PART IV

THE INSTITUTIONAL RESPONSE

The institutional response to the HIV/AIDS pandemic also has a history. Almost immediately following the recognition of AIDS in the early 1980s, nongovernmental and community organizations arose to provide care and then prevention services to severely affected groups. At that time and for several years thereafter, virtually no national programs for prevention or care were developed. Then, generally in response to public pressure, national governments began to consider what they should do. During the same period in the early to mid-1980s, the World Health Organization became the first major organization and the first intergovernmental agency to begin mobilizing for HIV/AIDS prevention and care.

National governments and WHO tended to view their roles in relatively similar and complementary ways. True to the traditions of public health, governments initiated programs of information and education and related health services such as testing and counseling. From WHO's perspective, the need for a global mobilization implied catalyzing and supporting national AIDS programs in countries that were either already affected but were passive in their response, or were not yet affected. Together, WHO and national governments (or ministries of health) developed common policies and models for HIV prevention and care work. Donor nations rapidly responded to WHO's appeal for resources and by 1988 the Global Program on AIDS had become WHO's largest and most dynamic activity. Relatively soon thereafter, and partially in response to the UN General Assembly Resolution of late 1987[1], other members of the UN family, including notably United Nations Development Programme (UNDP), United Nations Children's Fund (UNICEF), United Nations Educational, Scientific and Cultural Organization (UNESCO), United Nations Population Fund (UNFPA), International Labour Organization (ILO), and the World Bank began to make their own contributions to HIV/AIDS prevention and care. The goal was to ensure that compre-

hensive national programs were in place worldwide. What is the status today of these collective efforts—at the nongovernmental, national governmental, and intergovernmental levels?

This part of *AIDS in the World II* explores the current work at each of these levels, with particular attention to the new challenges each is encountering. In summary, the major findings are as follows:

- National AIDS programs have experienced considerable difficulty fulfilling their central responsibilities for prevention and care (see Chapter 30).
- The challenge of ensuring that national AIDS programs are carried out (including policies, programs, and practices) in a manner which respects the human rights and dignity of HIV-infected people and people with AIDS has only been partially met (see Chapter 31).
- Nongovernmental organizations are undergoing a difficult transition period in their internal evolution, their relationship to official agencies, and their financial sustainability (see Chapter 32).
- The private sector is having difficulty fulfilling its potential role in promoting HIV prevention (see Chapter 33).
- The United Nations has created a new program, called UNAIDS, to better coordinate the work of the major UN agencies working on HIV/AIDS (see Chapter 34).
- International funding for HIV/AIDS prevention and care is relatively static, and this is failing to keep up with the rapid growth in prevention and care needs. Official development assistance for HIV/AIDS is becoming increasingly bilateral, so that in relative terms, support to multilateral efforts is diminishing (see Chapter 35).
- The cost of care for HIV-infected people and people with AIDS is increasing as the pandemic expands. The nature of HIV/AIDS care in the developing world is severely and increasingly disadvantaged compared with the industrialized world (see Chapter 36).
- Global spending on HIV/AIDS prevention, care, and research now exceeds U.S. $18.4 billion. Spending on care is five times greater than spending for prevention, and over 92 percent of prevention and care spending occurs in the industrialized world, while the developing world has over 90 percent of the global total of HIV-infected people and people with AIDS (see Chapter 37).

Of course, the collective response is really a complex mosaic, including some highly successful efforts in both prevention and care. Yet overall, the collective response seems enmeshed in trying to carry out the difficult tasks that it defined and that were defined for it nearly a decade ago. Meanwhile, the pandemic has intensified and expanded, organizational and institutional practices (even if less than effective) have tended to become fixed, and resources (especially since 1990) have not kept pace with the needs.

Thus the collective response seems to harken back to the mid-to-late 1980s, seeking to fulfill a mission which is necessary but now recognized to

be insufficient to bring the pandemic under control. In the meanwhile, the pandemic is evolving (Part I), and as described in Parts II and III, a new approach is needed to address the social dimensions of vulnerability to HIV.

REFERENCES

1. United Nations General Assembly: *Resolution 42/8 of the Forty-second General Assembly of the United Nations: Prevention and Control of Acquired Immune Deficiency Syndrome (AIDS)* (New York: UN, 26 October 1987).

30

Governmental National AIDS Programs

This chapter focuses on the governmental response to AIDS and specifically on governmental national AIDS programs (GNAP). It is based on the most extensive survey of GNAP managers thus far conducted.

In *AIDS in the World* (1992), a framework to assess GNAP work was proposed using 11 criteria: (1) voicing commitment; (2) translating commitment into action; (3) coalition building; (4) planning and coordinating; (5) managing; (6) responding to prevention needs; (7) responding to care needs; (8) securing financial resources; (9) sustaining the effort; (10) evaluating progress; and (11) evaluating impact.[1] This framework was applied to the questionnaire of the survey conducted by AIW II (Box 30-1). Detailed responses by country are listed in Appendix D.

BOX 30-1

A survey of government national AIDS programs

The first edition of *AIDS in the World* presented a framework for the assessment of national programs.[1] This framework served as the template for the survey of government national AIDS programs (GNAP) presented in this volume. That survey, including both a mailing and follow-up telephone inquiries, was carried out between December 1993 and June 1994. The survey questionnaire was designed and tested with six GNAP managers, then revised and distributed in English, French, Spanish, and Japanese. Follow-up contacts with respondents were also made in Arabic, Chinese, French, Portuguese, and Spanish. While the first edition of *AIDS in the World* surveyed a panel of 38 countries, the present study sought responses from 187 countries/territories ("countries"), including the 184 member states of the United Nations as of June 1994, plus Hong Kong, Switzerland, and Taiwan. The effort involved the collaboration of WHO Regional Offices and multiple inquiries with embassies and ministries of health and resulted in the most complete directory of GNAP contacts available to date. Areas and Territories that are geographically distant from the mainland of the state of which they are part were also sent a questionnaire in order to collect information on differing epidemiological, cultural, or social features.* That information was used in commentaries included in various chapters of this book, but not included in the quantitative analysis.

*Responses were received from American Samoa, Cook Islands, Guam, New Caledonia, Niue, Tokelau, Tuvalu, Bermuda, Cayman Islands, Montserrat, and Netherlands Antilles.

Table 30-1.1 Governmental national AIDS programs (GNAP) response rate to *AIDS in the World II* survey

GAA	Total number of countries in GAA	Number of responding countries	Percentage of countries responding	Total population in GAA (millions)	Population of responding countries (millions)	Percentage GAA population in responding countries
1 North America	2	1	(50%)	286	258	(90%)
2 Western Europe	24	17	(71%)	383	301	(79%)
3 Oceania	9	9	(100%)	27	27	(100%)
4 Latin America	20	15	(75%)	427	405	(95%)
5 Sub-Saharan Africa	48	31	(65%)	560	337	(60%)
6 Caribbean	13	7	(54%)	30	12	(39%)
7 Eastern Europe	27	16	(59%)	418	287	(69%)
8 SE Mediterranean	21	9	(43%)	473	92	(19%)
9 Northeast Asia	11	6	(55%)	1,490	1,407	(94%)
10 Southeast Asia	12	7	(58%)	1,435	1,021	(71%)
Total world	187	118	(63%)	5,529	4,147	(75%)

Source: *AIDS in the World II* survey.

Responses were received from 118 of the 187 countries surveyed (63%) (Table 30-1.1). The total population of respondent countries was 75 percent of the world population. The highest response rate was achieved in Oceania (100 percent) and the lowest in the Southeast Mediterranean region (43 percent). The degree of completeness and specificity of the information provided in the returns varied from complete and detailed information (about one-quarter of respondents) to sparse and fairly general responses, of which about half were improved through active follow-up. The extensive collaboration of respondents was very much appreciated, especially given the enormous operational and administrative demands on their time and the growing number of GNAP surveys that followed from many sources in the wake of the first-ever survey carried out by *AIDS in the World* in 1992.

The summary information originates from GNAP managers, usually located within ministries of health. Although GNAP managers were invited to seek information on specific issues from the best-informed sources within other government sectors, they may not have done so. For example, questions on HIV/AIDS-related laws and practices assumed that GNAP managers would be fully aware of the legal context within which their program operates or that they would verify the legislation with ministries of justice (Chapter 31).

An important constraint involved the growing difficulty GNAP managers have in tracking financial resources allocated to and spent on HIV/AIDS prevention and care. In some countries, the integration of HIV/AIDS with broader health and social programs has been accompanied by a multiplication of funding sources, a dispersion of resource allocation, and a consequent decline in financial tracking capability. In all likelihood, the financial information provided in this volume is therefore only a partial representation of the resources allocated to and spent by government-controlled HIV/AIDS initiatives.

The questionnaire sought quantified, documented information obtained by GNAP managers from records and reports. When such information was unavailable, the questionnaire invited GNAP managers to provide an informed opinion on the degree to which a particular value or situation might have changed over time. Such entries are marked in the tabulation of results as an *opinion* sought from the GNAP manager, in order to differentiate such information.

Finally, in some cases, GNAP managers had been prevented by higher authorities from releasing information. When this censorship occurred, it had generally been provoked by the section of the questionnaire that sought information on human rights issues.

Detailed responses are displayed in Appendixes D and E, for each responding GNAP regrouped in

"Geographic Areas of Affinity." Tabulated results are presented and analyzed in various chapters throughout this volume.

The editors are grateful to GNAP managers who responded to this survey despite their heavy workload.

References

1. J. M. Mann, D. Tarantola, T. W. Netter, and The Global AIDS Policy Coalition, eds., *AIDS in the World* (Cambridge, MA: Harvard University Press, 1992):282–283.

Voicing commitment

Are high governmental officials expressing publicly their commitment to prevent the spread of HIV and care for those infected? Since the beginning of the pandemic 60 percent had done so and 40 percent had not (Table 30-1). High governmental officials in those geographic areas of affinity (GAAs) that have experienced visible HIV epidemics (North America, Western Europe, Oceania, Caribbean, sub-Saharan Africa, Latin America, Southeast Asia) were nearly three times more likely to have addressed the issue publicly, compared to those in less affected GAAs (Eastern Europe, Southeast Mediterranean and Northeast Asia).

Translating commitment into action

The reporting of the first AIDS case in each country and the creation of GNAPs have followed two waves of similar shape (Figure 30-1). Most GNAPs were established between 1985 and 1990; by mid-1994, essentially all countries had a GNAP. The translation of commitment into the allocation of financial resources is reflected in the financial analysis carried out to estimate national spending on HIV/AIDS prevention, care, and research (Chapter 37).

Table 30-1 Public addresses on AIDS made by high governmental officials[a]

GAAs	Top governmental authority made a statement on AIDS	Top governmental authority did not make statement on AIDS	Total respondents
GAAs with visible or severe HIV epidemics[b]	59 (71%)	24 (29%)	83
Less affected GAAs[c]	8 (28%)	21 (72%)	29
All GAAs	67 (60%)	45 (40%)	112

Source: *AIDS in the World II* survey.

[a]"Top governmental authority" was defined by the respondent and may include heads of state, presidents, prime ministers, and ministers of health.

[b]North America, Western Europe, Oceania, Latin America, sub-Saharan Africa, Caribbean and Southeast Asia.

[c]Eastern Europe, Southeast Mediterranean, Northeast Asia.

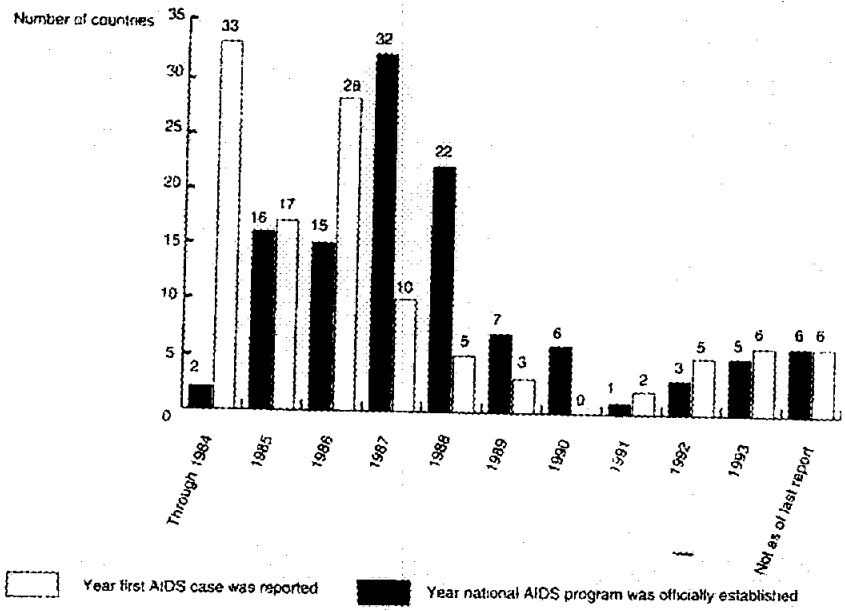


Figure 30-1 Number of countries developing national AIDS programs and reporting first AIDS case, by year, 1984–1993.

Coalition building

Coalition building by GNAPs requires expanded partnership between ministries of health and other government ministries, nongovernmental organizations (NGOs), and the private sector. An indication of attempts to build such coalitions can be obtained by noting the participation of groups outside the ministry of health in AIDS policy development. WHO has recommended that policy development be guided by national AIDS advisory committees (NACs) or the equivalent advisory bodies, in most cases appointed by the minister of health.

Overall, 85 percent of responding countries reported having an NAC. This proportion was lowest in Latin America and Eastern Europe (53 percent and 63 percent, respectively). NAC membership averaged 21 people, with a range of 7 to 74 participants. Gender representation for these committees varied widely; the proportion of women committee members averaged 30 percent (ranging from 0 to 67 percent). An average of 27 percent of NAC participants were from NGOs; 14 of 88 countries had no NGO representative on their NAC.

GNAP managers were also asked who had been consulted in AIDS policy development. Health professionals had been consulted in virtually all (96 percent) of the 94 countries; other government ministries in 82 countries (87 percent); other agencies in 77 (82 percent); state or regional authorities in 72 (77 percent); people with HIV/AIDS were involved in 41 countries (44 percent); and members of parliament in 29 countries (31 percent). In only 17 countries (18 percent) had all of the above groups been consulted.

Table 30-2 Contents of national AIDS policy and program documents

Key element	Does the document contain the key element listed? (Number and percentage of countries responding)			
	Yes	No	Did not respond to specific key element	Total
Statement of national policies on HIV/AIDS	79 (85%)	12 (13%)	2 (2%)	93 (100%)
Description of strategic approaches for the health sector	81 (87%)	11 (12%)	1 (1%)	93 (100%)
Description of strategic approaches for the health sector and other sectors such as ministries of development, education, and justice	61 (66%)	29 (31%)	3 (3%)	93 (100%)
Description of specific activities for the health and other sectors	77 (83%)	13 (14%)	3 (3%)	93 (100%)
Proposed budget for central/federal expenditures on HIV/AIDS	68 (73%)	24 (26%)	1 (1%)	93 (100%)
Evaluation plan for government activities	53 (57%)	37 (40%)	3 (3%)	93 (100%)

Source: *AIDS in The World II* survey.

Planning and coordination

By early 1994, 82 percent of 118 responding countries had developed an AIDS policy and program document. Further information was available from 93 countries on the content of these documents (Table 30-2). Document completeness varied widely; only 31 percent of GNAP policy and planning documents included all six of the key elements.

The responsibility for GNAP activities was vested primarily in the ministry of health for over half of the countries, but the dominant ministry of health role in major GNAP tasks diminished from 1991 to 1993 (Figure 30-2). In addition, the survey revealed that AIDS programs have occasionally been created in other ministries such as education (in 88 percent of the countries surveyed), defense (61 percent), and other ministries (between 11 and 39 percent), as shown in Figure 30-3. Nevertheless, GNAPs remain identified with ministries of health in most countries, raising important questions about the ability of governments to develop and disseminate a broader and expanded response to the HIV/AIDS pandemic.

Managing

The survey focused on two aspects of GNAP management: staff training and program decentralization (Figure 30-4). Strikingly, GNAP managers had been trained in only 40 percent of responding countries; levels of training for other important management staff were uniformly lower.

Decentralization of AIDS programs to regional or provincial levels was

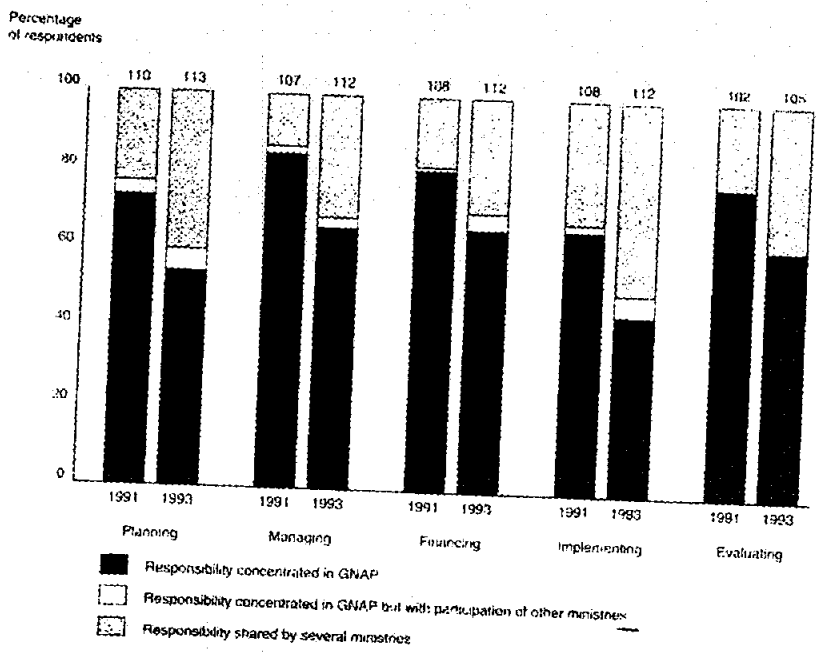
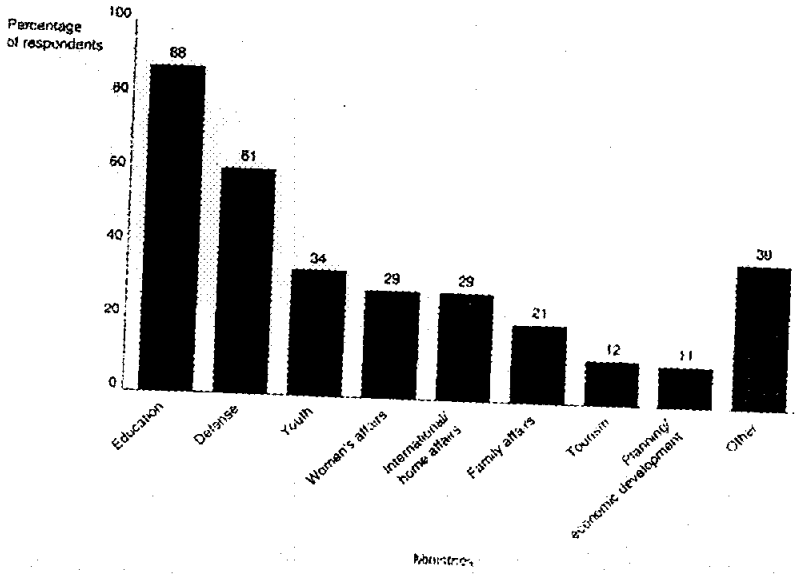


Figure 30-2 Division of responsibility for several tasks of GNAP, among ministries of health, 1991 and 1993.

Figure 30-3 Countries with AIDS programs in ministries other than the ministry of health. Eighty-three countries responded to this question.



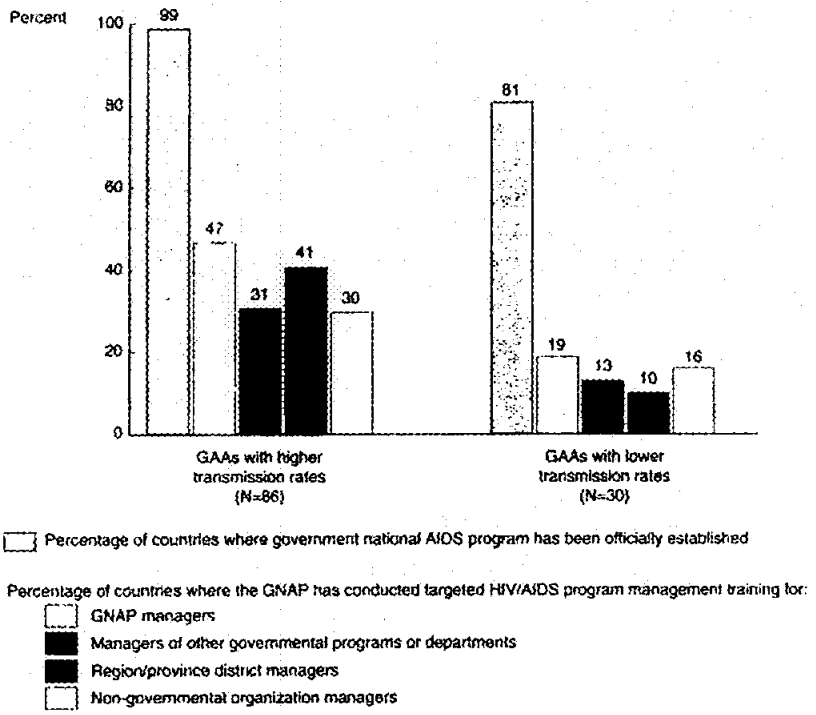


Figure 30-4 Percentage of countries with officially established national AIDS programs and where GNAP conducted targeted training on managing HIV/AIDS programs.

reported by about half (48 percent) of responding countries; 29 percent were partially decentralized and the remaining 23 percent were still completely centralized.

Responding to prevention and care needs

Assessments regarding prevention had been conducted in 70 percent of the countries surveyed and care needs in 54 percent (Table 30-3). To assess GNAP responsiveness to prevention and care needs, two measures were chosen: condom distribution and availability of voluntary testing with counseling.

Condom distribution

A large majority of countries reported that the distribution of condoms was allowed in certain sites (e.g., pharmacies and drug stores) (93 percent), and in sexually transmitted infection (STI) and other clinics (91 percent). However, substantially fewer reported that distribution was allowed in other settings such as hotels, bars, universities, and high schools. From 1990 to 1992 there was a very modest increase in the variety of sites where condoms were allowed to be distributed.

Table 30-3 Needs assessment conducted by government national AIDS programs

	Number and percentage of countries responding			
	Yes	No	No response	Total
Needs assessment for prevention	66 (70%)	24 (26%)	4 (4%)	94 (100%)
Needs assessment for care	51 (54%)	39 (41%)	4 (4%)	94 (100%)

Source: *AIDS in the World II* survey.

