



Focus

The essential role of people living with AIDS

Around the world, wherever HIV spreads, people living with HIV often quickly establish networks of self-help, support, and empowerment.

In June 1983 in Denver, United States of America, a movement of people living with HIV emerged at the Second National Forum on AIDS. The ‘Denver Principles’ adopted at the forum called for those living with HIV to be supported when they opposed AIDS-related stigma and discrimination. The Principles also stated that people living with HIV should “be involved at every level of decision-making [...], serve on the boards of directors of provider organizations, and participate in all AIDS meetings with as much credibility as other participants, to share their own experiences and knowledge” (Senterfitt, 1998). By 1988, the publication *AIDS Treatment News* listed more than 20 coalitions of people living with HIV across the Canada, United States, and the United Kingdom.

National and global groups emerge

In Uganda, The AIDS Support Organisation was the pioneer. It was formed in 1987 in Kampala by a group of 16 volunteers, 12 of whom were living with HIV. Such groups often form around clusters of people caring for a loved one. For example, Jamaica AIDS Support started up unofficially in 1991 as a result of a group of men helping a friend dying from AIDS. In other cases, a courageous individual has been prepared to be open about living with HIV, and has inspired others to

take positive action. In 1990, Joe Muriithi in Kenya was one of the first Africans to publicly disclose his HIV-positive status, and he and his wife, Jane Muriithi, started the Know AIDS Society. In 1992, Auxillia Chimusoro—one of the founders of the International Community of Women with HIV/AIDS—was one of the first people in Zimbabwe to publicly disclose her seropositive status, and she went on to form the Batanayi support group.

In Brazil, the Grupo Pela Vidda of Rio de Janeiro was founded in 1989 by writer and civil rights activist Herbert Daniel. The group’s Declaration of the Rights of People Living with HIV/AIDS was adopted unanimously by more than 50 organizations at the second National Meeting of HIV/AIDS NGOs in Porto Alegre, Brazil in 1989. In India, at a 1997 national workshop, some 35 HIV-positive individuals formed the Indian Network of Positive People. Ashok Pillai was elected General Secretary, and he assumed a public and prominent role on behalf of those living with HIV. Today, the Network has more than 1000 members from 14 states, and includes a positive women’s network. Sadly, like so many other pioneers of the AIDS movement, Ashok Pillai has passed away.

Globally, an international network of people living with HIV was initially formed in 1986, and later became the Global Network of People Living with HIV/AIDS. In July 1992, the International Community of Women Living with HIV/AIDS was formed by a group of HIV-positive women from 30 different countries who were attending the 8th International

Conference on AIDS in Amsterdam. The Community drew on the growing movement of HIV-positive women in Africa, which led to a new kind of activism extending beyond the immediate concerns of creating self-help and support groups.

The GIPA principle

The principle of the Greater Involvement of People Living with HIV/AIDS (GIPA) was formally recognized at the 1994 Paris AIDS Summit, when 42 countries agreed to support an initiative to “strengthen the capacity and coordination of networks of people living with HIV/AIDS and community-based organizations”. They added that, “by ensuring their full involvement in our common response to the pandemic at all—national, regional and global—levels, this initiative will, in particular, stimulate the creation of supportive political, legal and social environments”.

The Paris Declaration also expressed “determination to mobilize all of society—the public and private sectors, community-based organizations and people living with HIV/AIDS—in a spirit of true partnership”, as well as to fully involve “people living with HIV/AIDS in the formulation and implementation of public policies [and] ensure equal protection under the law for persons living with HIV/AIDS”.

In 2001, the United Nations Declaration of Commitment on HIV/AIDS endorsed the GIPA principle, which was further upheld in the Guiding Principles of the ‘3 by 5’ Treatment Initiative. These guiding principles state that, “The Initiative clearly places the needs and involvement of people living with HIV/AIDS in the centre of all of its programming” (WHO, 2003). UNAIDS has promoted GIPA since its beginning by involving people living with

HIV at all levels, including on its Programme Coordinating Board.

Roles of people living with HIV: national leadership

Despite these endorsements, the active involvement of people living with HIV in decision-making is still far from universal. Furthermore, the involvement of HIV-positive women, youth and children has lagged far behind that of men in most parts of the world. One constraint is that, globally, only about 10% of those living with HIV know their seropositive status. Others are unable to be open about their status because they fear they will face discrimination and stigma. Nevertheless, progress is being made.

