held in Jakarta to explore the concept of the “Three Ones” and facilitate the involvement of civil society. Their recommendations cited the need to make documentation about the “Three Ones” more comprehensible to ordinary Indonesians and communicate the principles widely among stakeholders, including community-based groups which are distanced from global dialogue.

In Nigeria, the Civil Society Network on HIV/AIDS organized a consultation on the “Three Ones” in 2005 to define the roles of different civil society players within the national AIDS framework. The consultation culminated in a civil society Declaration of Commitment on the “Three Ones.” Nigeria’s network of people living with HIV, NEPWHAN, already has two seats on the national AIDS committee, two seats on the antiretroviral therapy committee and is expected to secure two seats on AIDS committees at state level.

promoting the key theme of coordination and greater cooperation that underpins the “Three Ones” Principles.

In Indonesia, civil society organizations in Bali, East Java, Jakarta and Papua are involved in drafting provincial regulations that will determine budgeting for the AIDS response as well as presenting as experts in the parliamentary hearings. In addition to assisting in the planning of AIDS work, civil society is also active in service provision and monitoring. Spiritia, a national support network in Indonesia formed in 1995, assists 65 groups of people living with HIV throughout the country by providing treatment education, basic fact sheets and training in advocacy. Members of the Spiritia team regularly visit most of

Indonesia’s 35 provinces, documenting treatment, care and support and encouraging local government to improve services.

The role played by civil society is often underestimated, largely because it is not systematically measured. Yet it is clear that without the nongovernmental sector’s participation—including the work of vast numbers of volunteers at community level—many of the strategies and targets set by countries and the international community for responding to HIV would be unattainable. The experience and knowledge of these front-line providers is of utmost importance to national policy-making and to the development of stronger public health sectors.