Voluntary HIV testing and counseling

Testing for HIV was available widely in only 58 percent of 113 countries and only in large cities in the remaining 42 percent (Table 30-4). Pre- and/or post-test counseling was said to be available in nearly all countries (106; 95 percent). However, only 45 percent of countries reported always providing pre-test counseling; 70 percent of countries always counseled persons who were found HIV seropositive; and 32 percent of countries always counseled persons found HIV seronegative (Figure 30-5). The lack of systematic pre- and post-test counseling was apparent in both industrialized and developing countries. For example, only 4 of 15 Western European countries (27 percent) reported systematic pre-test counseling; a similar proportion reported counseling of persons found HIV seronegative and 69 percent systematically counseled persons found HIV seropositive.

Seventy-seven countries also provided estimates of the number of HIV tests performed in 1993 (Table 30-4). Comparing 1990 and 1992, 22 percent of countries reported a considerable—greater than twofold—increase in the number of HIV tests performed and 42 percent reported a moderate increase (one- to twofold). Thirty percent of countries reported that the number of HIV tests had either stabilized or decreased.

It is evident that major gaps still exist in the availability of HIV testing facilities in several regions in the world and when available, testing is not accompanied with systematic pre- and post-test counseling in a significant number of developing and industrialized countries.

Securing financial resources and striving toward sustainability

Financial resources spent on HIV/AIDS prevention, care, and research are drawn from multiple sources: public, private, and, in the case of developing countries, international. Patterns of program spending are presented in Chapter 37. A comparison of the estimated overall spending on HIV/AIDS prevention, care, and research in low economies, inclusive of grants from official development agencies (ODAs) and of World Bank loans, show that developing countries are already bearing the brunt of AIDS program costs. It was estimated that in 1993 low economies spent $1.4 billion on national HIV/AIDS programs (Chapter 37). In that year, the external funding made available to them through ODAs totaled about $257 million, including the institutional costs and overhead levied by implementing agencies (UN Agencies, NGOs, private voluntary organizations, and other contractors) (Chapter 35). Thus the external financing from ODAs to NAPs in low economies

Table 30-4 Voluntary HIV testing—availability and number of tests performed, by GAA, 1993

GAA	Availability (No. and percentage of countries responding)			No. of tests performed per 1,000 adults (aged 15–49) in country as reported by GNAP			Number responding
	Everywhere in the country	Only in large cities	Total	Lowest	Mean	Highest	
1 North America	1 (100%)	0 (0%)	1 (100%)				
2 Western Europe	16 (94%)	1 (6%)	17 (100%)	8.7	115.9	322.5	11
3 Oceania	3 (33%)	6 (67%)	9 (100%)	17.6	68.8	215.9	6
4 Latin America	8 (57%)	6 (43%)	14 (100%)	1.8	24.6	42.0	7
5 Sub-Saharan Africa	7 (24%)	22 (76%)	29 (100%)	0.7	22.6	195.0	21
6 Caribbean	4 (67%)	2 (33%)	6 (100%)	27.4	48.2	93.1	6
7 Eastern Europe	12 (80%)	3 (20%)	15 (100%)	3.5	214.5	484.2	13
8 SE Mediterranean	4 (44%)	5 (56%)	9 (100%)	11.1	116.3	350.0	5
9 Northeast Asia	5 (83%)	1 (17%)	6 (100%)	1.3	43.4	148.2	5
10 Southeast Asia	5 (71%)	2 (29%)	7 (100%)	27.9	56.0	111.4	3
All GAAs	65 (58%)	48 (42%)	113 (100%)	0.7	94.1	708.1	77

Source: *AIDS in the World II* survey.

Figure 30-5 Frequency with which HIV counseling is provided in the country.

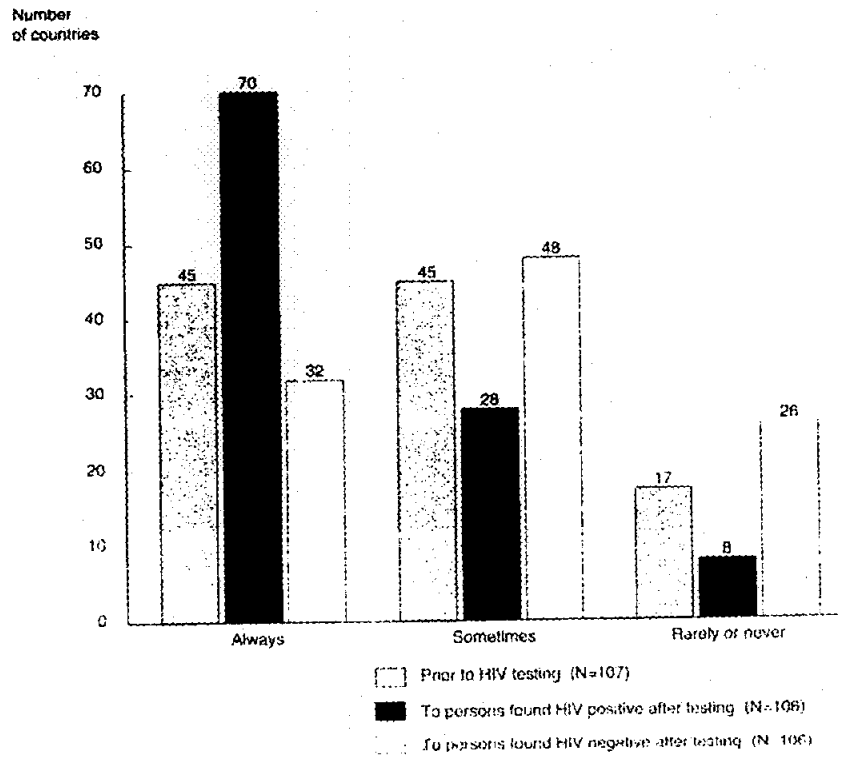


Table 30-5 Outcome indicators used to evaluate government national AIDS programs*

Outcome indicator	Number and percentage of countries responding		
	Evaluated outcome	Outcome not evaluated	No response
Number of people provided with targeted HIV/AIDS prevention message/education	74 (82%)	11 (12%)	5 (6%)
Number of people HIV tested	70 (78%)	16 (18%)	4 (4%)
Number of condoms distributed	64 (71%)	19 (21%)	7 (8%)
Number of people reached by program	60 (67%)	24 (27%)	6 (7%)
Number of people who are HIV positive	59 (66%)	20 (22%)	11 (12%)
Noted behavior change	50 (56%)	29 (32%)	11 (12%)
Other	20 (22%)	0 (0%)	70 (78%)
Needles/syringes exchanged	18 (20%)	51 (57%)	21 (23%)

Source: *AIDS in the World II* survey.
*90 countries responded.

Table 30-6 Influence of evaluation on GNAP

	Number and percentage of countries reporting			
	Major change	Minor change	Population	No response*
Change in program strategies	35 (44%)	13 (16%)	27 (34%)	5 (6%)
Reformation of the national HIV/AIDS plan	31 (39%)	15 (19%)	26 (33%)	8 (10%)
Personnel changes	23 (29%)	21 (26%)	28 (35%)	8 (10%)
Redirection of a specific needed service	17 (21%)	13 (16%)	31 (39%)	19 (24%)
Change of a certain project focus	20 (25%)	20 (25%)	24 (30%)	16 (20%)
Ending a program component	7 (9%)	9 (11%)	45 (56%)	19 (24%)
Beginning a new program component	29 (36%)	14 (18%)	22 (28%)	15 (19%)

Source: *AIDS in the World II* survey.
*A country was counted as not responding to a segment of this question only if it had responded to another segment.

represented less than one-fifth of the estimated expenditures incurred in the developing world to cover the direct cost of HIV/AIDS prevention, care, and research. While this relatively modest external contribution has helped developing countries to better cope with the rising cost of HIV/AIDS, the mere fact that they mobilized more than 80 percent of the overall direct cost of AIDS from national sources increases the likelihood of long-term sustainability of their response to the pandemic at a time when international grants are harder to obtain.

Evaluating progress and impact

Of the 105 countries responding to this part of the survey, 85 (81 percent) reported that their GNAP had been evaluated at least once. This proportion was higher in developing (93 percent) than in industrialized countries (67 percent). These evaluations involved the participation of ministries of health in 93 percent of countries; other ministries in 73 percent; NGOs in 68 percent; representatives of international agencies in 85 percent (largely involving developing countries); and of all groups mentioned above, in 52 percent of countries. The variety of outcome indicators used to evaluate programs are listed in Table 30-5. The indicator most frequently used was the number or proportion of people provided with specific HIV/AIDS prevention education or messages (82 percent). Overall, the majority of countries still focus their evaluation on management processes and service coverage, with a lower proportion reporting attempts to evaluate epidemiological or behavioral impact.

Do evaluation findings influence program strategies and activities? Countries were asked to describe the influence of evaluation on program design and decisions in seven categories (Table 30-6). Over half of the countries reported having introduced major or minor changes in program strategies and/or having reformulated their national HIV/AIDS plan as a result of program evaluation. No programmatic changes occurred following the evaluation in 31–56 percent of countries, depending on the category of design or section; and 7 (9 percent) GNAPs reported no change in any of the categories listed. While program evaluation has become a more regular feature of GNAPs, the application of evaluation for reorienting programs or making structural or operational decisions is not yet widely apparent.

REFERENCES

1. J. Mann, D. Tarantola, and T. Netter, eds., *AIDS in the World* (Cambridge, MA: Harvard University Press, 1992):202–283, 605–683.

31

Human Rights and Responses to HIV/AIDS

SOFIA GRUSKIN, AART HENDRIKS,
AND KATARINA TOMASEVSKI

The relationship between human rights and HIV/AIDS prevention and control has proceeded through three relatively distinct phases. In the first phase, starting in 1981, the proposed application of public health measures such as isolation, mandatory testing, and quarantine to the new health problem led to a direct confrontation between health officials and human rights advocates. In the second phase, starting around 1987, international health officials explicitly recognized that discrimination against HIV-infected people and people with AIDS reduced the effectiveness of public health prevention efforts and was therefore counterproductive. This perspective was espoused by the World Health Organization (WHO), the UN agency primarily responsible for health issues. WHO's governing board, the World Health Assembly, adopted a resolution in 1988 which stated that preventing discrimination against HIV-infected people and people with AIDS was an essential element in a successful HIV prevention program; the principle of nondiscrimination was consequently incorporated into WHO's Global AIDS Strategy.

The third phase developed in the late 1980s and early 1990s as independent analysis by groups such as the Global AIDS Policy Coalition led to a new perspective on the pandemic. This new perspective focused on vulnerability to HIV infection. When considering the personal, programmatic, and societal forces which contribute to vulnerability to HIV/AIDS, it became clear that a lack of respect for human rights and dignity was a major contributor to the HIV/AIDS problem. This awareness of a fundamental connection between HIV and human rights has slowly but increasingly led to new and deeper collaboration between public health officials and human rights advocates. Today, the basic, inextricable link between promoting and protecting human rights and health (HIV/AIDS or other major health problems of the modern world) is becoming more evident and serves as a new basis for action (see Part V).

This new collaboration between public health workers and human rights experts around HIV/AIDS issues is starting to influence the larger world of public health. One dimension of this work focuses on negotiation to ensure

that public health policies, programs, and practices respect—to the maximum extent possible—human rights and dignity.

The following chapter focuses on this issue from the perspective of international law and human rights. To readers interested in the language of public health, the discussion may seem legalistic. Yet it is part of a fruitful dialogue between public health and human rights, based on an increasingly mutual ability to explore and consider differing underlying assumptions and terminology. This chapter focuses on the largest current area of human rights–HIV/AIDS interaction, involving efforts to prevent discrimination against people living with HIV or AIDS and certain people considered by societies to be at high risk of HIV infection (e.g., gay men, injecting drug users, sex workers). How the promotion and protection of human rights are linked with vulnerability to HIV/AIDS is discussed in detail in Part V.

Human rights and HIV/AIDS: key principles

The importance of bringing public health policies and programs in line with human rights law is, at least in theory, increasingly acknowledged by the international community. However, in the context of HIV/AIDS, a review of national laws, policies, and practices worldwide reveal a lack of consistent adherence to human rights standards.

A specific problem in this regard involves discrimination, which ensues when a distinction is made against a person that results in their being treated unfairly and unjustly. (This discussion is limited to negative discrimination. Laws and policies that treat people differently in an effort to ensure equal enjoyment and exercise of rights [positive or affirmative action] are not addressed in this chapter.) Discrimination commonly results from prejudice and misinformation, a denial of human variety, and feelings of superiority towards those considered "different." The principle of nondiscrimination is central to human rights thinking and practices. Each of the major human rights treaties specifically details the principle of nondiscrimination with respect to race, color, sex, language, religion, political or other opinion, national or social origin, property, birth, and, as it is called, "other status." The prohibition of discrimination does not mean that differences should not be acknowledged, only that different treatment must be based on objective and reasonable criteria.

Although international human rights law does not explicitly prohibit discrimination on the grounds of health status, the United Nations Commission on Human Rights has stated that "all are equal before the law and entitled to equal protection of the law from all discrimination and from all incitement to discrimination relating to their state of health."[1]

Rectifying inequalities—including health inequalities—and protecting people against discrimination are at the very core of human rights work. Human rights law generally concerns the relationship between the individual and the state, and includes civil, political, economic, social, and cultural rights which human beings everywhere are entitled to enjoy. Certain rights

are absolute, which means that they can never be restricted—whether by governments or others. These rights include the right to life, the right to be free from torture, slavery, or servitude, and the right to a fair trial. However, interference with most human rights can, under narrowly defined circumstances, be justified if necessary for the achievement of an overriding public good. Public health is recognized as one of the legitimate grounds for restricting human rights. Nonetheless, such interferences with human rights are considered acceptable only if they are:

1. provided for and carried out *in accordance with the law;*
2. in the interest of a *legitimate objective* of general interest;
3. *strictly necessary* in a democratic society to achieve such a goal;
4. imposed *without a less intrusive means being available* to reach the same goal;
5. **not** imposed *arbitrarily,* i.e., in an unreasonable or otherwise discriminatory manner.[3]

Government health policies have not always taken this approach into account. Traditional public health measures have focused on curbing the spread of disease by imposing restrictions on those already infected or thought to be most vulnerable to infection. In fact, coercion, compulsion, and restriction have often been principal components of public health measures.[3] Interferences with the rights of individuals, justified as necessary to protect the public health, must be recognized as human rights violations if they do not satisfy the above-listed criteria.

Generally, the people most likely to experience discrimination are socially and/or economically disadvantaged and therefore have great difficulty preventing laws or actions that discriminate against them or seeking redress.

Data collected over the course of the AIDS epidemic has clearly shown that public health efforts to prevent and control the spread of HIV/AIDS are most likely to succeed (e.g., lower HIV incidence, increase the quality of life of those infected) if policies and programs respect, instead of violate, human rights.[4] Involuntary public health measures are hardly ever justified, let alone necessary.* In the context of AIDS, legitimate interferences with human rights can only occur in very exceptional circumstances.

International responses to AIDS and violations of human rights

Nongovernmental organizations

Information on human rights violations is usually made known to intergovernmental agencies through the work of individuals and national or international nongovernmental organizations (NGOs). Although the intergovernmental system has generated quite a bit of HIV/AIDS-related work, this pattern generally has not been followed with respect to AIDS-related human rights violations. In fact, the large international human rights NGOs

*The World Health Assembly adopted a number of resolutions stating that there is no public health rationale to restrict the rights of individuals in the context of HIV/AIDS. Cf. WHO/World Health Assembly, Resolution WHA45.35 (May 1992).

have only recently begun to consider HIV/AIDS-specific issues. The slow response of the established human rights NGOs to HIV/AIDS-related issues has resulted in intergovernmental organizations and agencies receiving the majority of their information from governments.

In most countries, human rights violations arising from HIV/AIDS have been identified and addressed by AIDS service organizations (ASOs). ASOs have mobilized to provide needed prevention and care services, and while often involved in advocacy efforts, they may not have had experience in working to redress human rights violations. Further, local or national human rights organizations have frequently not considered HIV/AIDS to be an important or relevant issue for their work. Nevertheless, an enormous amount of advocacy seeking to redress and prevent discrimination towards HIV-infected people, people with AIDS, and members of population groups considered at high risk of HIV infection has been generated and advanced by ASOs and other community organizations.

Stimulated by courageous efforts of many local and national groups, international human rights NGOs are gradually becoming active, for example:

- Amnesty International undertook a comprehensive study, including questionnaires addressed to ASOs worldwide, to determine in what circumstances AIDS-related issues are within Amnesty's mandate. Amnesty International has begun to note the impact of HIV/AIDS in their country reports and in their international advocacy efforts.
- The International Commission of Jurists (ICJ) has adopted items on its future agenda relevant to HIV/AIDS, including discrimination on the grounds of sexual orientation, drug use and addiction, and HIV/AIDS status.
- The International Human Rights Law Group submitted a petition in April 1993 to the UN Working Group on Arbitrary Detention. It was offered on behalf of the approximately 190 Haitian nationals seeking political asylum in the United States who were in detention because of their HIV status at the U.S. Naval Base in Guantanamo Bay. In addition, the International Human Rights Law Group has integrated HIV/AIDS concerns, including the application of human rights standards, into their international advocacy work.
- Asia Watch and the Women's Rights Project of Human Rights Watch highlighted AIDS-related issues in a report on the trafficking of Burmese women and girls into Thai brothels.
- The International Gay and Lesbian Human Rights Commission (IGLHRC), created in 1991, has acted as the action secretariat of the International Lesbian and Gay Association (ILGA), with a focus on the human rights of sexual minorities and people with HIV/AIDS. IGLHRC issues "action bulletins" to over 3,000 people and organizations around the world to catalyze campaigns in response to human rights violations.
- Other human rights NGOs have also studied related topics. For example, Article 19, the International Centre Against Censorship, has re-

cently completed a comprehensive report which includes AIDS-related issues in its analysis of how the denial of access to family planning information has an impact on the rights and health of women.

The intergovernmental system

Prior to HIV/AIDS, human rights principles only marginally influenced the design of international public health policies. While human rights norms are increasingly acknowledged by policy makers, the classic (non-human rights associated) public health approach is still apparent in many public health laws and regulations.

Beginning in 1987, the WHO Global Programme on AIDS introduced a number of guidelines that increasingly reflected a commitment to human rights. Guidelines were adopted on such diverse issues as testing, travel and immigration policies, blood safety, prison health, mother-to-child transmission of HIV, and employment.[5]

Following the lead of the World Health Organization, between 1987 and 1990 virtually every agency of the United Nations issued resolutions or undertook some activity intended to limit the impact of HIV/AIDS on individuals and society. Several agencies adopted explicit nondiscrimination policies with respect to HIV/AIDS within their areas of work.* Since that time, the UN bodies responsible for human rights have continued to varying degrees to concern themselves with HIV/AIDS–related issues. For example, the UN Commission on the Status of Women declared the effect of HIV/AIDS on the advancement of women a priority theme for 1993–1997.[6] In March 1993 the UN Commission on Human Rights called on all states to ensure the full enjoyment of civil, political, economic, social, and cultural rights, not only for people with HIV/AIDS but also for their families and anyone associated with them or presumed to be at risk of infection, with particular attention to be given to vulnerable groups.[7] The treaty-monitoring body for the International Covenant on Economic, Social and Cultural Rights continues to include AIDS-related questions in its communications with governments.

Since the late 1980s, both the UN Commission on Human Rights (Commission) and the Sub-Commission on the Prevention of Discrimination and Protection of Minorities (Sub-Commission) have demonstrated a particular interest in AIDS-related human rights violations. Prompted by widespread reports of discrimination against people with HIV/AIDS, both bodies strongly urged governments to offer adequate legal protection to affected persons. In 1989 the Sub-Commission suggested the appointment of a Special Rapporteur to investigate discrimination in the context of HIV/AIDS, a proposal endorsed by the Commission at its next meeting.[8] This ensured that HIV/AIDS and human rights was on the agenda at each subsequent meeting of the Sub-Commission and the Commission, until the Special Rapporteur had submitted the final report. The 1990 preliminary report exten-

*For example, ILO, UNHCR, UNICEF, and UN Population fund

sively discussed AIDS control measures that affect the enjoyment and exercise of human rights, including personal liberty and freedom of movement.[9] The 1991 progress report analyzed discrimination associated with the AIDS epidemic and raised some of the conceptual and legal issues that relate to discrimination.[10] The 1992 final report highlighted the need to tackle the underlying causes leading to discrimination in the context of AIDS.[11] The 1993 conclusions and recommendations urged states to take all necessary steps to eliminate AIDS-related discrimination, particularly against such groups as women and children.[12] These reports were all quite general and did not address specific HIV/AIDS–related human rights violations.

Although it is still not clear the degree to which work of the UN will focus on AIDS-related human rights issues, some action may result from the resolutions passed at the 1994 and 1995 sessions of the Commission on Human Rights.[13] The 1994 resolution asks that the UN Secretary General prepare a report on international and domestic measures taken to protect human rights and prevent discrimination in the context of AIDS, and it urges working groups, special rapporteurs, treaty-monitoring bodies, and others to consider AIDS-related human rights issues in their work. The 1995 resolution focuses on the need for the elaboration of guidelines concerning promoting and protecting respect for human rights in the context of HIV/AIDS. It further notes the need to consider appropriate methods by which to keep under continuous review the protection of human rights in the context of HIV/AIDS.

The importance of these resolutions will be determined by the degree to which they prompt reporting and monitoring by both intergovernmental bodies and NGOs of AIDS-specific human rights violations. Some initiatives have also been taken by regional intergovernmental organizations around the world. In 1989 the Parliamentary Assembly of the Council of Europe "instruct[ed] the Steering Committee for Human Rights to give priority to reinforcing the non-discrimination clause in Article 14 of the European Convention of Human Rights, either by adding health to the prohibited grounds of discrimination or by drawing up a general clause on equality of treatment before the law."[14] In seeking to implement this recommendation, the Steering Committee for Human Rights asked the Swiss Institute of Comparative Law to conduct a European study of AIDS-related discrimination. In May 1993, the Swiss Institute submitted a report outlining the main areas in which people with HIV/AIDS experience discrimination in various European countries. The report not only contains a wealth of information concerning discriminatory laws and practices, but also examines the scope and limitations of existing anti-discrimination legislation.[15] This report has been forwarded to the Steering Committee for Public Health for its opinion and for an indication of further steps to explore.

A selected chronology of international and regional documents on the human rights aspects of HIV/AIDS, 1990–1995, is provided in Box 31-1.

BOX 31-1

Updated chronology of selected international and regional documents on the human rights aspects of HIV/AIDS, 1990–1995*

1990: Preliminary Report on Discrimination Against HIV-Infected People and People with AIDS, from the Special Rapporteur of the Sub-Commission on the Prevention of Discrimination and Protection of Minorities, E/CN.4/Sub.2/1990/9.