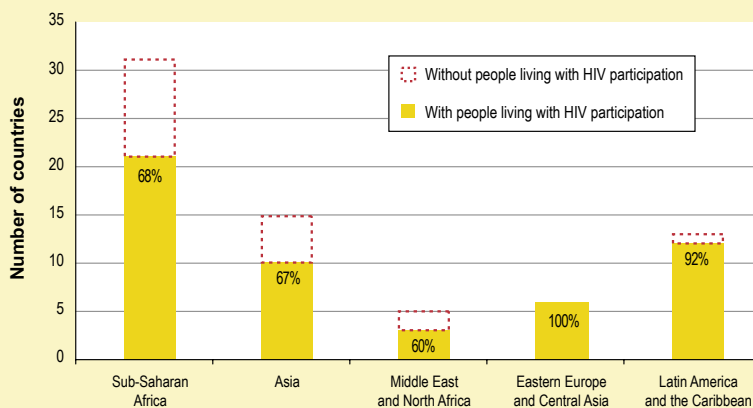
In Eastern Europe and Central Asia, the epidemic is still relatively new, but few people know their HIV status. Even fewer are willing to be open about it, and there is little tradition of civil society involvement. But, in recent years, the movement of people living with HIV has become stronger and more influential. For example, in Ukraine, the All-Ukrainian Network of Persons Living with HIV/AIDS has helped shape the National AIDS Prevention Programme, and is increasingly involved in providing HIV-related care services (UNDP, 2003).

The Cambodian People Living with HIV/AIDS Network has been actively involved in policy development. As a member of the Country Coordinating Mechanism, it helped formulate Cambodia’s successful funding proposal to the Global Fund to Fight AIDS, Tuberculosis and Malaria. Similarly, partnership forums have been established in many countries, bringing together people living with HIV and other government and nongovernmental partners in shaping AIDS responses (see Figure 51).

Elsewhere, the Asia-Pacific Network for People Living with HIV/AIDS has united people from over 20 Asian countries under the United Nations Development Programme's (UNDP) 'Leadership for Results' programme. This regional network has fostered developing national organizations of people living with HIV. One of these is Spiritia, in Indonesia, which has also received UNAIDS support. In cases of more recently emerging epidemics, UN Theme Groups on HIV/AIDS have encouraged and supported AIDS activist groups that are starting up.

Figure 51

Participation in partnership forums by people living with HIV, 2003



Source: UNAIDS Secretariat country offices, 2004

Providing services and encouraging local participation

In other cases, people living with HIV have long been involved in national decision-making. Increasingly, HIV-positive people are actively participating in local decision-making processes, and in providing services to others with HIV. Often, they are at the front line of care and support. For instance, in Cambodia, through the 'Friend Help Friend' units at district health centres, volunteers living with HIV

provide AIDS information and support, and help people adhere to their treatment regimens.

The link between providing services and national advocacy has most prominently come into play around the issue of extending access to treatment—one of the main priorities of AIDS activism. For example, in Thailand, the Thai Network of People Living with HIV/AIDS and the Thai NGO Coalition on AIDS encouraged the government to provide antiretroviral drugs under its national health insurance scheme. In December 2001, the Thai Government announced that it would extend health care to cover these medicines, and created a panel with Network representatives to oversee implementation.

In Kazakhstan, 30% of the country's HIV-positive people live in the city of Temirtau, where, since 1998, the NGO *Shapagat* ('mercy' in Kazakh) gives them a voice. The local municipal government provides *Shapagat* with offices, and the NGO works with its local AIDS centre, United Nations agencies, and the Open Society Foundation. *Shapagat* makes regular presentations to the local parliament and the government's executive authority. Temirtau's HIV-positive people have served on the

country's National AIDS Commission, and have also participated in the Global Fund's Country Coordinating Mechanism for Kazakhstan.

Employment and workplace issues

The presence of people openly living with HIV in the workplace shows it is possible to go on living and working normally, a critical first step in successfully dealing with work-

related discrimination. The United Nations Volunteers Programme has backed GIPA in Southern Africa by placing people living with HIV in mining companies, parastatal organizations, and United Nations agencies, among others. Programme participants carry out advocacy and education programmes, and actively help to develop AIDS workplace action plans. Similarly, in the Caribbean, since 2000 about 50 HIV-positive members of the United Nations Volunteers Programme have worked to counter AIDS-related discrimination in seven countries in the region.

Rarely do HIV-positive people get paid for caring for and supporting others living with the virus. One exception is Botswana, where a member of the country's Network of People Living with HIV/AIDS works as a community liaison officer with the infectious diseases clinic in the capital, Gaborone. Her personal experiences encountered in the process of living with HIV have been particularly important in helping patients (especially those who have come from distant villages) talk about the difficulties they have with adhering to their drug regimen, or the pressures that relatives exert on HIV-positive mothers to breastfeed their newborn children (UNAIDS, 2003).

Corporate, trade union and government support for AIDS workplace programmes exists in many places (see 'Impact' chapter and 'Prevention' chapter). However, the informal work sector still poses a significant challenge. India is a case in point. Some 92% of India's people work in the informal economy. The International Labour Organization (ILO), along with employers' and workers' organizations, has supported the Network of Positive People of Delhi's work in the informal sector.