1991: Progress Report on Discrimination Against HIV-Infected People and People with AIDS, from the Special Rapporteur of the Sub-Commission on the Prevention of Discrimination and Protection of Minorities, E/CN.4/Sub.2/1991/10.

1992: Rights and Humanity Declaration and Charter on HIV and AIDS, submitted by the Gambian government to the Commission on Human Rights at its 48th session, E/CN.4/1992/82.

1992: Declaration on the AIDS Epidemic in Africa, Organization of African Unity, Dakar, 1992.

1992: Final Report on Discrimination Against HIV-Infected People and People with AIDS, from the Special Rapporteur of the Sub-Commission on the Prevention of Discrimination and Protection of Minorities, E/CN.4/Sub.2/1992/10.

1993: Conclusions and Recommendations from the Special Rapporteur on Discrimination Against HIV-Infected People or People with AIDS, Sub-Commission on the Prevention of Discrimination and Protection of Minorities, E/CN.4/Sub.2/1993/9.

1993: Decision on The Protection of Human Rights in the Context of HIV or AIDS, United Nations Commission on Human Rights, E/CN.4/1993/L.74.

1993: Discrimination in the Context of HIV or AIDS, United Nations Sub-Commission on the Prevention of Discrimination and Protection of Minorities, E/CN.4/Sub.2/1993/L.11/Add.2.

1993: United Nations, World Conference on Human Rights, The Vienna Declaration and Programme of Action, Vienna, 1993, U.N. Doc. A/Conf.157/24 (1993).

1993: Swiss Institute of Comparative Law, Comparative Study on Discrimination Against Persons with HIV or AIDS, Council of Europe, Strasbourg, 1993, Doc. H (93) 3.

1994: The Protection of Human Rights in the Context of HIV and AIDS, United Nations Commission on Human Rights, E/CN.4/1994/L.60.

1994: Resolution passed at the Ninth Plenary Session of 10 June 1994, included in Annual Report of the Inter-American Commission on Human Rights and Special Report on the Human Rights Situation.

1994: Tunis Declaration on AIDS and the Child in Africa, Organization of African Unity, Tunis, Tunisia, 13–15 June 1994, AHG/Dec. 1.

1994: United Nations, Report of the International Conference on Population and Development and Various Recommendations of the World Health Organization, Cairo, 1994, U.N. Doc. A/Conf.171/13 (1994).

1994: Declaration of the Paris AIDS Summit of Heads of Government or Representatives, Paris, 1994.

1995: United Nations, Report of the World Summit for Social Development, Copenhagen, 1995, U.N. Doc. A/Conf.166/9 (1995).

1995: The Protection of Human Rights in the Context of HIV and AIDS, United Nations Commission on Human Rights, ECN.4/1995/44.

1995: Beijing Declaration and Platform for Action, Fourth World Conference on Women, Beijing, China, 15 October 1995, U.N. Doc. A/CONF. 177/20.

*For a chronology of international and regional documents on the human rights aspects of HIV/AIDS, see *AIDS in the World* (1992), Chapter 13

Responses to human rights violations

In countries around the world, the number of individual and group complaints of human rights violations in the context of HIV/AIDS is steadily increasing. In some places, government-initiated investigations of the rights of people with HIV/AIDS has actually stimulated the complaints. Yet individual complaints and investigations of human rights violations concerning HIV/AIDS-related issues have seldom occurred at the international level. In this respect, it is important to recall that individual complaints only reach intergovernmental bodies as a last resort. In most cases, these bodies are authorized to consider complaints only after the exhaustion of all domestic remedies; that is, barring exceptional circumstances, the highest judicial body in the country must review a complaint before an international body will consider it.

However, HIV/AIDS issues have been relevant to several cases brought before international human rights bodies. In April 1994, for example, the UN Human Rights Committee, the treaty-monitoring body for the International Covenant on Civil and Political Rights (ICCPR), ruled on a related issue when it stated that the sodomy law of the Australian state of Tasmania violated the right to privacy under international human rights standards.[16] The Committee rejected the argument of the government of Tasmania that its laws were partly motivated by a concern to protect Tasmania from the spread of HIV/AIDS as well as being necessary to protect public health and morality. The Committee noted that the criminalization of homosexual practices can neither be considered a "reasonable means nor a proportionate measure" to achieve the aim of preventing the spread of HIV. It noted the observation of the Australian government that statutes which criminalize homosexual acts tend to impede public health programs "by driving underground many of the people at risk of infection" and stated that "criminalization of homosexual activity would thus appear to run counter to the implementation of effective education programmes in respect of HIV prevention."[17] The Committee went on to note the lack of any apparent link between the continued criminalization of homosexual acts and the effective control of HIV/AIDS.

Various cases brought before the European Commission and Court of Human Rights have also made reference (usually indirect) to HIV/AIDS. For example, in March 1992 the European Court of Human Rights ruled in a case concerning financial compensation to a person, meanwhile deceased, with hemophilia. The Court held that the person, who had been infected with HIV through blood transfusions in a French public hospital, was entitled to compensation on account of the excessive length of the proceeding, both before the administrative authorities and the Paris Administrative Court.[18]

When balancing conflicting interests, the European Court and Commission—in line with WHO guidelines—appear to attach great value to human rights. In the *Norris* case, for example, the Court dismissed a claim made by the Irish government that the laws criminalizing homosexual acts were necessary to protect, as the Irish Supreme Court had phrased it, "the spread of all forms of venereal disease." According to the European Court, this and

other reasons were insufficient justification to interfere with a person's right to a private life, which includes the right to develop a sexual life.[19]

Actions within the intergovernmental system

In the context of HIV/AIDS, striking differences exist between the statements and the actual practices of various United Nations bodies and other intergovernmental agencies. While resolutions and declarations on nondiscrimination and the promotion of human rights in the context of HIV/AIDS remain a constant of human rights bodies, UN recruitment, personnel, and organizational practices are frequently contradictory. The Director of the Joint UN Medical Services has drawn attention to the conflict between official UN policy which does not permit refusal of recruitment solely on the basis of HIV infection and other personnel rules and regulations.[20] For example, some UN agencies practice mandatory HIV testing for personnel, and current medical standards allow for the refusal of recruitment because of other medical conditions, some of which are comparable to HIV infection. In addition, as a general rule, military or police who are HIV infected are not deployed to peacekeeping mission areas, and those persons diagnosed as having AIDS while on mission are repatriated.[21] An internal UN study is under way to develop a uniform policy.

Similar problems have been reported in the European Union. Candidates for employment in Community institutions were systematically tested for HIV until 1988.[22] Under public and political pressure, the Community's medical service eventually stopped this practice.[23] However, candidate employees are currently *requested* to undergo an HIV test. Those who refuse will—without their knowledge and without their informed consent—be subjected to a T4/T8-cell count, a test to assess the impact of HIV infection on a person's immune system.[24] In 1989 a case was brought before the European Court of First Instance by a candidate employee, *X*, who was denied a job after the Community's medical officers had—in spite of the candidate's explicit refusal to undergo an HIV test—performed a T4/T8-cell count. In 1992 the Court decided that a T4/T8-cell count was fundamentally different from a test for HIV antibodies and disregarded the fact that *X* had not consented to the test.[25] *X* immediately appealed to the European Court of Justice.[26] On October 5, 1994, the Court of Justice annulled the judgment of the Court of First Instance. The Court held that it is illegal to subject candidate employees to a disguised HIV test without their knowledge and will, since obtaining a job applicant's informed consent is an absolute requirement for the lawful carrying-out of a preemployment medical examination.[27]

Current issues

Human rights questions continue to be a major part of the global HIV/AIDS debate. A number of controversies have emerged in the 1990s, each with an important human rights component. To illustrate the complexity of some of these issues, several are briefly reviewed.

HIV testing

The mandatory testing of individuals continues to raise human rights concerns. After numerous resolutions and analyses discouraged the implementation of mandatory testing programs, calls for obligatory testing are once again gaining support. For example, some claim that mandatory HIV testing of persons obligatorily tested for multidrug resistant tuberculosis (TB) is a legitimate measure to control the spread of disease, since undetected HIV infection may obscure the results of a TB test. Mandatory HIV and/or TB testing is being imposed particularly on confined populations, such as prisoners and persons in refugee camps. Persons in closed institutions are often thought to be at increased risk for both HIV and TB infection as a result of crowding and poor sanitary conditions. Testing, even without consent, is therefore proposed to be in the interest of the individual, as well as of the institutional population.

HIV/AIDS and the rights of migrants

Debate is also building over the rights of non-nationals in the context of HIV/AIDS. The health care systems in many countries are increasingly unable to care for the needs of people with HIV/AIDS. In these settings, the needs of foreigners with HIV/AIDS may be considered a low priority.[28] Xenophobic groups publicize reports of the few people with HIV/AIDS who have sought refuge in countries with more advanced health care systems and use these reports to demand stricter entrance and resident criteria for foreigners. This has led to catastrophic consequences for some migrants. A growing number of countries test refugees and asylum seekers for HIV/AIDS and then deny them status if they are HIV infected, even if they have entirely legitimate reasons for seeking refugee status or asylum. Also, some countries test various categories of foreigners (including workers and students), and if found to be HIV infected, require them to prove that they were unaware of their HIV status when entering the country. In addition, these foreigners may face denial of benefits, such as free or subsidized health care, and most commonly, deportation.

Human rights aspects of national responses to AIDS: national laws, policies, and practices

The magnitude of the HIV/AIDS epidemic requires governments to design comprehensive policies to minimize the impact of HIV/AIDS on individuals and society as a whole. Governments derive the authority to introduce policy measures by law ("the rule of law"). Whereas some laws relevant to the epidemic are quite old, the bulk of AIDS legislation has been enacted in response to the epidemic itself. Some AIDS laws specifically deal with HIV/AIDS–related issues, while others seek to complement existing, more general laws.

There are notable differences in the types of laws enacted and applied in the context of HIV/AIDS. Governments in many countries have outlawed certain forms of behavior and/or enforced compulsory control measures in

efforts to prevent further spread of HIV infection. Examples of these practices include the mandatory testing of certain groups of people, including immigrants, foreign students, applicants for residence and/or work permits and sex workers, as well as restrictions on certain rights, such as the right to marry. In other countries, legislation has been used primarily as a tool to emphasize individual responsibility.

An increasing number of laws, either explicitly or through judicial interpretation, prohibit HIV/AIDS–related discrimination. Provisions that prohibit discrimination against individuals on the basis of health, health status, or disability typically complement information and education programs carried out in these countries. Many of these laws, like the Americans with Disabilities Act of 1990, offer protection against discrimination in the context of employment, education, and housing. Under some of these laws, including the Australian Human Rights and Equal Opportunity Act of 1986 (revised), special mechanisms deal with allegations of human rights violations, including those that are HIV/AIDS-specific.

There has been—and sometimes continues to be—an intense debate about the measures most useful to responding to the AIDS epidemic. Tensions inevitably arise between those who emphasize protection of the public health in the traditional sense—and thus the restriction of rights of certain individuals considered dangerous—and those who advocate a minimum amount of interference with the lives of individuals. Policymakers often have to reconcile these conflicting concerns. Although the importance of full recognition of human rights as an integral part of HIV/AIDS policies and programs is increasingly acknowledged, numerous actions by governments reinforce existing patterns of discrimination and clearly violate human rights norms.

In practical terms, how can a policy be evaluated to determine if it complies with human rights standards? An initial assessment of a state's human rights obligations can be made by ascertaining which human rights treaties it has ratified. Treaties contain a number of provisions ("articles" or "sections") that define the rights that the ratifying states have committed to uphold. These rights are often phrased in general terms, leaving room for interpretation. In order to better understand the documents, a review of the genesis of various provisions, notably by studying the so-called *travaux préparatoires*, may help. In addition, learning the views of the official body established to monitor the particular international or regional human rights treaty under consideration may be useful.

Survey of national laws and practices

A review of legislation pertaining to HIV/AIDS conducted in 1992 by the Global AIDS Policy Coalition was summarized in the first volume of *AIDS in the World*. In 1993–94, managers of governmental national AIDS programs (GNAP) were requested to provide information on both laws and practices in the context of HIV/AIDS in their country. A survey questionnaire was sent to 187 GNAP managers; 116 responses were received, of

which 115 had completed, either partially or fully, the section pertaining to laws and practice (Appendix E).

The survey found that involuntary testing remains part of many AIDS prevention and control programs. Governments continue to categorize individuals into "high-risk" groups in order to impose testing and to restrict their activities. The responses also dramatically highlight the differences that exist between law and practice in some countries. According to GNAP managers, policies that interfere with human rights are often being carried out without legal justification.

The survey of national legislation and practices as well as discussion with ASOs and human rights NGOs confirms two major conclusions. First, discrimination towards HIV-infected people, people with AIDS, and people considered within each society at high risk for HIV infection is an important and enduring problem. Second, bringing community, national, and even international organizations into conformity with the international consensus on nondiscriminatory approaches to HIV/AIDS prevention and control will require vigilance and enormous continuing effort. To achieve an optimal balance between public health objectives and human rights norms, public health policies and programs will benefit from the application of an analytical human rights framework (Box 31-2).

BOX 31-2

Assessing the human rights impact

SOFIA GRUSKIN

In order to assist policymakers, the Global AIDS Policy Coalition and the International Federation of Red Cross and Red Crescent Societies created an international working group to help assess the human rights impact of HIV/AIDS policies, programs, and practices.*

In mid-1995, the International Federation of Red Cross and Red Crescent Societies and the François-Xavier Bagnoud Center for Health and Human Rights (Harvard University) published a comprehensive manual on HIV/AIDS and human rights.[1] The manual, entitled "AIDS, Health, and Human Rights" includes a complete explanation of a methodology for balancing public health objectives and human rights norms, including illustrative examples involving both prevention and care.†

The intent of the public health/human rights impact assessment instrument is to ensure that conflicts are negotiated rationally, since—and this is the underlying assumption—public health and human rights are inextricably linked and largely share the same goal of promoting human well-being.

A schematic diagram in the form of a 2 × 2 table is presented in Figure 31-2.1. On one side of the diagram is "public health quality," on the other, "human rights quality." Each side represents a spectrum from "positive," meaning high quality public health or high respect for human rights and dignity, to "negative," meaning low public health quality and low respect for human rights and dignity. The goal is to ensure that any proposed policy or program reaches Box *A*, which means high quality public health plus high quality human rights. Briefly, the process involves four steps:

*The Working Group also included representatives from the Danish Centre for Human Rights, the McGill Centre for Medicine, Ethics and Law, the International Commission of Jurists, and the Society of Women Against AIDS in Africa.

†Copies of the manual may be ordered from the International Federation of Red Cross and Red Crescent Societies, Geneva, Switzerland, or from the François-Xavier Bagnoud Center for Health and Human Rights, Harvard School of Public Health, 8 Story Street, Cambridge, MA 02138, USA.

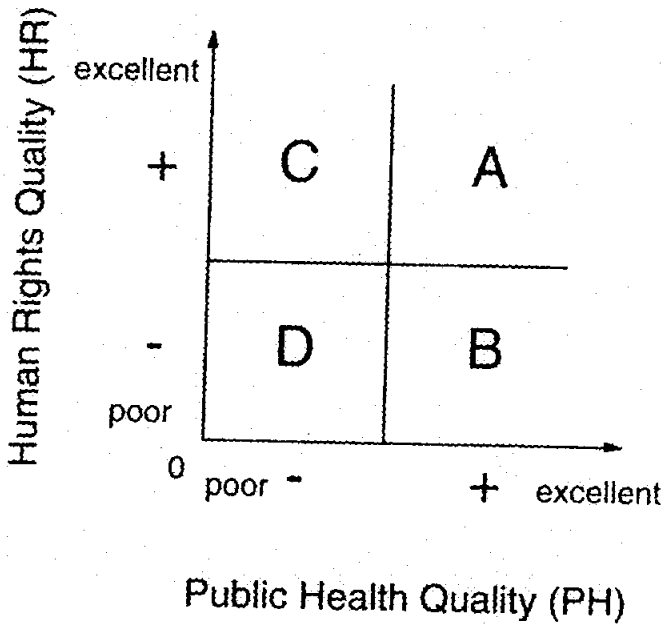


Figure 31-2.1 Assessment of interaction between public health and human rights quality. The four-setp approach is based on the Public Health/Human Rights Impact Assessment Instrument, developed at *AIDS, Health and Human Rights*, an explanatory manual, International Federation of Red Cross and Red Crescent Societies, and François-Xavier Bagnoud Center for Health and Human Rights, Harvard School of Public Health, 1994, Geneva, Switzerland and Boston, MA, 1994, p. 42.

1. Does the policy or program represent *good public health?* Locate the proposed policy or program along the horizontal axis from poor to excellent. The emphasis at this stage is entirely on the health benefits, risks, and harms, not on the human rights impact.
2. Is the proposed policy or program respectful and protective of human rights? In answering the question, the potential *benefits and burdens on human rights* which will occur as a result of the policy or program are described. The emphasis is entirely on the human rights component. Locate the proposed policy or program along the vertical axis from poor to excellent.
   Determine in which quadrant of Figure 31-2.1 the proposed policy or program is located (A, B, C, or D).
3. Next, how can the policy or program best move into quadrant *A*, thereby achieving the optimal *balance between protection of the public health and the protection and promotion of human rights and dignity.* The goal is to minimize to the greatest extent possible the burdens on human rights resulting from the policy as well as having the best policy.
   Specific steps are outlined to ensure a systematic approach to this complex negotiation process.
4. Review the basic approach. For completing this assessment, alternative approaches may have emerged that will be both more respectful of human rights and more effective in achieving public health goals.

References

1. François-Xavier Bagnoud Center for Health and Human Rights and the International Federation of the Red Cross, *AIDS, Health and Human Rights* (Cambridge, MA and Geneva: Harvard School of Public Health), 1995:42–43.

REFERENCES

1. UN Commission on Human Rights, *Non-Discrimination in the Field of Health*, preamble, Resolution 1989/11 (March 2, 1989).
2. Cf. P. Sieghart, *AIDS & Human Rights—A UK Perspective* (London: British Medical Association Foundation For AIDS, 1989):12.
3. K. Tomasevski, "AIDS pandemic and human rights," in *Collected Courses of the Academy of European Law*, Vol. II, Book 2, Academy of European Law, ed. (Boston: Kluwer Academic Publications, 1993):107.
4. Global AIDS Policy Coalition, *Towards A New Health Strategy for AIDS: A Report of the Global AIDS Policy Coalition* (Boston: GAPC, 1993).
5. J. Mann, D. Tarantola, and T. Netter, eds. *AIDS in the World* (Cambridge, MA: Harvard University Press, 1992):564–566 for overview.
6. UN Commission on the Status of Women, *Resolution of the Commission on the Status of Women*, adopted at the 34th Session of the Commission on the Status of Women (March 1990).
7. UN Commission on Human Rights, Resolution 1993/53 (March 9, 1993).
8. UN Commission on Human Rights, Resolution 1990/65 (March 7, 1990).
9. UN Commission on Human Rights, Sub-Commission on Prevention of Discrimination and Protection of Minorities, *Discrimination Against HIV-Infected People or People with AIDS*, UN Doc. E/CN.4/Sub.2/1990/9 (August 2, 1990).
10. UN Commission on Human Rights, Sub-Commission on Prevention of Discrimination and Protection of Minorities, *Discrimination Against HIV-Infected People or People with AIDS*, UN Doc. E/CN.4/Sub.2/1991/10 (July 24, 1991).
11. UN Commission on Human Rights, Sub-Commission on Prevention of Discrimination and Protection of Minorities, *Discrimination Against HIV-Infected People or People with AIDS*, UN Doc. E/CN.4/Sub.2/1992/10 (July 28, 1992).
12. UN Sub-Commission on Prevention of Discrimination and Protection of Minorities, *Discrimination Against HIV-Infected People or People with AIDS*, UN Doc. E/CN.4/Sub.2/1993/9 (August 23, 1993).
13. UN Commission on Human Rights, *Protection of Human Rights in the Context of HIV and AIDS*, UN Doc. E/CN.4/1994/L.60 (March 1, 1994).
14. Parliamentary Assembly of the Council of Europe, Recommendation 1116 on AIDS and human rights (September 29, 1989):para. 8A.
15. Swiss Institute of Comparative Law, *Comparative Study on Discrimination against Persons with HIV or AIDS* (Strasbourg, France: Steering Committee for Human Rights, Council of Europe, 1993).
16. Cf. UN Human Rights Committee, *Fiftieth Session Communication* No. 488/1992, CCPR/C/50/D/488/1992 (April 4, 1994).
17. *Ibid.*
18. Cf. European Court of Human Rights decision, *X v. France*, 81/1991/333/406 (March 31, 1992).
19. European Court of Human Rights decision, *Norris v. Ireland*, 6/1987/129/180 (October 28, 1988).
20. Inter-Agency Advisory Group on AIDS, *UN Personnel and Operational Policies Dealing with the Impact of HIV/AIDS* (October 28, 1993).
21. UN, *UN Medical Service Guidelines for Contributing States on Medical Preparation of Military and Police Personnel for Service with UN Peacekeeping Missions*, annex to UN Medical Standards.
22. H. Schröder, "Pratiques de dépistage du SIDA aux Communautés européennes," *Revue Belge de Droit International* 1(1990):171–189

23. Cf. Cardoso e Cunha, response to written question 232/90, *Official Journal of the European Communities* C90(1991):47–48.
24. A. Hendriks and S. Gevers, "(Pre-)employment medical examinations and the law with particular reference to the European Union," *European Journal of Health Law* 1(1994):229–264.
25. Court of First Instance decision, *X v. Commission*, Case 94/92, *NJCM-Bulletin* 18(1993):36–45, annotated by A. Hendriks.
26. Court of First Instance decision, *X v. Commission*, Case 94/92, *Official Journal of the European Communities* C313(1992):17–18.
27. Court of Justice decision, *X v. Commission*, Case 404/92 (October 5, 1995); para. 20.
28. R. Rector, ed. *Migration, Health and AIDS, Phase I, Final Report to the Commission of the European Communities* (Copenhagen: HIV Denmark, 1994).

32

Nongovernmental Organizations

JEFFREY O'MALLEY, VINH KIM NGUYEN, AND SARAH LEE

To slow the spread of HIV, people need to change their most personal and private behaviors. Likewise, the most important aspect of care for people with HIV/AIDS is at an interpersonal level—ensuring self-respect, freedom from discrimination, and love and support. Thus, the heart of HIV/AIDS prevention and care is at the community level, where people help people, often through groups—typically known as CBOs (community-based organizations).

In addition to CBOs that are formed within (and are accountable to) particular communities, many other groups outside government are involved in responding to HIV/AIDS. Collectively, such groups are referred to as NGOs (nongovernmental organizations).

The first edition of *AIDS in the World* described the emergence of new community organizations in response to AIDS and outlined some of the issues faced by specialized AIDS groups as the epidemic spread and diversified.[1] How have the challenges changed in recent years? Are AIDS groups still serving the same functions as in the past? What is the role of other groups outside government in responding to AIDS? And how do NGOs decide on priorities as governmental commitments continue to decline and the epidemic expands and intensifies worldwide.

The range of NGOs responding to AIDS

In every nation, the impact of AIDS was first felt by a small number of people. At the beginning of the epidemic, first actions against AIDS were invariably organized locally by some of the people affected by the disease. While many governments ignored HIV/AIDS and health care systems reacted with fear and prejudice, people with AIDS, their loved ones, and their families often organized into groups that became known as "AIDS Service Organizations"—delivering care and support and offering prevention programs.

Groups formed by these early activists have become world famous, from TASO (The AIDS Support Organization) in Kampala, Uganda, to the Gay

Men's Health Crisis in New York City. Often AIDS service organizations (ASOs) evolved in response to growing demands and changing needs; for example, TASO has grown from a small group focused on service to families coping with HIV/AIDS in Kampala, to a national network with branches across Uganda. In Manila, "Reach Out" started by teaching about HIV prevention to mainly middle-class gay men, but it now operates a wide range of educational programs, including special services for women sex workers and for young people.

As the epidemic continued in initially affected communities, and spread to new cities and countries, established organizations working on different issues soon decided to do something about AIDS. For example, ENDA Tiers Monde, a large NGO working on community development and environmental issues in Senegal, started providing AIDS service activities in the late 1980s, as well as AIDS training to a range of small groups and community activists across the country. In 1987, the U.S. government launched what was to become the largest donor-driven AIDS program in the world, channeling a significant part of its foreign aid related to HIV/AIDS through nongovernmental subcontractors, which had more flexibility than national governments in starting new programs and in dealing with governmental and political restrictions. There are now examples of NGO involvement in AIDS in almost every sector and country (indeed, some have sought to secure their own funding base or legitimacy through AIDS activities), including "development" NGOs like Oxfam, human rights groups like the International Gay and Lesbian Human Rights Commission, and the Society for Women and AIDS in Africa (Box 32-1) women's groups such as Advocacy for Women's Health, and even trade union federations and farmers' networks.

BOX 32-1

Society for women and AIDS in Africa

EKA ESU-WILLIAMS

The Society for Women and AIDS in Africa (SWAA), a pan-African NGO led by women, works to empower women to address the causes and consequences of the HIV/AIDS epidemic on women in Africa. The birth of SWAA in 1988 resulted from the realizations that (a) women are critically affected by HIV/AIDS, (b) that they have limited access to information and education, (c) programs promoting their good health, social, and economic advancement are in short supply, and (d) because they face several constraints, a forum is needed both to enhance a large-scale mobilization of women for action against HIV/AIDS and to provide the voice to raise women's concerns about the epidemic and their lives in general.

From an initial nucleus of a handful of women in 1988, SWAA members now number several hundred in 30 African countries. Since 1990 it has grown from an NGO whose initial engagement was in providing education, information, and general awareness to one advocating for the development of policies to ensure that women and AIDS become an important program focus of national HIV/AIDS control programs. The rights of women at risk of or infected by HIV/AIDS and the advancement of strategies for the empowerment of women, especially young girls, toward reducing their vulnerability to HIV/AIDS have also been a major component of SWAA's advocacy work.

SWAA is working hard to extend its activities to areas it has not reached, such as northern Africa,

and to consolidate activities in countries where new branches have only recently been established. Internationally, SWAA is extending its collaboration for the purpose of exchanging experiences with other women's groups, and influencing global and regional agendas in the area of women and AIDS. This networking allows for increased opportunities for SWAA branches and members to acquire new skills and information that will assist them in pursuing SWAA's objectives more effectively.

There have been many constraints. The voluntary nature of SWAA's operations has hampered timely and extensive input by members. Difficulties in communication within Africa have caused inadequate exchange among countries. As experienced by many other women's organizations, we face difficulties in accessing support, influencing policy-makers, and gaining acceptance for our mission from official structures. Because we have to discuss issues that are mainly within the domain and control of men, or that may invoke a feeling of threat among men, finding support from men is often difficult. Given these barriers, it is taking more time than we would like to break through to communities at the grassroots level, where the greatest impact needs to be made. To increase its outreach to the grassroots, SWAA is encouraging other women's groups to include HIV/AIDS concerns as a major activity focus. In this way, we hope to expand both our scope and our targets, preparing women and communities to deal with the escalating problems resulting from HIV/AIDS.

SWAA's approach to community participation also relates to its concern about the prevailing high degree of stigma and discrimination people with HIV/AIDS encounter. We hope that this community-based approach will support other initiatives in creating an atmosphere where women, men, and family members, whether infected or not, can be empowered to cope with or prevent HIV/AIDS. Such an approach can also assist the acceptance and support of children orphaned by AIDS, many of whom suffer abuse and neglect.

A key challenge facing SWAA and the AIDS prevention initiatives in Africa is that of enlisting the full participation of men and ensuring that they take on their responsibilities with respect to HIV/AIDS. Connected with this is the emerging picture of HIV/AIDS as a disease that affects the family, a social unit in which men play a dominant role. Responsibility for safe sex, sexual communication between partners, and ways of ensuring that the appropriate messages are communicated to children are areas in which men can play a significant role.

Overall, SWAA wishes to project its vision that, tragic as the consequences of the HIV/AIDS epidemic are for women in Africa, it has created the opportunity to address more appropriately the broader issues of women's subordination, gender inequity, and the neglect of the rights of women. HIV/AIDS programs that are more reflective of women's needs should be developed—providing long-term economic viability for women, mobilizing women for economic and social advancement, and supporting overall health concerns of women.

Typically, as NGOs spend a longer time involved in AIDS work, they diversify, grow, and become more professional in planning and evaluating their services. In their wake, new voluntary groups emerge with highly specialized or localized missions. Many countries thus benefit from a wide range of diverse and complementary organizations working on AIDS—from small groups catering to a very specific community, to comprehensive national service providers. Each voluntary organization working on AIDS has limitations as well as strengths, but the private sector as a whole is typically much more able than the government to reach and help vulnerable people avoid infection or cope with their illness.

The ubiquity and diversity of groups working on AIDS have led many

authors to propose typologies of NGOs.[24] However, no single listing or typology can adequately illustrate the variety of organizational origins, members, goals, and functions.

Several relevant questions may help differentiate among organizations and the work they do: Does the group provide direct services or does it act as an intermediary between different institutions or organizations? Is the group essentially a self-help group or is it motivated by concern for others? Is the group functionally accountable primarily to its donors or funders, its members, or its intended beneficiaries? Is it primarily an HIV/AIDS group or if not, are its HIV/AIDS activities distinct (and measurable), or are they included within activities aimed at broader health or development issues?

The term "HIV/AIDS services" is used here in the broadest sense, embracing all prevention and care activities from handing out condoms or providing "buddies" to the ill, to fighting for women's inheritance rights or challenging homophobia. The concept of "HIV/AIDS services" does not include activities intended to have an impact on the epidemic only through the mediation of another institution, such as training of trainers, provision of funds and technical support to other groups, policy analysis without advocacy for change, and similar intermediary functions carried out by many NGOs.

NGO roles and achievements

One of the greatest strengths of NGOs responding to HIV/AIDS is their roots within communities. Responses based on the assessed needs, priorities, and dynamics of local people are not only more likely to have an impact on a local epidemic, but will also help to ensure "ownership," unity, and sustainability in community efforts. Appropriate, sensitive approaches have proven to be effective and can have a multiplying effect. By carrying out effective and positive care programs, for example, NGOs play a key role in breaking down local barriers to fighting AIDS (whether based on fear, ignorance, or stigmatization) while at the same time promoting prevention strategies.

The most effective NGO responses are embedded in a local context, and thus reflect and are sensitive to the actual norms of a community, rather than what outsiders (individuals or organizations) perceive to be the norms. NGOs can help to make HIV/AIDS care and support part of everyday life, demonstrating that everyone has a role to play as both an individual and a member of the community.

Most of the NGOs now involved in AIDS work are not AIDS-specific organizations, but are oriented to broader health or development goals. Many religious organizations, women's groups, farmers' unions, or youth organizations have been working within their communities for years and know a great deal about mobilizing and supporting vulnerable people, especially the poor. Just as importantly, many such NGOs are likely to stay involved in their communities for a long time and will help provide a sustainable response to challenges such as HIV/AIDS. When these groups become capable of working on HIV/AIDS alongside their other activities, HIV/AIDS services reach a wider range of people for a longer period of time.

Cavite City, the Philippines provides a typical example of how community

groups contribute to the fight against AIDS. KASAKA (Kalipunan Ng Mga Samahan sa Kabite), recently incorporated HIV/AIDS into their work among local farmers, after recognizing that many families in their community had tensions linked to post-harvest visits to brothels by men. KASAKA began with a participatory research project, which led to the development of HIV/AIDS information materials in the local language. They have now been asked to assist in the local health authority's HIV/AIDS training for health professionals. As the Chair of the KASAKA Health Committee, says: "We never thought that we who are just farmers would be asked to talk to doctors, nurses and other health experts about HIV/AIDS."

Most NGOs describe themselves as "community-based." In reality, however, many are based neither in geographic communities (like neighborhoods or villages) nor in identity communities (such as sex workers or migrant laborers). Many NGOs—even those dealing with specific communities on a daily basis—are both physically and philosophically "outsiders," much in the same way as governments tend to be. In reality, many NGOs carry on outreach work to community groups, and supposed beneficiaries may never have heard of an organization that claims to be working on their behalf. These NGOs may be medium-sized or even large-scale organizations with complex infrastructures, often with several branches or departments. Other NGOs are not directly involved in HIV/AIDS service, but have intermediary functions, such as passing on information, technical support, grants, or networking opportunities. NGOs not based in specific communities are more likely to be involved in programs that are larger scale and address broader sections or issues of society, to have paid professional staff, and to adopt approaches that are "for" rather than "with" and "by" communities. Despite rhetoric to the contrary, such larger NGOs are usually more accountable to their donors than to their beneficiaries. Their staff and governors are more likely motivated by concern for others than self-help.

Larger NGOs and intermediary groups tend to have different, often contrasting strengths and weaknesses. Such groups tend to be technically stronger, have more effective access to decision makers, and despite higher costs, can often be very cost-efficient because of the scale of their operations. Very few small community groups can distribute condoms as effectively and efficiently as a large social marketing NGO linked to an international network, but very few such large groups can actually convince a young man to use condoms if he has not tried them before.

Organizations that are based within (and known by) a specific community can typically boast of being flexible, working with volunteers, keeping potential beneficiaries in control, keeping costs down, being willing and able to work with the poor and marginal groups, innovating and advocating more effective approaches, building skills within vulnerable groups rather than relying always on outsiders, and being accountable to local people. In addition, such community-based NGOs are often the only institutions that are able to work closely with controversial groups in need of support, like sex workers, drug users, and illegal migrants—filling gaps left by governments due to political sensitivity or lack of contacts or expertise.

Nevertheless, public policy affecting NGOs, and public rhetoric, rarely

differentiate between these different kinds of institutions. Few governments that fund NGOs really debate and decide whether they wish to fund community groups directly, and whether they are capable of doing so. Even fewer ask themselves the purpose of "NGO representation" on national AIDS committees and similar bodies; whether they are seeking the voices of affected or vulnerable communities, or the technical expertise of highly motivated philanthropists. The individual and joint strengths of NGOs combine to make them a dynamic, multidimensional, and potentially powerful force. HIV/AIDS has highlighted, almost more than any other issue, the benefits of drawing on the wealth of experiences and expertise available by investing in developing and strengthening NGOs as a sector. Throughout the world, NGOs have demonstrated that, with appropriate support, they can reinforce one anothers' work, complement the activities of other sectors, and put effective pressure on the state to meet their needs and those of communities.

Needs, capacities, and priorities of service delivery organizations

In 1994 and 1995, the International HIV/AIDS Alliance conducted a series of participatory assessments with local AIDS-service NGOs in twelve developing countries. These assessments were intended to identify their perception of needs, priorities, and capacities in HIV/AIDS prevention, care, and community support. The countries ranged from low to high HIV seroprevalence, and from strong to weak in terms of the organized NGO response to the epidemic. Assessments were conducted in Bangladesh, Burkina Faso, Côte d'Ivoire, Ecuador, Morocco, Mozambique, Pakistan, Peru, the Philippines, Senegal, Sri Lanka, and Tanzania.

Despite the many differences, a number of common priorities were identified: attention and technical support for the promotion of symptom recognition and treatment-seeking for sexually transmitted infections; support to self-organizing and self-help for people with HIV; support to community and neighborhood level groups and interventions; linkages of action research to program development; and availability of subsidized condoms to small NGOs, not just government and large social marketing agencies.

The NGOs surveyed in most of the countries also cited the need for more action on the contextual (societal) factors which increase vulnerability to HIV, such as gender inequality. However, this was frequently cited as an area which would require significant technical cooperation with others, as NGOs found it difficult to identify appropriate program development or intervention strategies.

The most striking difference among countries was the uneven development of the "AIDS specialist" sector, and consequent services to marginal populations. While certain countries, especially those with a legacy of external support from USAID-funded projects (AIDSCOM, AIDSTECH, and AIDSCAP) had well-developed specialist service organizations, relatively few broad-based health or development NGOs had added a specific HIV/AIDS component to their programs. A priority in these countries was reach-

ing larger numbers of people, particularly the poor. For example, in Sri Lanka, Burkina Faso, and Bangladesh, health or development NGOs had taken the lead in responding to AIDS, and they identified a need for more specialist prevention and care services, and particularly, more effective work with marginal populations such as sex workers and men who have sex with men.

By the end of 1995, "linking organizations"—NGO support programs enabling the International HIV/AIDS Alliance to extend managerial and technical support to NGOs through local groups—had been created in six of these twelve countries.[2] An analysis of the priorities established for funding, requests for support received, and resources distributed, provides a unique insight into the strengths and weaknesses of NGOs in these countries, and the potential for a stronger response to HIV/AIDS from the NGO sector. The six NGO support programs were all autonomously responsible for deciding on funding priorities, reviewing applications, and allocating awards of funds and technical support. Of the 220 NGOs that were supported in these countries in 1995, sufficient data exist for 138. Only 8 of the 138 NGOs were AIDS-specific organizations, with the others coming from a wide range of sectors, particularly community development associations (46), youth groups (33), and women's groups (10). Most activities were intended to benefit either youth (50) or those in poverty (24), and almost three times as many focused activities on women in particular (17) then men in particular (6). Only 35 programs focused on broad contextual issues such as human rights or income generation, and only 42 of the prevention programs went beyond general information strategies to address behavior change. While, overall, funding decisions reflected the capacity of local NGOs, and as such resulted in good geographic coverage and access to vulnerable groups, only a minority of activities could be characterized as particularly innovative or likely to have a substantial impact.

Identity activism

In countries where HIV transmission was or is largely identified with "mainstream" sexual practices at the beginning of the epidemic, the development of "AIDS movements" and AIDS specialist NGOs has often been less widespread. In both high and low prevalence countries, from Burkina Faso to Bangladesh, there has rarely been a spontaneous social movement in response to AIDS where transmission had not disproportionately affected a marginal group that already had organizational or political cohesion. In contrast, in the United States, most western European countries, Australia, and Brazil, early AIDS organizing depended greatly upon gay politics and gay organizations and, in countries like the Philippines and Thailand, upon groups that were already working with sex workers.

In sub-Saharan Africa especially, and increasingly in parts of Asia, an NGO response to AIDS has often been built on a different sort of movement—the efforts of women and women's groups to address their own sexual health and sexual rights. The relationship between a response to AIDS

and a response to other issues, whether gay rights or gender equality, has often been mutually beneficial. NGOs based in such identity movements or communities have been among the most successful at accessing vulnerable populations, providing education and social norm support to help change behavior, and pointing to the broader changes in social norms, human rights standards, and public policy that are required to sustain prevention and care efforts. In turn, many of these movements and organizations have been significantly strengthened by the attention to their issues catalyzed by AIDS.[6]

Increasingly, however, mutual support and cooperation between social movements and their respective NGOs is breaking down in competition for resources, the desire to "scale up" or replicate activities to the "general population," and genuine philosophical differences.

In many industrialized countries, debate surrounds the "heterosexualizing" or "gaying/re-gaying" of AIDS movements as the profile of local epidemics is purported to change (see Chapter 38). While gay groups fight to retain some resources in countries such as the United Kingdom, where gay men still represent the vast majority of AIDS cases and new HIV infections, debates also rage in developing countries. For instance, Latin American NGOs differ dramatically in their assessment of the relative importance of different HIV transmission routes. These debates are inevitably divisive because of their linkage to both perceptions of life and death as they relate to HIV infection, and to the movements themselves as they struggle for both legitimacy and funding.

As the struggle against HIV/AIDS enters its second decade, AIDS activism is connecting more and more to identity activism. The potential for variety of movements is already apparent—from sex work activism to a new generation of "queer" activism to, perhaps most strikingly, a strong and growing post-Beijing international women's movement. Activists concerned with areas such as human rights, gender and sexual health, base their work within their societal context—enabling them to challenge societal obstacles and discrimination. Although AIDS may be an important common thread among many participants, the central catalyst bringing people together is their social identity. A group of sex workers, for example, may form a movement because they share common concerns about stigmatization, safety on the streets, employment rights, and access to health care—as well as issues relating to HIV/AIDS. However, such groups may not seek common cause with other groups—also strongly affected by HIV/AIDS—yet based on other identities (e.g., gay men).

The greater involvement of people with HIV: principles and problems

One of the most striking social movements in response to AIDS involves the PWA or person with AIDS. In every language, the debate about which words (and acronyms) to use to describe people with either the HIV virus or associated illnesses has been controversial and catalytic. From *personnes at*

teintes to the ironic "diseased pariah," from PWAs to P+ HIV/AIDS seems to have built on an earlier experience, such as with breast cancer, diabetes, lateral sclerosis, or coronary artery disease, to create identities, movements, and organizations based on a medical diagnosis.

Undoubtedly, some of the most effective specialized AIDS groups are self-help groups of people living with HIV/AIDS (see Box 32-2). These organizations ensure that HIV/AIDS work is not neglected and develop expertise specific to it. They are also usually the most convincing advocates and campaigners, encouraging governments and others to engage in AIDS work more effectively.

BOX 32-2

Women living with HIV/AIDS

WINNIE CHIKAFUMBWA

To be told that you are HIV positive by your doctor is just like receiving a death sentence on a judgment day. I was first told that I was HIV positive when I went to my postnatal clinic in January, 1989. The tests were taken without my consent at one of the Mission Hospitals in mid-1988 when I was attending an ante-natal clinic. At the time they were taking my blood, I did not suspect anything because I thought it was something to do with my pregnancy. They did not tell me the results until after I had the baby, and they tested my baby who was also found positive. There was no pre-counseling or post-counseling for me, the doctor just broke the news during my post-natal check-up. It was very shocking because he just told me that they took my blood and that of my child for an HIV test and the results were found positive, and that the child was not going to live past five years. Indeed my child did not live up to five years, she passed away when she was only four months old.

Although I was shocked, I instantly gathered courage and prayed to God to give me strength and stand by my side during the trying time. It really worked. I didn't break down until after I got home. Later in the evening when my husband came home, I broke the news to him and hell broke lose. I got the worst reaction from him. He walked out of my life that very same evening, calling me all sorts of names and blaming me that I had been unfaithful to him and that I was a prostitute. He left me with four children under my care and went to stay with another woman, and thus infected that other woman too, because I later learned that he had already been tested and found HIV positive but could not gather courage to tell me.

I spent most of my time crying, and the loss of my baby made my condition worse. But still I prayed to God to let me live for the sake of the remaining three children, and indeed God has given me strength because I have a will to live. Apart from my husband, I only told my elder sister about my status, and she advised me not to tell anyone else. People in Malawi, until now, think AIDS is a shameful disease, and anyone diagnosed with HIV is often taken as a promiscuous person. Therefore, I had to close my mouth and take it as my own problem. Up to now people in Malawi are still resisting to change their behavior, and the rate for HIV infection is increasing each day. According to the report from the National AIDS Control Program, the 1995 AIDS Analysis estimates that about 727 people are being infected every day. The cumulative figure will reach an estimated 1.3 million in a country of 10 million people. This is alarming.

In March, 1992, a lady from the Netherlands wrote her friend in Malawi, a woman who is working as a nurse with my sister, informing her that the Dutch HIV-positive women have organized a pre-conference of HIV-positive women from different parts of the world to be held in the Netherlands. When my

sister heard about this, she asked me if I was interested in attending the conference. I accepted although I was afraid to talk about my status, and although I have never been involved in any AIDS activities, I accepted because I wanted to meet my "fellow dying people." I was wrong. I learned from these women that some had lived with the virus for 10 years. This gave me hope that I, too, could live longer. I can assure everyone that I am not dying any more.

The international pre-conference was attended by 54 HIV-positive women from different parts of the world. We shared experiences and exchanged information. It is at this conference in Amsterdam that the women decided to establish a recognized organization, which is now known as the International Community of Women Living with HIV/AIDS (ICW) to address the issues that affect women.

The conference gave me self-confidence and the courage to start getting involved in AIDS activities and talk about my status to friends and my whole family, including my own children. This approach also gave me a chance to come across some of the women who were experiencing the same trauma I was. It is this destitute nature of most HIV-positive women in Malawi that made me found The National Association of People with HIV/AIDS in Malawai (NAPHAM).

Because of the active part I have played in the fight against AIDS, my fellow African People living with HIV/AIDS elected me to be one of the key contacts for Africa in the International Community of Women Living with HIV/AIDS.

In Berlin, at the International AIDS Conference in 1993, I was also elected by the African PWAs to be one of their representatives on the Global Network of People with HIV/AIDS (GNP+). Although communication with other PHWAs in Africa is limited, due to lack of funds, I always pass any information through ICW London and the GNP+ London office to pass it over to PWHAs.

Being HIV positive has taught me to be forgiving, patient, loving, and caring. I am happy that my HIV status has taught me to prepare for my children and my own future. It has brought me closer to God. I feel God has kept me for a purpose, which I am now trying to fulfill; the purpose of supporting and empowering HIV/AIDS people in Malawi. It has also kept me on the run. I am no longer ashamed of my status, and my hope is to see that PWAs all over the world do not suffer as I did during my early days of living with HIV. The struggle continues.