The Network's members provide training, job assistance, and care and support to both HIV-positive workers and the families of those who have died of AIDS.

Commitment and courage require support

Involving people living with HIV in national AIDS responses has proved extremely valuable. However, doing so effectively requires recognizing a range of needs. Many programmes depend on the commitment and courage of HIV-positive individuals. An HIV diagnosis is already a life-changing event causing shock, grief, and a sense of loss of control over one's life. Disclosing one's HIV-positive status can be traumatic, even under the best of circumstances. Doing so publicly—as many HIV-positive activists have—is never easy, even when done with the support of the organizations in which they are active. Many United Nations, governmental and NGO initiatives around the world encourage such disclosure in order to prevent further spread of the virus, but they often fail to help HIV-positive people prepare for it, and they do not provide adequate support for the ongoing work the activists do.

Financing is crucial. People living with HIV need access to antiretroviral drugs and other essential care, and they need to receive a salary or other paid compensation for their time and contributions. Otherwise, their capacity to participate in the AIDS response is seriously hindered. One example of an innovative effort to plug the gap is in Uganda. A Treatment Fund for HIV/AIDS Advocates in Uganda currently provides six advocates with antiretroviral treatment, and is funded by Rotary International, and its Belgian and Ugandan

branches (Uganda AIDS Commission and UNAIDS, 2003). The Fund is co-managed by the Persons Living with HIV/AIDS Forum, which brings together all of Uganda's relevant networks and associations.

HIV-positive African women taking on activist roles have faced enormous challenges. They are frustrated over the pressures they encounter to disclose their status as part of prevention campaigns, while their own financial, medical and emotional needs are ignored. The commitment and volunteerism of people living with HIV has been exploited by NGOs and government programmes that use this cheap or free labour in place of health-care services (Manchester, 2003).

A study of 17 NGOs providing HIV and AIDS services in four countries (Burkina Faso, Ecuador, India and Zambia) revealed that failure to account for the needs of HIV-positive people reduced the effectiveness of the services provided. Involving people living with HIV in outreach education, before they receive the necessary training and ongoing support, can have a negative impact on service quality, and can also harm the individuals themselves (Horizons Program, 2002). Participation of people living with HIV at the international level can be hindered by difficulties obtaining travel insurance to cover any HIV-related illnesses or travel restrictions that many countries impose on people living with HIV.

Greater involvement comes from a supportive enabling environment

There are no simple answers to these problems. Within organizations seeking real (and not token) involvement, creating a supportive,

enabling environment requires a great deal of thought and commitment. HIV-positive people need training and support so they can participate more actively, and institutions need to make their procedures more participatory and accessible to people who may not be used to the customary formality of meetings and other institutional requirements. This is especially necessary if more HIV-positive women and young people—traditionally excluded from decision-making processes—are to be empowered to contribute in a meaningful way.

All of this means it is more essential than ever to provide more funds for capacity-building, financial compensation for work performed, and treatment and psychological support for HIV-positive people involved in such work. But more formal involvement of networks and organizations of people living with HIV (as opposed to informal personal involvement) would also help in implementing the GIPA principle in a sustained manner. The transition from self-help groups to representative organizations has taken place in many countries, creating additional needs to build organizational, management, advocacy, and leadership capacities.

The theme of the September 2003 International Conference of People Living with HIV/AIDS—The Dawn of New Positive Leadership—recognized these new roles. The Conference Declaration noted that “Our communities and organizations are still starved of the resources they need to effectively fulfil their potential and perform the role that is being demanded of us”. The Declaration demanded “That we are supported in our efforts to build capacity

to effectively contribute as equal partners in the response”.

Conclusion

Experience has shown that involving people living with HIV in a meaningful way is a core element of an effective response to the epidemic. Strengthening and sustaining this role requires:

- i) **that people know their HIV status** (which, in turn, requires vastly increased access to voluntary counselling and testing facilities);
- ii) **keeping people alive** with antiretroviral treatment so they can remain active in their chosen fields of work; and
- iii) **creating the practical and political space for people living with HIV to expand their role and contribution** by addressing HIV-related stigma and discrimination; promoting appropriate legal and policy environments; and supporting participation with resources, including organizational development.

Already, AIDS organizations exist in many forms—from support and service-delivery bodies to advocacy and representational organizations. In the face of a long-standing but constantly changing epidemic, the range of these organizations needs to be extended even further. In particular, as more people know their HIV status, it means reaching out beyond recognized AIDS networks, to non-health-care settings—for instance, to workplaces, places of worship, schools and other institutions. Networks of people living with HIV are demonstrating their commitment to forging new partnerships; now they need help in order to enhance their organizational capacities and meet these new challenges. 