Like NGOs in general, it is important to stress that there are many different types of PWA groups. Many start as groups of friends helping one another with peer support, income opportunities, or housing ("self-help groups"). Some self-help organizations evolve into offering AIDS services (prevention, care, policy, or advocacy work) to a wider public in return for grants, donations, or contracts. Other PWA groups bring together like-minded activists to engage in advocacy, monitoring, or providing treatments or treatment information, or human rights work. There are also local, national, and international PWA networks, some of which help smaller PWA organizations share information or collaborate on projects, others of which function as self-help groups where members provide direct support through e-mail and airplane tickets. Finally, many groups are closely identified with people with HIV or their loved ones, but do not actually restrict their membership or staff to people with HIV—TASO in Uganda and ACT-UP chapters around the world are somewhat imprecisely referred to as PWA groups by many commentators.

Supporting organizations of people living with HIV/AIDS seems to make

eminent sense in the fight against the epidemic; indeed, a broad consensus has been reached on this issue among activists, health care providers, and funders. Large PWA organizations exist in many countries, and in most Western countries it is reasonable to refer to this as a movement, replete with various factions differing politically and its own panoply of styles of social intervention. The acceptance—perhaps even mainstreaming—of PWA groups is indicated by the representation of such groups on governmental advisory boards and even pharmacological monitoring agencies such as the U.S. FDA (Food and Drug Administration).

This consensus concerning PWAs arose from experiences with the epidemic in the 1980s in North America and Europe and, to a limited extent, in Africa. PWA organizations were in the vanguard, stimulating effective responses from government and other large institutions (such as hospitals and pharmaceuticals firms). While not all groups achieved the notoriety of ACT-UP New York, local groups in major western cities formed a constituency to which these large social actors were to be held accountable.

Over the years, recognition of the role of PWA groups has extended to the international arena. In December 1994, the Paris AIDS Summit, which brought together Heads of Governments and other officials from 42 countries, culminated in the signing of a declaration that included as one of its commitments a greater involvement of people with HIV/AIDS (GIPA), promising to:

> Support a greater involvement of people living with HIV/AIDS through an initiative to strengthen the capacity and coordination of networks of people living with HIV/AIDS and community based organizations. 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.[7]

This text represents a significant public policy victory for PWA activists as well as NGO activists, but its interpretation and implications remain controversial. An informal alliance had evolved for inclusion of the GIPA statement in the Paris summit, and to subsequently ask for alliance groups to receive financing to fulfill government pledges to "the GIPA initiative." While many NGOs, both PWA and others, felt excluded from this lobbying effort, there were also divisions amongst the key protagonists as to whether the initiative includes community-based organizations only as a route to supporting people with AIDS, or whether the initiative is intended to address both networks of people living with HIV/AIDS and, separately, networks of community based organizations. In any case, France was the only major government that pledged funds to the GIPA initiative (although, as of early 1996, France had reduced its 1995 commitment from 100 million FF to 15 million FF, or as characterized by French spokespersons, the government had decided to make pledged funds available over a longer period of time than had initially been anticipated).

Locally, PWA organizations have also had important achievements. As self-help groups, they provide the kind of supportive environments that motivate PWAs to "come out" and get involved in local prevention and care

activities. This has contributed immensely not only to the visibility of AIDS but also to an awareness of its impact on people for whom, otherwise, the epidemic would have remained a distant reality until it struck closer to home. In this sense, PWA visibility has provided powerful experiential motivation for behavioral change on an individual level while at the same time advocating against discrimination at the social level.

However, despite support within their immediate environment, it is likely that people revealing their HIV status will continue to face sustained prejudice and discrimination from the broader society. The "coming out" of PWAs and the adoption of "positive" identities raises many issues both for individuals and for communities. It is not uncommon, for example, for "romantic myth-making" to surround the figures of PWAs—where they are seen as heroic characters.[8]

The success of PWA groups in carrying out this work has led to "mainstreaming" in another sense. The political pressure to include PWAs in policy making and service delivery, and the proximity of these groups to affected communities and their efficacy in outreach, has made them attractive to funders wishing to support service providers.

The attractiveness of PWA groups as service providers is also economic. As pressures to move services to less costly infrastructures are increasingly felt throughout the world, community groups provide tempting alternatives to funding hospitals, outreach workers, and traditional public health campaigns. The relationship between PWA groups and funders can also be contentious and divisive. PWA groups often start with minimal financial resources, usually contributed by the members themselves. The arrival of external funding—particularly on a large scale—to a PWA organization can have considerable impact on the group. The need to meet funding criteria can change, even distort, the rationale and priorities of the organization. In some cases, pressures—both positive and negative—can lead to the "professionalization" of PWAs, with considerable consequences, particularly in relation to the distribution of power within a group.

The potential and risks of "self-help" organizations in developing countries is illustrated by the experience of an association of PWAs created in a West African country in 1994. The founding of the group was linked to the presence and promotion of anonymous HIV testing as a prevention strategy, itself a controversial approach. With some instigation from the director of the testing program, the PWA group was founded by a small group of young people with HIV who felt impelled to "come out into the light," both in response to their own personal experience of isolation and because it was still too easy to deny the reality of the disease in many circles. The group's founding occurred when three young people declared their status at a meeting on AIDS involving government representatives as well as multi- and bilateral aid agencies. The interest of donors was sparked, and the minister of health promised that they would be welcomed at the headquarters.

Subsequently, the group became an official association, complete with bylaws and officers. Enthusiastic donors funded the organization to undertake

prevention and care activities: members offered their testimonies through fora and education activities organized by the National AIDS Control Program and other NGOs, and "field" activities were undertaken. The articulate founding members gained notoriety and were quickly identified as national and international representatives of HIV-positive people, a responsibility involving frequent travel (paid for by donors and other NGOs) to conferences and meetings around the world.

Although they lack headquarters, the association has an office within the National AIDS Control Program (NACP). In weekly meetings—for which a stipend is received—members report on conferences and prevention activities, as well as specific cases. In reality, however, little can be done to address issues that arise, other than to offer supportive counseling—a situation that often ends in frustration and anger directed at those in power and perceived to be indifferent.

Although the overall mission of the group (to provide support to PWAs and to reduce their sense of isolation) is relatively clear, its exact goals and strategies remain vague. Some members emphasize the urgent need for individual material assistance—such as medicines and housing—and see membership as a way of ensuring privileged access to such resources. Others emphasize that it is the association that requires more facilities—including a headquarters, office equipment, and a drop-in center—ideas are already expressed in the organizational chart which contains an extensive tree of executives, committees, and subcommittees despite the lack of structure in the organization's current work.

Thus, in just over a year, divisions are apparent both within and outside the group. PWAs speak openly about how they must be "in" with the association's core group, articulate, young people who are often attending conferences where they seek additional support. Furthermore, the locally based donor community—who had pushed for funding for this PWA group—is increasingly disappointed. One representative, who had hoped that the group would break the complacent consensus that had settled around AIDS in the early 1990s, now expresses her deep concern that donor interest in the group has somehow destroyed solidarity and stifled initiative. Of particular concern was her impression that individually, the women in the association had strong ideas and initiative, but collectively, the women were silenced by the overall power dynamics.

Overall, although some evolutionary experiences of self-help groups are mirrored by those of service delivery organizations, others are unique to such bodies. Both types of organizations face the challenges of "professionalization," expansion and changing external climates. However, the sensitivities surrounding issues such as power structures, avoiding conflict of interests, and agreeing on systems for resource allocation, are heightened when members are both the governors and the beneficiaries. As self-help groups mature and evaluate their impact, they often face growing pressure (from both within and outside) to become service providers—a move that can fundamentally change the nature of their organization, its goals, and work (Box 32-3).

BOX 32-3

Empowerment and gay community in Australia

GEOFFREY WOOLCOCK AND DENNIS ALTMAN

The contrasting approaches of societies and governments in responding to the AIDS epidemic is intriguing. For example, Australia's response has been frequently touted as a model of effective community empowerment. The relationship among community agencies, health and medical institutions, and federal and state governments, popularly referred to as "The Partnership," continues to serve as the basis for the implementation of the Second National Strategy (1993–1996) and the proposed third national strategy.[1] This document consolidates the spirit of cooperation among different stakeholders in society as part of a collaborative effort to reduce the annual number of new HIV infections to fewer than 500 by 1996. The affected communities have been at the forefront of these efforts, arguably the pivotal factor in ensuring a swift and efficient response in Australia.

In Australia, as in other western countries, the great majority of early HIV infections were transmitted through homosexual intercourse. In Australia this remains true; in 1994 homosexual intercourse was involved in 82 percent of reported infections. The gay community throughout Australia was the primary activist group and source of initial information about AIDS. They were also the principal sources of support and creativity for the prevention and education-based community cooperation model, which fought successfully to establish a legitimate place alongside the traditional medical contain-and-control model championed by conservative forces. In this struggle, they were substantially assisted by the critical decision of the Federal Health Minister to fund gay community-based programs as the primary means of prevention. Prominent and politically active members of the gay community also became the leading figures in the work of AIDS Councils to complement the work of the broader, non-political gay community regarding care and support services.

Other affected communities created their own representative organizations, including the Australian IV League (injecting drug users), the Scarlet Alliance (sex workers), the National People Living with AIDS Coalition, and the Haemophilia Foundation. All played critical roles in framing and shaping policy and program responses and in ensuring that community groups remained the most effective and appropriate disseminators and education and preventive messages. The success of these proactive policies has in turn established a platform for the empowerment of various other sectors of the community facing the epidemic. As a result, some of the most innovative peer education and treatment and care programs in the industralized world have been developed and implemented in Australia.

The concept of community development has underpinned most of the effective strategies. This emphasizes health belief principles, empowering people to develop their own skills and to have the confidence to identify health concerns and then to develop appropriate programs. In adopting this model, however, most of the successful education programs in Australia have also recognized the need to enable individuals and communities to work toward changing the broader social and political context.

These developments have not emerged without some tensions. Official recognition of the community sector in government committees has been taken further in Australia than in most countries; accordingly, a number of gay men now have a legitimacy and access to government unimaginable before the epidemic. This has led to fears of co-option by the state, and the emergence of Australian chapters of ACT UP in the early 1990s was in part fueled by frustration at the perceived accommodationist stance of the AIDS Councils. Indeed, because the AIDS Councils have become large service delivery organizations—the largest, the AIDS Council of New South Wales, has about 75 full-time staff—their dependence on government for funding raises questions about how successfully they might resist government pressures.

Furthermore, there is a danger that the autonomy won by HIV/AIDS community-based organizations (CBOs) in Australia over the past decade will mask the problems that the community sector faces at

present and for the future. The changing nature of the epidemic poses greater demands on both governments and community groups, but inevitably it is the latter that will continue to bear the brunt of the political shifts in priorities. Some of the problems that have emerged in Australia over the first few years of the current decade include:

- the growth of professionally staffed HIV/AIDS CBOs, which has reduced the impact of the role of volunteers and has raised problems in relation to meeting the wishes and needs of the affected communities
- the increasing bureaucratic nature of CBOs as they adopt organizational structures similar to those of their funding bodies, potentially reducing the capacity to respond rapidly to the changing needs
- the lack of ability to meaningfully involve HIV-positive people in the work of CBOs
- the tension between those who see CBOs as principal advocates for clientele and service delivery and those who view the CBOs primarily as political lobbyists
- the nature of identity in defining the constituency, and thus the commitment, of CBOs
- the escalation of efforts by other public health sources to channel scarce resources into other pressing health issues (e.g., breast cancer) and hence, the need to ensure ongoing funding
- the tend toward complacency, apparent in the assumption that the effective education work among homosexual men does not necessitate continual funding
- the concern about the sustainability of informed social research guiding prevention and care programs in CBOs

Many of these concerns have been addressed, if not resolved, in the debates currently taking place around a third national strategy. Australia's development of peer education and organization within the gay and PWHIV/AIDS communities has had some influence in Southeast Asia, where a number of AIDS/gay groups have developed close links with their Australian counterparts. The provision of some Australian government money for "partnership programs" with groups in India, Indonesia, Malaysia, the Philippines, and Thailand has made it possible for groups to exchange ideas, programs, and personnel, and has been a factor in the emerging assertiveness of gay groups in Asia over the past few years.

In Australia, the nature of empowerment as a driving force in the fight against HIV/AIDS has altered significantly. Emphasis has shifted from building self-esteem and community development processes to a position in which CBOs are increasingly adopting a more professional structure replicating those of the state. The focus on empowerment is increasingly shifting to communities of people living with HIV/AIDS. In fact, their organizational structure is largely based on a model of "coming out" and self-articulation, directly derived from gay politics. Their growing assertion and leadership role highlights the fact that the potential empowerment of marginalized groups and their participation in all forms of decision-making is a great achievement whose potential remains undiminished.

References

1. Commonwealth of Australia, *National HIV/AIDS Strategy 1993–94 to 1995–96* (Canberra, Australia: Australian Government Publishing Service, 1993).

While some PWA groups in Australia, North America, and Western Europe have had unprecedented success in molding science and public health policy (and even the agendas behind research funding), this has been much less so where PWAs are severely marginalized (whether by the same struc-

tural conditions that underlie poverty or gender inequality or by more AIDS-specific discrimination). For example, PWA groups in West Africa have remained silent on a large multicenter clinical trial of AZT versus placebo in pregnant African women at the same time as their counterparts in Europe and America protested against the same trial; the African PWA groups simply do not have the expertise or access to the knowledge and resources necessary to affect local scientific research, especially when that research is driven by international research agendas.

Such experiences provide evidence that funding PWA organizations is not a panacea in the fight against AIDS. However, these complexities should not detract from the many positive examples and contributions of PWA groups that continue to emerge throughout the world.

The proliferation of NGO activities on AIDS and the dilemmas of funding

Why are NGOs now being supported? Is it due to prevention (and care?) success stories and to their proven efficacy and efficiency? Or is it due to the desire of ODA bodies to spend less for maximum political advantage?

Governments have not always been willing to fund generously NGOs for AIDS work. With few exceptions, NGOs, governments, and intergovernmental organizations responded to AIDS with remarkable independence from each other from the early 1980s until about 1987. If they did anything in response to HIV/AIDS at all, most governments largely restricted themselves to provision of care to the very ill, and to traditional public health responses of surveillance and infection control for blood. The intergovernmental response was largely restricted to WHO, which created a sectoral AIDS program focused on both international public health functions like epidemiology, and on technical advice and advocacy to mobilize national governments. As noted, NGOs typically pioneered home care, counseling, and prevention work, most notably inventing, adapting, and promulgating the notion of "safe sex."

In the latter half of the 1980s, these relationships began to change. NGO activists got to know each other at meetings and conferences, and they began to form networks and federations (including notably what has become the UK NGO Consortium on AIDS, a federation of international NGOs working on development from within the United Kingdom; and the first in a series of Brazilian NGO networks). This process was encouraged by WHO/GPA who, among other measures, organized the first meeting of AIDS NGOs in Vienna in 1988 which resulted in a declaration and the creation of the International Council of AIDS Service Organizations (ICASO). As these networks characteristically work to ensure three functions: sharing information on successes and failures in AIDS work; cooperating on advocacy work on such broad issues as human rights for people infected with HIV; and lobbying for funds and other support for NGOs from governments and intergovernmental organizations.

Over the same period, both governmental and intergovernmental organi-

zations began to increase cooperation with NGOs in policy development and, crucially, by passing along grants or contracts of public funds to these private organizations. (It is important to note, however, that this cooperation proceeded much more slowly in the United States than in Europe.) The trend towards subcontracting activities and granting public funds outside the apparatus of the state accelerated quickly, probably in response to lobbying by NGOs, in recognition of the relative successes and advantages of NGOs, and in many countries as part of a broader ideological shift toward the privatization of state functions.

Rapid increases in public funding of private organizations had a considerable impact on the effect of NGO activity on AIDS. Some community organizations that had struggled to deliver services using volunteer resources rapidly expanded their scope. Thus, more and more communities around the world benefited from locally delivered AIDS services. Groups involved in AIDS services differentiated into the "haves" and "have nots," and countries with public funding for NGOs (either by local governments or international aid donors) quickly saw their NGO sectors eclipse those of countries where no such funding was available. New intermediary nongovernmental organizations and networks were created to capture, manage, and make more efficient these public funds (at a transnational level, early examples included the AIDS Communication Project (AIDSCOM) and the AIDS Technical Support Project (AIDSTECH), which administered some USAID funds for developing countries until the launching, in 1991, of the AIDS Control and Prevention Project (AIDSCAP), implemented by Family Health International. A more recent example is the International HIV/AIDS Alliance in London. Other existing NGOs, motivated by the growing importance of AIDS, as well as by their instinct to respond to new funding sources (both service deliverers and intermediary groups), also sought and received grants and contracts. Community AIDS groups founded and run for years by volunteers began to resent the arrival of "professional" NGOs like the international CARE federation or ENDA Tiers Monde, perceived as having arrived on the scene with generous government support.

Funding trends and their impact on NGOs

The first edition of *AIDS in the World* pointed to the importance of ASOs and other NGOs, and their pioneering role. Current data reflect a constant increase in NGO involvement in the epidemic, as well as in net increases in resources granted to NGOs. Developing country governments still receive far more grant assistance for AIDS work than NGOs, but such grants to governments are declining and are being offset by World Bank lending to governments for AIDS (see Chapter 35). In industrialized countries, the same governments that are increasing aid to developing world NGOs for AIDS work are cutting back on funding for domestic groups involved in prevention and care. Recent data on the transfer of resources to NGOs also hides other trends. According to a survey of overseas development agencies and government national AIDS programs (GNAP) $40.5 million of the $226

million support delivered by donors in a year circa 1993 went to NGOs in developing countries—in addition to indirect support allocated through NACPs (see Chapter 35).

Development assistance funds are increasingly controlled at the national level—limiting central funds available to international organizations, while not necessarily increasing access to resources for local NGOs. There is also a decline in the amount of funding available for AIDS-specific activities or organizations. Also, as the pursestrings tighten, ODA bodies are becoming notably more likely to fund "safe," tried-and-tested NGOs as opposed to new organizations. "The world inhabited by CBOs is no different than that of the private sector: those which already have visibility and resources are awarded more."[9] This scenario has undoubtedly increased the challenge faced by small-scale CBOs in terms of accessing even small allocations of resources and funds, as well as intensifying the tension between "upstart" AIDS-specific groups and more established development organizations as they compete for diminishing resources.

In response to the changing funding and political climates, different models and mechanisms have been developed to support NGO responses to HIV/AIDS. In 1989, the World Health Organization Global Programme on AIDS first established a grant program whereby local groups were to be supported through international NGOs (the Partnership Program), and then had considerable success in encouraging national AIDS programs to set aside 15 percent of their budgets to be made available in locally administered grant funds for local NGOs. More recently, in December 1993, the International HIV/AIDS Alliance was established as a means to provide CBOs with local access to resources and to ensure that donor money could reach communities in need. The alliance channels international resources to "linking organizations"—bodies coordinated by local leaders in areas such as health, NGOs, and development. A linking organization would make decisions about local priorities and function as an NGO support mechanism—allocating resources to CBOs as well as playing an active part in the NGO sector's response to HIV/AIDS.

It is difficult to discern a coherent logic to donor actions in supporting NGOs for AIDS work. Stated policies often differ from actual allocation of funds, and one of the few safe generalizations that can be made is that donors are consistently concerned about being identified institutionally with particular projects, and are thus hesitant about multilateral and cooperative efforts. Ironically, while many governments start supporting NGOs as a way to reduce state expenditure on HIV/AIDS, successful funding programs tend to result in articulate constituencies that demand expanded public services in health and health promotion.

While it is difficult to identify indicators of NGO success, assessing the impact of donor support is also quite complex. Donors are only too aware of NGO criticisms—of dictating local responses, flooding nascent groups with funds, insisting on inappropriate overly technical programs, and of lack of accountability to local people. Nevertheless, with some support from outside, community groups can be remarkably effective. This is espe-

cially true in countries that do not yet have widespread HIV/AIDS epidemics and where NGOs working intensively with small but vulnerable populations may curb the spread of disease. Providing NGOs with local access to appropriate resources can enable them to play their full role of providing care and support and saving lives.

Relations between NGOs and governments

A strong national response to HIV/AIDS in any country requires a dynamic alliance among community groups, government, and the private sector.

Governments are typically in the best position to monitor trends in HIV infection, to ensure consistent supplies of quality condoms at a national level, to strengthen health care practitioners' capacity to recognize and treat STIs, and to promote the respect of human rights, especially for vulnerable populations. Governments also have a unique opportunity to teach about HIV/AIDS, STIs, and sexuality to young people in schools.

Private sector companies are often responsible for providing health care and health information to their employees. Private sector leaders can also set an example for others by encouraging HIV/AIDS services in the workplace, by not discriminating against people living with HIV, by calling on governments to act responsibly, and by supporting community groups.

A cooperative relationship among NGOs, governments, and the private sector is required on an international level. NGOs not only share lessons learned across borders through their networks but also push institutions like the United Nations to pay more attention to the importance of human rights in HIV/AIDS work, and lobby international companies to be global leaders in offering prevention and care services, and ensuring nondiscrimination in the workplace.

Responses to HIV/AIDS have demonstrated both the advantages and the disadvantages of cooperation between governments and NGOs. Close liaison has provided NGOs with access to both influence and resources, helping them to play a full and recognized role in shaping and building an integrated response. There is, however, a delicate balance to be achieved. Too close liaison has sometimes limited the independence and dynamism of NGOs—affecting their flexibility, as well as their access to support from nongovernmental sources.

NGO efforts in response to HIV/AIDS are not immune from existing national and regional issues and politics. In the UK, for example, the initial delay in the government response was partly attributable to the association of HIV/AIDS with controversial issues such as drug use and homosexuality. In Africa, addressing HIV/AIDS often involves sensitive cultural issues—such as polygamy and wife inheritance—which governments do not want to be seen to challenge. While effective NGO responses typically work within traditional structures of individual communities or tribes (or subcultures), some national governments are striving to promote "generic," national cultures. According to Alfred J. Fortin, "This state legitimisation strategy has the potential to undermine AIDS prevention efforts that stress involvement

with the authority structures of tribal communities."[10] Officials in both Côte d'Ivoire and Kenya, for example, have hesitated to endorse or support tribally identified NGO activities on AIDS, with the Kenyan program being delivered mostly in the two official state languages, English and Swahili.

Other governments seem willing to allow NGO activity to flourish in many languages and discourses, from Uganda's twenty-two language AIDS posters to the Netherlands's tailored programs for sex workers of particular ethnic backgrounds.

Sustaining community action on AIDS

As the HIV/AIDS pandemic progresses, funders are increasingly supporting established organizations—such as women's groups—to become involved in AIDS, rather than asking AIDS service organizations to serve broader populations. There are valid arguments for this strategy; such organizations may have better, more specific community connections, and more sustainable approaches, than AIDS-specific groups. Nevertheless there is considerable concern that the wealth of experience gained by AIDS service organizations will be lost, and that groups will have to repeatedly learn basic lessons through trial and error. More insidiously, donors can use the rhetoric of empowerment and solidarity with affected communities, while publicly misrepresenting funding reductions as increases. One solution is to put pressure on donors to differentiate funding for AIDS activities that are integrated with other programs, but that can be tracked and evaluated, from funding for "AIDS-related activities," which often describes programs that contribute to reducing HIV vulnerability, but that were being funded long before the HIV/AIDS epidemic began.

The lessons learned from over a decade of experience of NGOs in the fight against AIDS must not be lost. When they develop policies, practices, and expectations about "NGOs" as a nondifferentiated group, governments and intergovernmental organizations risk undermining many of the unique contributions to be made by NGOs. The efforts of AIDS-specific and non-AIDS-specific organizations can be complementary—mutually reinforcing areas of expertise, experience, and access.

The HIV/AIDS pandemic, and its attendant trauma and loss for individuals, families, and communities, is with us for many years to come. Community action is an efficient way to deliver prevention, care, and support services. For an effective and sustained response to HIV/AIDS, people cannot rely too much on outside experts. Communities need to take control themselves, communicate messages among themselves which are understood and respected, follow their own leaders, and take actions that are appropriate and effective.

REFERENCES

1. J. O'Malley, "AIDS Service Organisations in Transition," in *AIDS in the World*, eds. J. Mann, D. Tarantola, and T. Netter (Cambridge, MA: Harvard University Press, 1992): 774–787.

2. D. Altman, *Power and Community* (New York: Taylor and Francis, 1994):27.
3. T. Brodhead and J. O'Malley, "NGOs and Third World Development," World Health Organization, Global Programme on AIDS, Geneva, 1989, GPA/GMC (2) / 89.5 Addendum 1.
4. P. Aggleton, J. Weeks, and A. Taylor-Laybourn, "Voluntary Sector Responses to HIV and AIDS: A Framework for Analysis," in *AIDS: Facing the Second Decade*, eds. P. Aggleton, P. Davis, and G. Hart (London: Falmer Press, 1993).
5. "The Alliance," "Community Action," "Alliance Programmes," "Programme Development," "Mission Vision and Values," sections of International HIV/AIDS Alliance information pack, November 1995.
6. M. Roberts, "Emergence of Gay Identity and Gay Social Movements in Developing Countries: The AIDS Crises as Catalyst," *Alternatives* 20 (1995):243–264.
7. Conference Declaration, Paris AIDS Summit, Paris, December 1994.
8. M. Benjamin, "A human condition," *New Statesman and Society* (August 20, 1993):34.
9. A. Klouda, "Shifting Patterns in International Financing for AIDS Programs," in *AIDS in the World*, J. Mann, D. Tarantola, and T. Netter, eds. (Cambridge, MA: Harvard University Press, 1992):795 (note 20).
10. A. J. Fortin, "AIDS, Development, and the Limitations of the African State," in *Action on AIDS: National Policies in Comparative Perspective*, B. A. Mesztal and D. Moss, eds. (Westport, CT: Greenwood, 1990).

33

The Private Sector: How Are Corporations Responding to HIV/AIDS?

BEA BEZMALINOVIC

An enlightened business community can provide critical leadership and help catalyze political will to deal with issues affecting the labor force, the economy, and the welfare of the nation as a whole. In the context of HIV/AIDS, the private sector can contribute effectively to prevention efforts for employees; to the provision of health care and social support to workers and their families; to advocacy for broader government actions on AIDS; and to philanthropic actions.

The workplace has been considered an appropriate and effective setting for HIV prevention programs. Fears and misconceptions about AIDS can be alleviated, discrimination against people with HIV can be prevented, managers can be helped to deal fairly with HIV-infected workers, and employees can be educated to reduce their risk for HIV transmission. These efforts may help corporations contain and even reduce other costs related to treatment and health insurance, decreased productivity, and "de-skilling" (the loss of workers with specific training or skills), or retraining of the workforce.[1] In many countries, workplaces also provide a unique opportunity to provide accurate information about HIV to sexually active adults who would be difficult to reach through other channels.

According to the World Health Organization, workplace HIV/AIDS policies should address a range of issues in order to create an environment conducive to promoting the health and human dignity of workers[23] (see Box 33-1).

BOX 33-1

Workplace guidelines on HIV/AIDS

A. Persons applying for employment: Pre-employment HIV/AIDS screening as part of the assessment of fitness to work is unnecessary and should not be required. Screening of this kind refers to direct methods (HIV testing) or indirect methods (assessment of risk behaviors) or to questions about HIV tests already taken. Pre-employment screening for insurance or other purposes raises serious concerns about discrimination and merits close and further study.

B. Persons in employment:

1. HIV/AIDS screening: HIV/AIDS screening, whether direct (HIV testing), indirect (assessment of risk behaviors), or asking questions regarding tests already taken, should not be required.

2. Confidentiality: Confidentiality regarding all medical information, including HIV/AIDS status, must be maintained.

3. Informing the employer: There should be no obligation of the employee to inform the employer regarding his or her HIV/AIDS status.

4. Protection of employee: Persons in the workplace affected by, or perceived to be affected by HIV/AIDS, must be protected from stigmatization and discrimination by co-workers, unions, employers, or clients. Information and education are essential to maintain the climate of mutual understanding necessary to ensure this protection.

5. Access to services for employees: Employees and their families should have access to information and educational programs on HIV/AIDS, as well as to relevant counseling and appropriate referral.

6. Benefits: HIV-infected employees should not be discriminated against including access to and receipt of benefits from statutory social security programs and occupationally related schemes.

7. Reasonable changes in working arrangements: HIV infection by itself is not associated with any limitation in fitness to work. If fitness to work is impaired by HIV-related illness, reasonable alternative working arrangements should be made.

8. Continuation of employment relationship: HIV infection is not a cause for termination of employment. As with many other illnesses, persons with HIV-related illnesses should be able to work as long as medically fit for available, appropriate work.

9. First aid: In any situation requiring first aid in the workplace, precautions need to be taken to reduce the risk of transmitting blood-borne infections including hepatitis B. These standard precautions will be equally effective against HIV transmission.

This box was excerpted from WHO/Global Programme on AIDS, *Statement on the Consultation on AIDS and the Workplace*, meeting on June 27–29, 1988 (Geneva: WHO, 1988).

However, relatively few corporations have addressed HIV/AIDS in their programs and policies. For example, a 1994 survey of 794 U.S.-based firms, including many large multinational corporations, found that only 32 percent had an AIDS awareness program, less than half (49 percent) offered AIDS-related services through their employee assistance program (EAP), and only 19 percent trained supervisors and managers to deal with HIV/AIDS.[4]

AIDS in the World II surveyed selected national and multinational corporations to determine *how* and *how well* corporations with HIV/AIDS programs were addressing issues related to HIV/AIDS in the workplace. The corporate respondents included: Anglo-American Corporation of South Africa, Avon Products, Banco de Brasil, Botswana Meat Commission, British American Tobacco Company, Ltd., Debswana Diamond Company, First Pacific Company, Ltd., Heineken NV, Gold Fields of South Africa, Ltd., Interna-

tional Business Machines (IBM), Kgalagadi Breweries, Matsushita Health Care Center, Metro Pacific, Nestlé, Polaroid Corporation, Saison Palette, Schlumberger, Shell International, Sony-U.S., Southwestern Bell, Sun Life, Syntex, 3M-Thailand, Tata Iron and Steel Company, Ltd., Volkswagen, and Zambia Consolidated Copper Mines.

Employee assistance programs and services

Traditionally, employee assistance programs (EAP) and services have been developed to deal with problems such as alcoholism, drug use, or mental disorders that affect workplace performance.[5] Survey respondents reported that in most cases (13), management leadership provided the impetus for developing HIV prevention programs and policies (other surveys have suggested that management may wait until they have an employee with AIDS to respond[6]).

Corporations generally have responded to HIV/AIDS by creating or modifying traditional EAPs. Nineteen respondents (70 percent) have trained staff in their EAP or the relevant department (personnel, health staff, etc.) about HIV/AIDS, and twenty-one corporations (78 percent) also have specially trained HIV/AIDS counselors. More than half the respondents (16) felt that individual counseling was well addressed in their company's current programs.

However, few corporations have extended their activities to include HIV-specific services beyond individual counseling and referral. For example, only six of the corporations with HIV education programs organize support groups for people with AIDS. In addition, fewer than one-third (8) of the firms distribute condoms at most work sites, only six (22 percent) make condoms available at some work sites, and nearly half (13; 48 percent) do not distribute condoms at any work sites. Corporations operating in developing countries were more likely to participate in community education activities and to distribute condoms in most work sites.

Corporate policies regarding HIV/AIDS

The responding corporations appear better prepared to provide support services for personal or health-related concerns of employees with HIV than to address the managerial or work-related policy issues that arise when an employee is HIV infected. Corporate policies should provide guidance to managers; respondents' reports on major policies on hiring and promotion and the accommodation of HIV-infected employees raise some concern about policy design and implementation.

Hiring and promotion

Virtually none of the corporate respondents have a policy requiring an HIV test (25) or CD4 count (26) as part of pre-employment procedures. However, only two corporations explicitly prohibit such tests as employment requirements. Twelve corporations (44 percent) also have written policies

regarding training and promotion opportunities for employees with HIV and AIDS.

Accommodation of HIV-infected employees

Are employees with HIV/AIDS allowed to continue to work and in what capacity? Most respondents reported that HIV-infected individuals are allowed to continue in their current job as long *as feasible* and can be transferred to more suitable workplaces *if necessary*. However, respondents did not have a stated policy regarding work-related travel (24; 88 percent) or long-term assignments abroad (22 or 81 percent) of HIV-infected individuals. The majority (13; 48 percent) of the corporations surveyed did not have a policy of conducting work performance assessments for employees who are ill or disabled. Presumably, such decisions are made on a case-by-case basis. Among the 11 corporations that did evaluate performance of HIV-infected workers, most did so as part of routine evaluations similar to those conducted for every employee.

Creating policies is only the first step. These policies must be clearly communicated to ensure clarity and compliance. Sixteen of the corporate respondents (52 percent) provide managers with specific training in HIV/AIDS, but only three corporations (13 percent) require managers to participate. Given the complexity of issues associated with HIV/AIDS, managers may need special training to ensure confidentiality, accommodation, and equity in regard to employees with HIV/AIDS.[78]

HIV/AIDS prevention programs

Nearly all (23; 88 percent) responding corporations had at least one type of HIV prevention program. Corporate prevention programs frequently use brochures and posters to distribute written information to employees. Interactive educational presentations and discussions are less commonly utilized. Most corporations (21; 88 percent) consider staff attendance at HIV/AIDS programs voluntary.

Few corporations have extended their efforts beyond reaching workers. Only seven corporations (30 percent) worked with community groups or others outside the workplace. Contact with governmental entities is also sporadic. Currently, more than half the corporate respondents (16; 60 percent) report that they coordinate policy and programs with the government of the country where the corporation is based, but only five corporations (19 percent) also work with governments where nondomestic operations are located. A minority of corporations, mostly in Africa, report that they work closely with the local government or NGOs.

Management information needs

Respondents reported that most managers have access to general information on HIV/AIDS; 16 (60 percent) receive information or statistics on HIV/AIDS from either the local ministry of health, the World Health Organiza-

tion, or through other journals and newspapers. Nevertheless, managers lack information on critical workplace-related issues such as program efficacy, specific information on local conditions, and costs of HIV and HIV prevention programs.

Program efficacy

Few corporations (9; 38 percent) have performed a formal needs assessment prior to initiating an HIV prevention program. Corporate HIV prevention programs also tend to be informally designed, and fewer than half (13; 48 percent) have been formally evaluated. Among corporations that have evaluated their programs, surveys of knowledge, attitude, and practices were most frequently used. Although rapid and easy to administer, they have limited capacity to measure accurately behavioral changes.

Financial information

Managers do not generally collect information about the direct and indirect costs of HIV/AIDS or the potential cost-savings of HIV prevention programs.

Summary

With some important exceptions, the corporate sector is just beginning to respond to HIV/AIDS in the workplace. The corporate sector has also organized to address challenges presented by HIV/AIDS by creating business coalitions in countries including the United Kingdom, Thailand, Brazil, and South Africa.* Currently, business coalitions focus on coordinating efforts at a national level, sharing experiences, and disseminating information to members. These business coalitions have the potential to be powerful forces in organizing the corporate response to AIDS and influencing the nature of their response (Box 33-2).*

Given the number of employees and workers worldwide, it is clear that prevention programs in the workplace and policies on HIV infection and infected workers can contribute importantly to the global response to HIV/AIDS. However, many corporations and smaller businesses have not thus far developed or systematically applied guidelines and models for workplace HIV/AIDS policies and programs. In addition, the specific issues raised by HIV/AIDS may require a substantial rethinking of broad and traditional health and work policies and programs.

While the private sector can clearly do more within the workplace setting, including outreach to households of workers, their potential contribution extends far beyond the workplace. In many communities, business leaders are de facto leaders of public opinion.

*An incomplete list of coalitions would include: the AIDS Consortium in Brazil, the National AIDS Coordination Organization of India, the National AIDS Convention of South Africa, the Thai Business Coalition in Thailand, the AIDS Information Clearinghouse in Uganda, the Business Exchange on AIDS and Development (BEAD) Group in the United Kingdom, and the National Leadership Coalition and New England Consortium on AIDS in the United States. More information on international AIDS organizations and coalitions can be obtained from the Business Responds to AIDS Program at the Centers for Disease Control (CDC) by calling 1-800-458-5231 or writing BRTA Resource Service, P.O. Box 6003, Rockville, Maryland 20849.

BOX 13-2

Corporate response to AIDS in India

A. K. GANESH AND S. SUNDARARAMAN

The socialist era in India contributed to the formation and strengthening of labor unions and collectives. India has a large unemployed skilled labor force and a vast unskilled and semi-skilled labor force migrating from rural areas and the primary sectors of agriculture, in addition to labor displaced under the new economic agenda. Corporations believe that replacing labor lost to AIDS or infected with HIV will be fairly easy in India and therefore tend to dismiss HIV as another manageable issue while denying the crisis status of the explosion of HIV infection in India.

Thus, responses to HIV/AIDS in the corporate sector remain infrequent and limited. Well-developed business and trade forums, notably the Confederation of Indian Industries (CII) and other associations in which industrialists and industrial managers are members, such as the Rotary Club, the Lions Club, and the Round Table movement, have for decades nurtured social action. Recently, the CII indicated a collective corporate response to the AIDS pandemic, albeit on a small scale.

In 1990 the AIDS Research Foundation of India initiated a blue-collar HIV/AIDS education program based on a health education model developed with support from Family Health International Research, Triangle Park, North Carolina, U.S.A. The program employs small group dynamics and centers around behavior change. The program also assists management in developing systematic and noncoercive HIV workplace policies, including coping with HIV in the workplace, information on safe blood supply, staff (including family) orientation to HIV and AIDS, provision of condoms and other commodities that assist in the prevention of HIV within the workplace, and voluntary HIV testing.

Corporate support for the AIDS Research Foundation of India Program has varied; ANZ Grindlays Bank made meeting space available for NGO training; a travel service belonging to a large industrial group in South India offered subsidized rates; the first Asian display of the Names Memorial Quilt at Madras in 1991 would have been impossible but for generous contributions by local business houses. Industrialists, acting collectively through Rotary Clubs, have supported a rural outreach education mobile, a sexually transmitted disease (STI) clinic for truckers, and a mobile STI clinic, and have sponsored small events and provided office equipment. Finally, young entrepreneurs have offered to recruit people living with HIV who have been deprived of their employment on account of their infection.

To ensure the active involvement of the corporate sector in HIV/AIDS prevention and control, India urgently needs a catalyst, a multisectoral forum consisting of NGOs, corporations, and representatives from the government, to influence corporations to respond positively to the prevention and control of the HIV/AIDS pandemic and to impress upon the trade and business forums the need for including a response to AIDS as a social priority.

REFERENCES

1. J. K. Barr, J. M. Waring, and L. J. Warshaw, "Knowledge and attitudes about AIDS among corporate and public service employees," *American Journal of Public Health* 82(1992):225–228.
2. WHO, Global Programme on AIDS, *Guidelines on AIDS and First Aid in the Workplace*, WHO AIDS Series No. 7 (Geneva: WHO, 1990).
3. K. Brown and J. Turner, *AIDS: Policies and Programs for the Workplace* (New York: Van Nostrandt Reinhold, 1989).
4. American Management Association, "1994 AMA survey on HIV- and AIDS-related policies: Summary of key findings," *AMA News*, (1994):3.

5. D. A. Masi, *AIDS in the Workplace: A Response Model for Human Resource Management* (New York: Quorum Books, 1990):63–80.
6. American Management Association, "1994 AMA survey."
7. G. Banas, "Nothing prepared me to manage AIDS," *Harvard Business Review* (July/August 1992):26–33.
8. R. Stodghill, "Managing AIDS: How one boss struggled to cope," *BusinessWeek* (February 1, 1993):48–56.
9. J. K. Barr, J. M. Waring, and L. J. Warshaw, "Knowledge and attitudes about AIDS among corporate and public service employees," *American Journal of Public Health* 82(1992):225–228.

34

The UN Response

LISA GARBUS

The UN response to HIV/AIDS has been unique and remarkable in many respects. Under the leadership of the World Health Organization, a Global AIDS strategy was launched in the mid-1980s, which assisted countries in developing national AIDS programs and fostered extensive international collaboration. In October 1987, the UN General Assembly held an extraordinary session on AIDS, which led to a General Assembly Resolution acknowledging the multisectoral nature of the pandemic and calling for all parts of the UN system to become engaged in the global AIDS effort.

Even before 1987, several important UN agency initiatives were started. Historically, efforts to coordinate UN activities in any field have been difficult. Despite agreements on the leadership role of WHO and its relationship to other agencies (e.g., the WHO/UNDP Alliance), coordination on policies, strategies, and most critically, on support activities at the country level became increasingly problematic. In response to these difficulties, to the expanding pandemic, and to the growing awareness of the social and political complexity of HIV/AIDS, a new UN-level program was created. The new Joint United Nations Programme on HIV/AIDS (UNAIDS) brings together six agencies belonging to or affiliated with the UN system—WHO, UNDP, UNICEF, UNFPA, UNESCO, and the World Bank—under the aegis of a Program Secretariat. UNAIDS became operational on January 1, 1996.

To understand the challenges and opportunities facing UNAIDS, it is important to know the history of each UN partnership agency's involvement and perspective on HIV/AIDS (see Box 34-1). While new leadership and coordination will be applied by UNAIDS, each agency's past will undoubtedly influence UNAIDS, in obvious and less apparent ways.

BOX 34-1

Why UNAIDS?

PETER PIOT

Many lessons have been learned from the decade or more of struggle against HIV and AIDS. All point to the need for an expanded response—a response of greater quality, intensity, duration, and scope. Experience shows that in addition to focusing more and better quality action on the individual aspects of prevention and care, we need multisectoral action to address the societal causes and consequences of the epidemic, including its complex reciprocal links to human development.

To set an example and lead an expanded response of this kind, six organizations of the United Nations system have consolidated their efforts in a Joint United Nations Programme on HIV/AIDS. At the global level, UNAIDS serves as the global AIDS program of its six cosponsors: the United Nations Children's Fund (UNICEF), the United Nations Development Program (UNDP), the United Nations Population Fund (UNFPA), the United Nations Educational, Scientific and Cultural Organization (UNESCO), the World Health Organization (WHO), and the World Bank. At the country level, UNAIDS can be described as the joint action and collective resources of the cosponsoring organizations, with the backing of the UNAIDS central office in Geneva and UNAIDS country and intercountry staff.

The main focus of UNAIDS is on strengthening national capacity for an expanded response—that is, the capacity of a wide range of national partners from both government and civil society. Experience shows that efforts which are limited to one sector, or which exclude those most affected by the epidemic, are likely to fail. Thus, UNAIDS works with government departments and ministries of all kinds, people living with HIV, communities affected or threatened by the epidemic, nongovernmental and community-based organizations, academic institutions and the private sector, as well as bilateral and intergovernmental organizations. Technical soundness, inclusion, participation, gender sensitivity, ethics, and respect for human rights are among the values and principles that govern UNAIDS' staffing and operations and guide its work with national and international partners.

Mission and roles

As the main advocate for global action on HIV/AIDS, UNAIDS will lead, strengthen, and support an expanded response aimed at preventing HIV transmission, providing care and support, reducing the vulnerability of individuals and communities to HIV/AIDS, and alleviating the impact of the epidemic.

To this end it has four mutually reinforcing roles:

1. *Policy development and research.* UNAIDS identifies, develops, and serves as a major source of "international best practice." By this UNAIDS means the principles, policies, strategies, and activities that, according to collective experience from around the world, are recognized to be technically, ethically, and strategically sound. The Joint Program also promotes and supports biomedical, social science, and operations research on HIV/AIDS, especially research that fills critical gaps and that promises to be of benefit to developing countries.
2. *Technical support.* Technical support is the operational arm of international best practice. UNAIDS catalyzes and provides selected technical support in a way that builds on what countries have already put into place, and that takes advantage of the body of experience and expertise in the most-affected countries.
3. *Advocacy.* UNAIDS speaks out for and promotes a comprehensive, multisectoral response that is sound—technically, ethically, and strategically—and is provided with adequate resources.
4. *Coordination.* UNAIDS helps coordinate and rationalize action by the cosponsors and other UN bodies in support of the national response to HIV/AIDS.

Objectives

As this book went to press, UNAIDS had prepared a first draft of its strategic plan covering the period 1996–2000[1] and implementation and action plans, with specific outputs, were being developed. In support of the world's goals—preventing HIV transmission, providing care and support, reducing vulnerability and alleviating impact—UNAIDS has set itself four objectives:

- to foster an expanded national reponse to HIV/AIDS, particularly in developing countries
- to promote strong commitment by governments to an expanded response to HIV/AIDS
- to strengthen and coordinate UN action on HIV/AIDS at the global and national levels
- to identify, develop, and advocate international best practice

These are actions over which UNAIDS itself has some control. But in addition, through inclusion and participation, through a working culture of facilitation, UNAIDS hopes to leverage its own limited resources into far greater action, including by partners not yet involved in responding to HIV/AIDS. Because UNAIDS is built upon partnership, its own success needs to be seen in the light of the success of its partners.

References

1. Joint United Nations Programme on HIV/AIDS (UNAIDS): *Strategic Plan 1996–2000*. Background document for the second meeting of the Programme Coordinating Board, Geneva, 13–15 November 1995 (UNAIDS/PCB(2)/95.3, 31 October 1995).

Table 34-1 provides an overview of key elements for each of the six major UN agencies listed above. While a tabular form limits the amount of detail presented, it facilitates a comparison of AIDS program missions, primary clients or interlocutors at the national level, and funding and staffing levels.

Table 34-2 presents a cross-agency analysis which summarizes the information in Table 34-1. Together, this information provides insight into the kinds of coordination challenges and opportunities available to the new UNAIDS program. Melding the interests and capabilities of these six agencies will be difficult, but a truly synergistic, UN-wide approach to HIV/AIDS could make a major difference in the global AIDS effort and set a new precedent for global work through the UN system.

Table 34-1 UN response to HIV/AIDS: policies, programs, structures, and resources in 1994

	WHO/GPA	UNDP	World Bank	UNICEF	UNFPA	UNESCO
Mission	To mobilize an effective, equitable, and ethical response to the pandemic; to raise awareness and stimulate solidarity; to provide technical and policy guidance; to promote and support research	To strengthen the capacity of UNDP and of member states to respond to the development challenges of the HIV epidemic	To alleviate poverty (overarching institutional mission)	To support promotion of the health of youth and women, particularly their sexual and reproductive health	To provide support in line with national AIDS programs and within the scope of the Global AIDS Strategy	To foster development of efficient educational strategies to help young people avoid HIV infection
Primary clients	Ministries of health	Various ministries, especially planning	Various ministries, especially finance and planning	Various ministries, especially health, education, and information	Ministries of health, especially relating to maternal and child health	Ministries of education
Comparative advantage	Health expertise; technical and policy guidance; standard setting; socio-behavioral and vaccine-related research; intervention development; surveillance and forecasting; support to NGOs; discrimination-related activities	Central funding and coordinating mechanism for UN system operational activities in the field; extensive network of field offices; multisectoral experience; work with NGOs	Largest single source of long-term development finance for poor countries; ongoing policy dialogue with countries; research on socioeconomic impacts and on cost-effectiveness of interventions	Mobilize around children and youth; long-standing relationship with various ministries and with NGOs; experience with children in especially difficult circumstances and families affected by emergencies and disasters	Work centers on women's health and fertility. Key activity is support to training programs for maternal and child health/ family planning providers, who in many countries are the only health service providers that women see	Policy and planning in education; curriculum development
HIV/AIDS strategy	Global AIDS Strategy: (1) to prevent HIV infection; (2) to reduce the personal and social impact of HIV infection; (3) to unify national and international efforts against AIDS	To increase awareness of the development implications of HIV; enhance community capacity to respond to HIV; promote and assist prevention, care, and support programs for women; assist governments in developing effective multisectoral HIV strategies	To create a better socioeconomic environment whereby personal vulnerability to HIV is decreased	To promote young people's health, placing HIV/AIDS in the broader context of young people's needs and problems	To support AIDS prevention within the larger framework of ongoing programs in the population sector	To provide technical assistance in developing and implementing AIDS educational prevention strategies that are culturally appropriate

Current program structure	AIDS program established in Communicable Disease Division in 1986; elevated to special program in 1987; renamed Global Programme on AIDS (GPA) in 1988	Interregional project on HIV and development established 1991; became a formal program within Division for Global and Interregional Programs in 1992	No AIDS program (though semiformal AIDS in Asia Unit exists); HIV/AIDS integrated into Population, Health, and Nutrition projects	Interregional Program on AIDS established 1990; current HIV/AIDS activities housed in Health Promotion Unit within Health Cluster	No formal HIV/AIDS activities or program; guidelines suggesting possible areas where AIDS-related activities could be incorporated issued to country offices	Program for Education for the Prevention of AIDS 1987–94; AIDS now integrated into new project on human development
Current program focus	Technical cooperation (rather than operational activities); increased emphasis on care, STIs, women's status, socioeconomic impact, and discrimination	Policy and program development; awareness creation and advocacy; program support; liaison with development assistance community	Promotion of cost-effective interventions (e.g., STIs and TB treatment); training for high-level policymakers; research on socioeconomic impact of HIV/AIDS	Accelerate activities in 31 strategic programming countries by demonstrating successes that are or could be taken to scale	Activities suggested for country offices pertain to prevention of sexual and perinatal transmission	To strengthen education, training, and information activities to deal with population, environment, health, drugs, and AIDS, and their links with human development
Funding levels	Cumulative contributions for 1987–93 = $547.3 million; 1992–93 GPA budget = $140.4 million; revised 1994–95 budget = $140.1 million	1987–91 cycle = $41.85 million expended for regional and country activities;1992–96 cycle = approximately $90 million allocated for interregional, regional, and country activities	Total lending for HIV/AIDS–related activities (1986–94) = approximately $560 million	Interregional AIDS program funding approvals: 1990–91: $3 million; 1992–93, $3.4 million; 1994–95, $6 million; supplementary funds approval ceilings: 1990–91, $3 million; 1992–93, $4.5 million; 1994–95, $25 million	Total funds for HIV/AIDS activities not disaggregated	N/A
Staffing levels	GPA has 167 professional staff; for 1994–95, an additional 25 staff are proposed.	HDP HQ = 5.75 staff; regional projects = 7 staff; funding for 22 country-level HIV-specific posts recently approved	13 staff (in full-time equivalents) throughout Bank	5 approved posts for interregional AIDS program in 1992–93; 7 posts proposed for 1994–95	No designated staff for HIV/AIDS; requests for technical inputs forwarded to head of MCH/FP	N/A

Note: UNESCO did not provide funding or staffing data for this study. N/A, not available.

Table 34-2 UN response to HIV/AIDS: cross-agency analysis

	WHO/GPA	UNDP	World Bank	UNICEF	UNFPA	UNESCO
Agency-wide HIV/AIDS strategy document	√	√		√		√
Stated policies on and distinct activities in HIV & human rights	√	√		√		
Discrete AIDS program	√	√		√		√
Scope of activities:						
Prevention	√	√	√	√	√	√
Care	√	√	√		√	
Research	√	√	√	√	√	√
Socioeconomic impact	√	√	√		√	
External review conducted	√	√				
Channel funds directly through government	High	High	High	Low	High	Medium
Channel funds directly through NGOs	Low	Medium	Low	Medium	Medium	Medium
Funds its own activities in-country	Low	Low	Low	High	Low	Low
HIV/AIDS specifically assigned country-based staff	High	Medium		Low		
Systematic country-based planning and evaluation	√		√			
Marginal use of government				√		
Funding (as a percentage of overall agency resources)	9%[1]	2.10%[2]	0.38%[3]	0.43%[4]	N/A	N/A
	High	High	Medium	Medium		
Staffing (as a percent of overall agency staff)	6.90%[5]	0.43%[6]	0.22%[8]	0.07%[7]	0.00%	N/A
	High	Medium	Medium	Low		

Note: Information on UNESCO refers to its program on preventive AIDS education, which ended in April 1994. Because of the limited data UNESCO made available for this study, this table may not accurately reflect all components of that program.

[1]From personal communication with WHO/GPA, April 6, 1994.

[2]Represents proposed 1992–96 planning cycle figures for global/interregional, regional, and country HIV/AIDS activities as a percentage of total UNDP 1992–96 anticipated resources.

[3]Represents cumulative lending for HIV/AIDS (1986–94) as a percentage of total Bank commitments for FY87–FY93.

[4]Represents 1993 approved interregional AIDS programs' general and supplemental funds as a percentage of estimated 1993 total UNICEF resources.

[5]Includes overall resources, regional, and recently approved country-level posts.

[6]Based on 13 full-time equivalents.

[7]Based on number of approved posts for interregional AIDS program in 1992–93.

35

International Funding of the Global AIDS Strategy: Official Development Assistance

MARGARET LAWS

The first edition of *AIDS in the World* chronicled the evolution of international development assistance funding for HIV/AIDS based on the World Health Organization's Global AIDS Strategy (1987) and the efforts to fund it.[1] This support came from and continues to involve predominantly official development assistance (ODA), which transfers funds from the industrialized donor countries to international agencies, governmental, and nongovernmental (NGO) AIDS programs in developing countries. Official development assistance is defined as aid administered with the promotion of economic development and welfare as the main objective; it is concessional in character and contains a grant of at least 25 percent.[2]

Official development assistance: donor countries

Twenty-four countries are members of the Organization for Economic Cooperation and Development (OECD). Twenty-one of these countries plus the European Union are members of the OECD's Development Assistance Committee (DAC) which issues an annual report on overall international financial assistance to the developing world.[3]

Development assistance from members of the OECD/DAC to low-income countries and multilateral institutions increased from an annual total of $7 billion in 1970 (the first year for which data were available) to $60.9 billion in 1992.* However, while ODA from members of DAC almost doubled in real terms between 1985 and 1990, disbursements rose only 0.5 percent between 1991 and 1992.[4] Then, in 1993, total ODA declined for the first time (by 10 percent) to $54.5 billion (Figure 35-1). In that same year, Japan made the largest single contribution on record ($11.26 billion), outranking the United States ($9.72 billion) for the first time. France was the third largest donor, with a total contribution of $7.91 billion.

The declining aid phenomenon is not unique to a particular donor country, region, or sector; with few exceptions, it has been a universal trend.

*Unless otherwise indicated, financial data in this chapter are expressed in U.S. dollars.

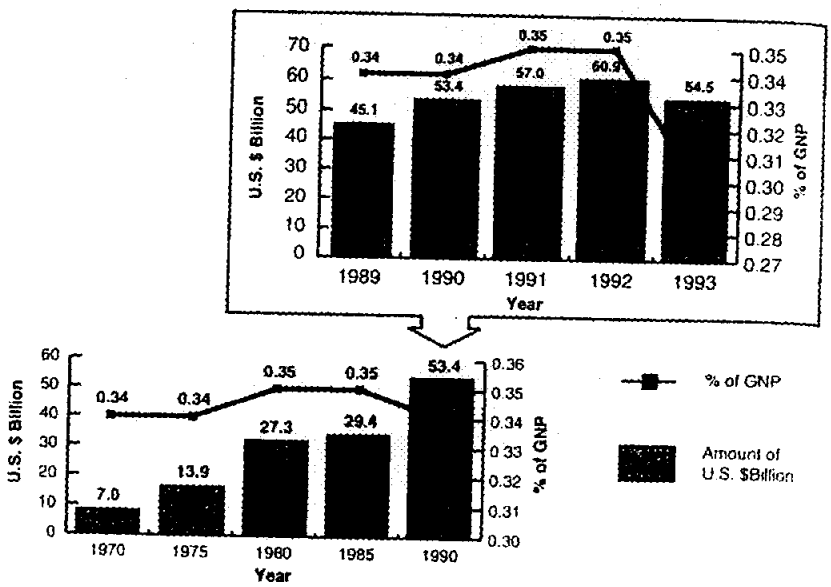


Figure 35-1 Evolution of all development assistance from OECD member countries, 1970–1993. Source: The World Bank, *World Development Report, 1995* (New York: Oxford University Press, 1995):216.

This decline in development assistance exacerbates an already serious funding shortfall: in 1970, the United Nations proposed that each country contribute 0.7 percent of its gross national product to development assistance.[5] Only four of the 21 DAC member countries achieved this target in each of the years 1990–1993: Denmark, the Netherlands, Norway, and Sweden. Overall in 1993, only a dismal 0.3 percent of OECD country GNP was provided as official development assistance.

Unfortunately, neither the OECD/DAC report nor any of the other published summary reports on development assistance (e.g., the *World Development Report*) provides detailed information on the allocation of funds to HIV/AIDS.

The *AIDS in the World II* 1994 financing survey: data sources

There is no single definitive source of information on international and national contributions to AIDS prevention and control in the developing world. In 1994 the Global Management Committee of the WHO Global Programme on AIDS undertook development of a database on international financing of HIV/AIDS programs, yet as of mid-1995, no financial data had been released.

Drawing primarily on the results of an international financing survey conducted for *AIDS in the World II*, this chapter attempts to address some of these information gaps.[6] The *AIDS in the World II* survey collected data on financing trends from ODA agencies and on their policies and practices for grant-making decisions. Survey participants were asked to provide data for

the most recent 12-month period for which they had complete records. All respondents provided information from 1992, 1993, or a fiscal year circa 1993. The time period covered by the group of survey countries was therefore quite broad, a situation complicated by some agencies' provision of multiyear grant totals. In addition, the 1993 figures should be viewed with an important qualification: most large grants span several years, and many programs fail to disburse most or all of the funds allocated during the initial year of the grant. Therefore, 1993 data may significantly overestimate the amount of money actually *spent* in 1993, while data for previous years were generally adjusted to reflect the actual disbursement pattern of the grants.

Multilateral and multi-bilateral data were collected from WHO/GPA, and all bilateral data came directly from donor survey responses. Grants reported in a multiyear format were divided into equal increments according to the stated years of the project. The resulting figure was used as a 1-year average and then converted into U.S. dollars at the official International Monetary Fund (IMF) exchange rate for each year. Annual contributions were therefore expressed in current U.S. dollars, or the dollar equivalent of every contribution at the rate of exchange prevailing in each year for which data were collected.

Each ODA agency provided a funding profile, estimating the percentage of total resources devoted to all development assistance, health and social development assistance, and HIV/AIDS assistance. ODA agencies were also asked to break down their annual grants according to funding channels (multilateral, multi-bilateral, or bilateral) and recipients (international agencies, governments, NGOs, or others). They then provided information on projected trends in both overall funding amounts and channels through which AIDS funding will be distributed to developing countries in future years. The survey also inquired about funding policies, including criteria for funding of AIDS projects, organization of the agency budget, and tracking of development assistance funds.

Data collection was complicated by the fact that several countries have more than one government entity involved in ODA; for example, in France, both the Ministry of Foreign Affairs and the Ministry of Cooperation have ODA roles. Other countries may not have a distinct ODA agency but rather a department within their ministry of foreign affairs which handles development assistance disbursement (e.g., Switzerland and Luxembourg).

A portion of the funds committed to HIV/AIDS programs from European countries flows through the European Union (EU), which serves as a development assistance funding intermediary. The EU made available data on expenditures for HIV/AIDS-related programs for the period 1987 through 1993; these funds were classified as multilateral/bilateral. It is important to note that in some instances, these EU data may duplicate funds reported by European countries as bilateral grants. For example, if a European country designated funds for an African country but channeled the money through the EU, the funds might be reported by the donor country as a bilateral grant to the African country and also by the EU as a multilateral/bilateral grant.

Thus, the *AIDS in the World II* global financing survey pursued a variety of approaches in an attempt to accurately track funding and determine

Table 35-1 Twelve ODAs surveyed: contributions to the Global AIDS Strategy for a year circa 1993*

Country	Channel ($U.S. millions)			
	Bilateral	Multilateral	Multi- and bilateral	Total
Australia	$7.10	$0.53	$0.29	$7.92
Canada	$8.19	$3.07	$0.30	$11.56
Denmark	$2.09	$2.72	$4.07	$8.88
France	$18.50	$1.40	$0.10	$20.00
Germany	$7.81	$0.92	$4.07	$12.80
Japan	$1.00	$4.54	N/A	$5.54
Luxembourg	$0.99	$0.25	N/A	$1.24
The Netherlands	$2.70	$2.45	$0.93	$6.08
Norway	$4.58	$2.54	$2.25	$9.37
Sweden	$3.71	$5.05	$1.04	$9.80
United Kingdom	$7.76	$8.40	N/A	$16.16
United States	$82.00	$34.04	$1.00	$117.04
Total	$146.43	$65.91	$14.05	$225.39
Percent of total	64.68	29.11	6.21	100.00

*Total contribution to the Global AIDS Strategy, circa 1993 = $257.29 million. Percent of this total contributed by the 12 ODAs surveyed = 87.99%. N/A, not available
Source: *AIDS in the World II* survey.

policy developments within each ODA agency. Despite all obstacles, data presented in this chapter are probably accurate within a 10 percent margin of error and therefore reflect the real trends in international aid to AIDS.

Survey responses

Responses from 12 countries provided data adequate for analysis: Australia, Canada, Denmark, France, Germany, Japan, Luxembourg, the Netherlands, Norway, Sweden, the U.K., and the U.S.. The Russian Federation, Spain, and New Zealand also returned survey questionnaires but did not report AIDS-related information in sufficient detail to be included. Together these 12 countries accounted for $226.39 million (87 percent) of the estimated $257.29 million* assigned to support the Global AIDS Strategy through all funding channels circa 1993 (Table 35-1). The 12 countries also provided approximately $49 billion (89 percent) of the $54.5 billion estimated total ODA from OECD/DAC countries to developing countries and multilateral organizations in that year.[7] Thus, although not entirely complete, the survey was sufficient to draw the profile of the international aid extended in support of the Global AIDS Strategy in 1992–1993.

Funding disbursement channels

Schematically, the survey examines funding distribution occurring in three broad channels: multilateral, multilateral/bilateral, and bilateral (Box 35-1).

*$16.66 million, or approximately 15 percent of the total multilateral and multilateral/bilateral funding in 1993 came from the European Union. These funds represent significant additional dollars contributed by the survey participants, most notably, France.

Of these, the multilateral/bilateral channel requires further examination. This channel allows ODA agencies to assign funds through WHO (or another UN agency) to a specific country, usually involving funds already designated by the donor for a recipient country under its overall ODA plan. In 1987, WHO created the multilateral/bilateral option to help increase support from ODA agencies for countries in desperate need of resources for AIDS work. For example, through a multilateral/bilateral arrangement, Sweden could support a national AIDS program in a country in which its ODA agency did not have an office.

BOX 35-1

BOX 35-1 Channels of official development assistance and sources of information on AIDS financing

Channel	Definition	Source of information
Multilateral	Transfer of funds from an ODA agency to the UN or any of its specialized agencies	Reports from WHO,[1] UNDP,[2] UNICEF,[3] and the World Bank[4]
Multilateral/Bilateral	Transfer of funds to a specific recipient country through WHO/GPA	WHO reports[5]
Bilateral	Transfer of funds from an ODA agency to a recipient country	*AIDS in the World* (1992)[6] *AIDS in the World II* survey (1994)[7]

References

1. WHO, Global Programme on AIDS, *Tenth Meeting of the Management Committee, Financial Implementation, Funds Available, and Obligations Incurred: 1992–1993*, WHO/GPA/GMC(10) 94.9, Rev 1 (May 19, 1994).
2. UN Development Program, Governing Council, *Annual Report of the Administrator for 1992 and Program Related Activities: HIV, AIDS and Development*, final draft, DP/1993/12 (New York: UNDP, May 1993).
3. UNICEF, *UNICEF 1993 Annual Report* (New York: UNICEF, 1993).
4. World Bank, *World Development Report 1993: Investing in Health* (New York: Oxford University Press, 1993).
5. WHO, Global Programme on AIDS, *Tenth Meeting*.
6. J. Mann, D. J. M. Tarantola, and T. W. Netter, eds., "The Global AIDS Policy Coalition," in *AIDS in the World* (Cambridge, MA: Harvard University Press, 1992): 511–535.
7. *AIDS in the World II* survey (1994).

Funding the Global AIDS Strategy

International funding for AIDS research, treatment, care, and program management grew steadily from 1986, when the Global AIDS Strategy was launched, through the end of the decade (Table 35-2). Total funding increased from less than $1 million in 1986, to about $59 million in 1987, to over $212 million in 1990—more than a threefold increase in the 4 years following the creation of the WHO Global Programme on AIDS. The total ODA funding assigned to AIDS increased rapidly through 1990; the annual rate of increase of 127 percent between 1987 and 1988 then declined to 4–11 percent during 1990–1993.

Taking inflation into account, a real decline in international AIDS financing occurred between 1991 and 1994. Two main factors may explain the flattening of the financing curve in the early 1990s. First, the ODA agencies responded to increasingly competing demands for resources, which were compounded by economic recession. Second, donors' commitment to subsi-

Table 35-2 Total contributions to the Global AIDS Strategy, 1986–1993*

Channel	1986	1987	1988	1989	1990	1991	1992	1993	Total
Bilateral	$0.11	$15.30	$39.40	$64.80	$98.90	$125.01	$129.80	$146.49†	$[illegible]
Percent increase over prior year			158	64	53	26	4	13	
Multilateral/bilateral		$13.21	$30.69	$30.16	$31.58	$23.53	$26.69	$31.11†	$[illegible]
Percent increase over prior year			132	-2	5	-25	13	17	
Multilateral		$30.26	$63.42	$65.58	$81.73	$75.00	$75.50	$79.69†	$[illegible]
Percent increase over prior year			110	3	25	-8	1	6	
Total	$0.11	$58.77	$133.51	$160.54	$212.21	$223.54	$231.99	$257.29†	$1,277.96†
Percent increase over prior year			127	20	32	5	4	11	

*Amounts are in $U.S. millions.
†Provisional figures as of August 1995; these amounts include multiple year grants extending beyond 1993.
Source: *AIDS in the World II* survey.

dizing HIV/AIDS programs—and more generally, international development—appears to be eroding, which perhaps reflects skepticism about the efficiency and impact of past efforts and/or complacency about the global HIV/AIDS pandemic. ODA funding figures are shown, by channel, in Tables 35-3, 35-4, and 35-5.

HIV/AIDS funding trends of major donors

In the early stages of the global mobilization, donors channeled most of their resources through WHO, the only multilateral agency that had embarked aggressively on a global program on AIDS. Thus in 1987, WHO/GPA received $43.47 million, representing 74 percent of the total ODA for AIDS of $58.77 million. Donors have become dissatisfied with this funding strategy, which relies largely on multilateral channels. Consequently, there has been a major shift towards bilateral funding since 1990: by 1993 less than one-third of ODA funding for HIV/AIDS ($79.69 million, or 31 percent of the $257.29 million total) was channeled through multilateral agencies and over half was provided bilaterally ($146.49 million; 57 percent; Figure 35-2).

Donor country projections for ODA funding for AIDS-related assistance over the next year are shown in Table 35-6. With the exception of Japan, all countries expected to sustain or reduce their 1993 levels of development assistance to all sectors. While most reported that grants to the health sector would remain constant, Australia and the Netherlands projected some increase. Of the 12 countries responding to the survey, only Japan, Luxembourg, and the Netherlands (which together accounted for less than 5 percent of ODA to AIDS in 1993) expected to increase multilateral funding for HIV/AIDS in 1994–1995; seven countries indicated that they intended to increase or maintain bilateral HIV/AIDS funding while decreasing multilateral funding in 1994–1995. Donors displayed a marked trend towards more focused bilateral and local project financing in their future support to HIV/AIDS programs.

Table 35-3 Multilateral contributions in support of the Global AIDS Strategy, 1987–1993, as reported in June 1992 and May 1994*

Contributions to WHO/GPA by Country/Organizaton	1987	1988	1989	1990	1991	1992	1993	Total
Australia	$0.00	$0.38	$0.38	$0.69	$0.22	$0.48	$0.53	$2.68
Austria	$0.05	$0.00	$0.03	$0.03	$0.04	$0.05	$0.15	$0.35
Belgium	$0.00	$0.00	$0.19	$0.52	$0.28	$0.00	$1.13	$2.12
Canada	$3.73	$4.01	$3.80	$7.77	$4.95	$4.80	$3.07	$32.13
Denmark	$2.18	$3.13	$2.96	$3.32	$2.89	$3.05	$2.72	$20.25
Finland	$0.07	$0.99	$0.70	$0.88	$0.88	$0.00	$0.00	$3.52
France	$0.17	$0.33	$1.56	$1.09	$1.20	$1.31	$1.40	$7.06
Germany	$0.08	$0.79	$0.32	$0.33	$2.59	$0.51	$0.92	$5.54
Italy	$0.00	$0.00	$1.27	$0.00	$0.48	$0.00	$0.29	$2.04
Japan	$0.00	$1.45	$1.75	$2.10	$2.20	$2.40	$4.54	$14.44
Kuwait	$0.00	$0.00	$0.05	$0.00	$0.00	$0.00	$0.00	$0.05
Luxembourg	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00	$0.25	$0.25
The Netherlands	$3.75	$3.31	$3.05	$3.62	$4.13	$4.98	$2.45	$25.29
New Zealand	$0.00	$0.34	$0.00	$0.00	$0.00	$0.00	$0.00	$0.34
Norway	$1.93	$2.38	$2.30	$4.27	$5.78	$3.47	$2.54	$22.57
Russian Federation	$0.80	$0.82	$0.77	$0.82	$0.34	$0.00	$0.00	$3.55
Spain	$0.00	$0.00	$0.00	$0.00	$0.00	$0.24	$0.21	$0.45
Sweden	$5.06	$14.27	$8.60	$16.82	$7.99	$9.49	$5.05	$67.28
United Kingdom	$5.19	$8.22	$7.27	$8.47	$8.27	$7.83	$8.40	$53.65
United States	$6.64	$11.06	$25.65	$20.71	$23.00	$25.06	$34.04	$146.16
UN Development Program	$0.15	$2.91	$0.28	$0.51	$0.28	$0.14	$0.00	$4.27
IBRD[a]	$0.00	$0.00	$1.00	$1.00	$1.00	$1.00	$1.00	$5.00
Sasakawa Foundation	$0.00	$0.88	$0.00	$0.00	$0.75	$0.00	$0.00	$1.63
IBM	$0.00	$1.50	$0.00	$0.00	$0.00	$0.00	$0.00	$1.50
Swiss Red Cross	$0.00	$0.00	$0.00	$0.00	$0.03	$0.07	$0.00	$0.10
World AIDS Foundation	$0.00	$0.00	$0.00	$0.59	$0.25	$0.00	$0.00	$0.84
Miscellaneous/interest/refund	$0.56	$2.77	$3.65	$4.54	$3.80	$3.47	$3.85	$22.64
Total WHO/GPA	$30.26	$59.54	$65.58	$78.08	$71.35	$68.35	$72.54	$445.70
To other multilateral agencies								
UNDP[b]	N/A	N/A	N/A	$0.65	$0.65	$3.25	$3.25	$7.80
UNICEF[c]	N/A	N/A	N/A	$3.00	$3.00	$3.90	$3.90	$13.80
UNFPA[d]	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
UNESCO[d]	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Total to other multilateral agencies				$3.65	$3.65	$7.15	$7.15	$21.60
Total to all multilateral agencies	$30.26	$63.42	$65.58	$81.73	$75.00	$75.50	$79.69	$467.30

*Amounts are in $U.S. millions N/A, not available.

[a]International Bank for Reconstruction and Development.

[b]UNDP financial information provided for a period of several years, which varied depending on the type of funding; funding totals were apportioned evenly across the grant period.

[c]Includes interregional AIDS program funding approvals and supplementary funds approval outlays; biennial figures have been evenly divided between the two years.

[d]No financial information provided.

Source: *AIDS in the World* (1992); WHO/GPA, Tenth Meeting of the Management Committee, Financial Implementation, Funds Available, and Obligations Incurred, 1987–1993, WHO/GPA/CMC(10) 94.9 Rev 1 (May 17, 1994).

Table 35-4 Multilateral/bilateral contributions in support of the Global AIDS Strategy, 1987–1993*

Country	1987	1988	1989	1990	1991	1992	1993	Total
				($U.S. millions)				
Australia					0.06		0.29	[illegible]
Austria								0.00
Belgium				0.06				0.06
Canada	0.03		0.64	0.87	0.22	0.50	0.30	2.56
Denmark		0.43	1.55	0.16	0.38		4.07	6.59
Finland			0.02					0.02
France				0.25			0.10	0.35
Germany		2.18		0.25		0.04	4.07	6.54
Japan			0.60			2.10		2.70
Kuwait								0.00
Luxembourg								0.00
The Netherlands		0.60	0.15	0.12	0.16		0.93	1.96
Norway	2.67	3.38	2.20	2.12	1.99	2.01	2.25	16.62
Spain								0.00
Sweden		1.84	2.00	2.83	2.25	1.78	1.04	11.74
Switzerland							0.27	0.27
United Kingdom		2.50	1.50		3.13	3.42	0.00	10.55
United States		4.91	0.36	3.13		1.86	1.00	11.26
European Economic Community/ European Union*	10.51	14.30	15.29	14.05	8.08	10.33	16.66	89.22
Agency								
UNICEF					0.06			0.06
Swiss Red Cross					0.10			0.10
World AIDS Foundation								0.00
UNFPA			0.20	0.12	0.09	0.04	0.00	0.45
Miscellanous/interest/refund		0.45	2.36	2.41	1.41	0.38	0.13	7.14
Total	13.21	30.69	30.16	31.58	23.53	26.69	31.11	186.97

*Amounts are in $U.S. millions.
†Includes $11 million from France (1987–1993), the balance from other EU countries.
Source: *AIDS in the World* (1992); WHO/GPA, GMC (10), May 1994; *AIDS in the World II* survey, 1994.

Tracking funds from ODA agencies to developing countries

In order to track ODA funding from its sources to its beneficiaries, donor countries participating in the survey were asked to categorize their HIV/AIDS–related grants according to the funding channels described in Box 35.1, and to indicate the intended recipient as well as any intermediaries.

The 12 survey respondents providing data in channel format represented a total of $226.39 million, or approximately 88 percent of all ODA provided for HIV/AIDS in 1993 (Figure 35-3). Certain grants did not clearly fall into any of the categories (e.g., grants to research institutions or to multicountry initiatives), while in other instances, respondents were unable to provide the required information. These funds are listed as "other." The data in Figure 35-3 overestimates the resources actually available, in cash or in kind, to recipient governments and NGOs, for the survey could not identify

Table 35-5 Selected donors' bilateral contributions to the Global AIDS Strategy, 1986–1993, as reported to the Global AIDS Policy Coalition in June 1992 and May 1994*

	($U.S. millions)								
Country	1986	1987	1988	1989	1990	1991	1992	1993	Total
Australia	0.00	0.00	0.00	0.20	1.80	N/A	7.17	7.10[a]	16.27
Canada	0.01	1.70	4.00	3.50	20.00	7.51	9.75	8.19	54.66
Denmark	0.00	0.00	0.00	6.70	0.90	12.30	2.97	2.09[a]	24.96
France	0.00	2.20	1.70	8.30	9.40	12.80	12.50[a]	18.50[b]	65.40
Germany	0.00	0.00	7.00	7.00	7.30	7.00[a]	7.02[a]	7.81	43.13
Italy	0.00	0.00	0.40	1.40	N/A	N/A	N/A	N/A	1.80
Japan	0.00	0.00	0.00	0.00	0.00	0.00	0.00	1.00[a]	1.00
Luxembourg	0.00	0.00	0.00	0.00	N/A	N/A	N/A	0.99	0.99
The Netherlands	0.00	0.00	0.50	0.50	1.70	1.10	2.41[a]	2.70	8.91
Norway	0.10	0.00	0.00	0.20	12.20	N/A	4.58	4.58[a]	21.66
Spain	0.00	0.00	0.00	0.00	N/A	N/A	N/A	0.06	0.06
Sweden	0.00	0.00	0.10	8.50	11.40	15.20	4.80	3.71[a]	43.71
United Kingdom	0.00	0.00	0.00	4.20	3.40	3.90	1.90	7.76[a]	21.16
United States	0.00	11.40	25.70	24.30	30.80	65.20	76.70	82.00	316.10
Total	0.11	15.30	39.40	64.80	98.90	125.01	129.80	146.49	619.91

*Amounts are in $U.S. millions. Figures for the year circa 1992 are estimates based upon available figures from 1991 and 1993. N/A, not available.

Note: European Economic Community/European Union.

[a]Estimate based upon figures supplied for fiscal year reported on in survey.

[b]In addition to this sum, France contributed $12.1 million to the European Union. This contribution is reflected in Figure 32-4.

Source: *AIDS in the World II* survey; Global AIDS Policy Coalition, International Financing Coalition, International Financing Survey, 1994.

Figure 35-2 International contributions to the Global AIDS Strategy, by funding channels, 1986–1993.

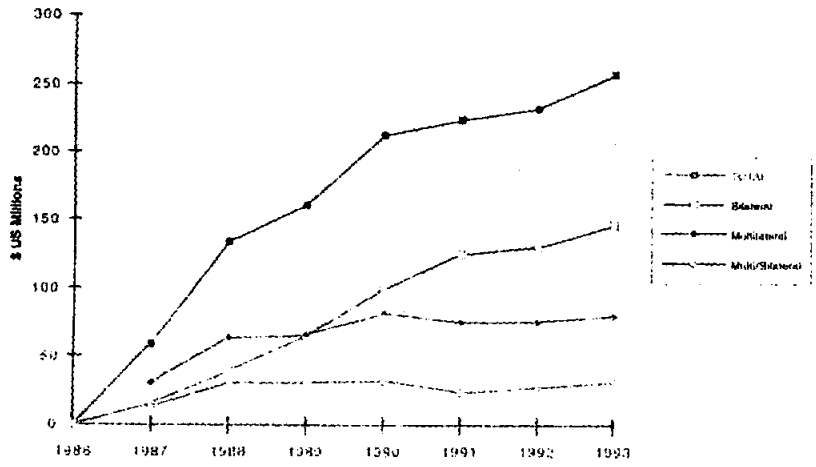


Table 35-6 Information provided by ODA agencies on foreseen trends in their HIV/AIDS funding and evaluation practices*

Country	Projected funding trends, 1992–1995				Project evaluations performed by agency or its ODA	
	$U.S. millions ODA HIV/AIDS circa 1993	Multilateral ODA	Bilateral ODA	ODA through NGO	Multilateral ODA	Bilateral ODA
United States	117.04	↓	→	↑	+	±
France	20.00	N/A	N/A	N/A	N/A	N/A
Canada	11.56	N/A	N/A	N/A	-	±
Sweden	9.80	↓	↑	↓	+	+
United Kingdom	16.16	→	↑	↑	+	N/A
Norway	9.37	N/A	N/A	N/A	+	±
Germany	12.80	N/A	N/A	N/A	N/A	N/A
The Netherlands	6.08	↑	↑	↑	+	+
Australia	7.92	→	↑	→	+	N/A
Denmark	8.88	→	→	→	-	±
Japan	5.54	→	↑	→	N/A	N/A
Luxembourg	1.24	↑	↓	N/A	N/A	±
Total	226.39					

*→ = no change; ↑ = increase; ↓ = decrease; + = performed; - = not performed; ± = partially performed.

each ODA agency's overhead and administrative costs. Of the $226.39 million that could be tracked from ODA agencies to their recipients (governments, NGOs, and others), $79.96 million (35 percent) was channeled through UN agencies, including $65.91 million through the WHO/GPA multilaterally and $14.05 million in a multi- or bilateral form, generally through the ODA agency's regional or country office, then through WHO/GPA, UN Development Program (UNDP), or United Nations Children's Fund (UNICEF).

The bulk of ODA for AIDS was disbursed through bilateral channels, $146.43 million (65 percent). These bilateral funds included: $85.46 million (38 percent of total funds) channeled to governments (channel 3); $2.95 million (1 percent) to local NGOs from funds disbursed from country-based ODA agency representatives (channel 4); $22.16 million (10 percent) from central funds to local NGOs through international NGOs (channel 5); $15.42 million (7 percent) from central funds provided directly to local NGOs (channel 6); and $20.44 million (9 percent) either allocated from central funds to "other" (channel 7), or for which the intended recipient was not indicated by the donor. Of these funds for HIV/AIDS in 1993, the largest proportion, $165.42 million (73 percent) was directed to government national AIDS programs (GNAPs) in developing countries, while $40.53 million (18 percent) was intended for NGOs. The amount of additional funds made available to local NGOs by GNAPs out of their own budget allocations could not be ascertained. Even without these data, it is apparent

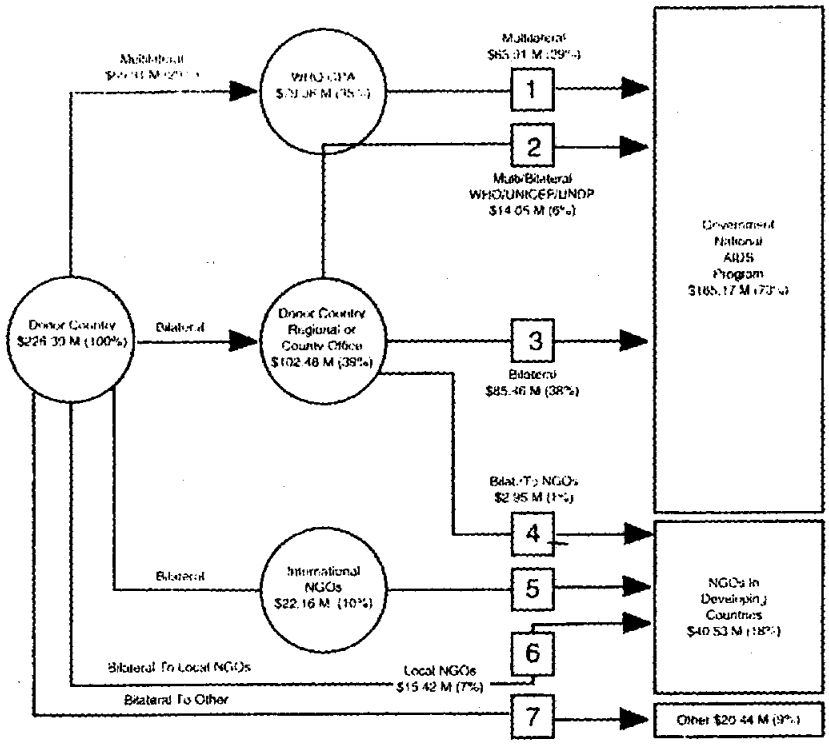


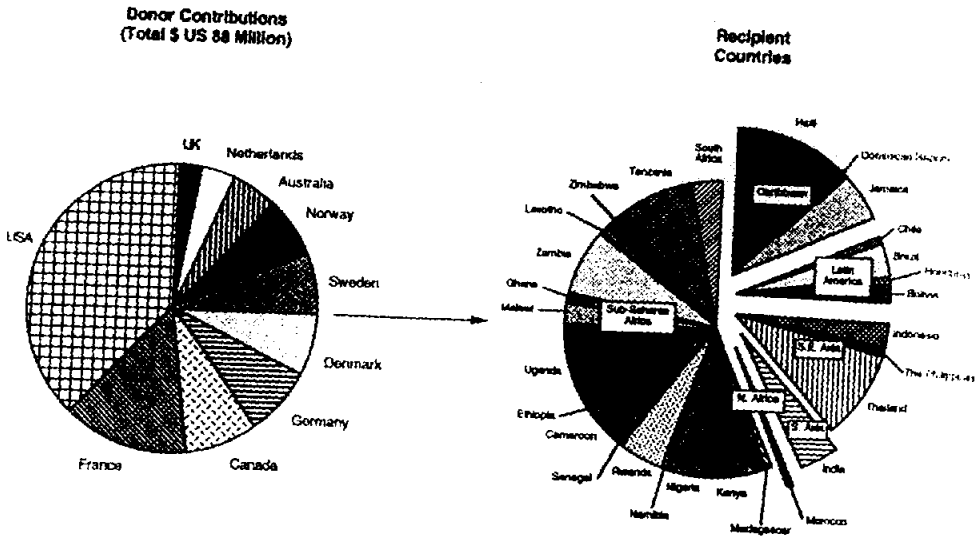
Figure 35-3 Global flow of official development assistance funds to HIV/AIDS programs, by funding channel, circa 1993.

that since the early 1990s, NGOs have received an increasing proportion of the resources allocated internationally to AIDS programs.

Concentrations of ODA funds: recipient countries

An attempt was made to discern patterns or concentrations of aid to specific countries during the period 1987–93. Nine of the ODA agencies surveyed reported bilateral and designated multilateral/bilateral donations to a total of 69 countries. The remaining three survey respondents contributed solely through undesignated multilateral or multilateral/bilateral grants. By 1993, United States Agency for International Development (USAID), the largest contributor to the Global AIDS Strategy, was implementing a centrally funded project—the AIDS Control and Prevention (AIDSCAP) Project of Family Health International—along with associate country projects as funds were assigned by local USAID missions. In 1993 France targeted its bilateral aid to 15 countries, the majority of which were in francophone Africa. Although it has funded a few projects in Southeast Asia, Germany also maintained a geographic focus on Africa. Finally, Scandinavian countries tended to concentrate their AIDS program funding in countries in which they were investing in overall socioeconomic development.

The grants that could be clearly attributed to specific recipient countries



* These charts include only those grants reported by donors participating in the survey as being directed to specific, identified countries through bilateral and multilateral channels.

Figure 35-4 Flow of funds from donor countries to specified recipient countries, circa 1993, total = $U.S. 88 Million.

(circa 1993) amounted to approximately $88 million. Six countries (Uganda, Haiti, Tanzania, Thailand, Zambia, and Kenya) received about $24 million, representing 27 percent of this total. Twenty-eight of the 69 recipient countries received support from only one donor country; five (Tanzania, Thailand, Uganda, Zambia, and Zimbabwe) received support from five or more of the nine donors (Figure 35-4).

There was a significant discrepancy between the financing reported by donor countries in the funding survey and the data reported in the *AIDS in the World II* national AIDS program surveys by recipient countries (Chapter 30). Developing countries reported receiving substantially less than donor agencies had reported to have promised. Factors contributing to this discrepancy include ODA and multilateral agency underspending and carryover of a significant portion of an annual grant into the next funding cycle; ODA agency inclusion of funds for administrative, staff, and consultant costs in the reported allocations to grantees; differing fiscal years of donor and recipient countries; and finally, ODA agency grants for combined health programs which include HIV/AIDS funding but do not come under the control of or even come to the attention of the national AIDS program manager.

World Bank loans

From 1986 to 1994, the World Bank awarded an increasing number of loans to developing countries for HIV/AIDS prevention and care totaling approximately $565 million.[4] By mid-1995, 49 Bank-supported projects, devoted partly or wholly to HIV/AIDS, were in operation in 35 countries. Of these, 37 were located in 25 countries in Africa with total funding of $258.5 million

Loans of $84 million and $160 million had also been awarded to India and Brazil, respectively, for HIV/AIDS work. An additional 19 projects involving $179 million in loans were to begin in 1995–1996, 16 of which were in Africa, including loans amounting to $120.5 million.[7] Although commonly defined as "soft" loans due to their low interest rates and long and flexible repayment periods, they will have to be repaid by recipient countries, many of which are already heavily indebted.

The apparent shift from government grant money to government and private loans for HIV/AIDS programs reflects two main factors. First, developing countries are turning to the World Bank as grant money is both becoming more difficult to obtain from other sources and is not increasing parallel to the growth of HIV/AIDS prevention and care needs in severely affected areas. Second, the World Bank has recognized the negative impact of HIV/AIDS on developing economies and is responding more favorably to loan requests for HIV/AIDS programs than in the late 1980s. World Bank loans have not been included as part of the international financial support of the Global AIDS Strategy but have been considered as part of the resources allocated by developing countries to their respective national AIDS programs.

Development assistance: supply, demand, and fatigue

In the period since 1989, the overall demand for development assistance has increased significantly. Countries traditionally receiving aid from the former Soviet Union have entered the OECD recipient pool, as have members of the former Soviet Union itself. The worldwide rise in ethnic conflicts and the need for peacekeeping and refugee assistance have added to the development assistance needs of already struggling countries. The proportion of all ODA spent on disaster relief has increased from approximately 2 percent in 1989 to 7 percent in 1993.[8] Aid to countries of Central and Eastern Europe and to the newly independent states has increased continuously in recent years: the total net disbursements from the 24 OECD countries to these nations rose from $18.6 billion in 1991 to $24.2 billion in 1992.[9]

The combination of a shrinking pool of donor countries, rising demands for aid, and the frustration within ODA agencies about their ability to demonstrate progress toward the goals of development have led to a complex state of donor fatigue (Box 35-2). Clear evidence of donor fatigue was revealed when the Summit of Heads of Governments on AIDS, held in Paris in December 1994 with the aim of mobilizing significant international funds in support of the Global AIDS Strategy, did not succeed in generating the expected resources.

BOX 35-2

"Donor fatigue syndrome"

Causes

- Increasing demand from national AIDS programs
- Increasing demands for allocations of ODA to new programs (e.g., Eastern Europe and newly independant states, humanitarian interventions, and ethnic conflict)

- Unfulfilled hope of demonstrating impact of funds assigned to AIDS programs
- Frustration arising from difficulties in coordination among UN agencies
- Frequent turnover of donor representatives on international ODA agency consultative and coordinating boards with loss of information about rationale underlying past decisions

Symptoms

- Pressure on UN agencies to develop evaluation and information systems that are in excess of ODA agencies' own practices
- Push toward the creation of new UN coordinating mechanisms
- Focus of ODA on a few countries in an attempt to "rationalize" funding efforts

Donor fatigue syndrome and the AIDS in the World II funding survey

- Complaints about multiple surveys from disparate sources requesting similar information
- Reluctance or inability to provide channel-specific funding information
- Average survey response time of over 6 months
- Surveys almost all incomplete and data often provided in donor's own format rather than in survey format

Conclusion

The second decade of the AIDS epidemic has been characterized by increasing demands for development assistance, growing fatigue among the major donors, and skepticism as to the effectiveness of the funding programs pursued by large, multilateral agencies. Donors are besieged by pleas for money and technical assistance.

The large ODAs have examined the experience of over 5 years of the Global AIDS Strategy and have attempted to devise and refine rational and effective funding policies. This effort, however, has not been coordinated effectively at a global level. Donors respond with frustration to efforts to standardize their reporting formats and clarify their policies and procedures, yet their inability to respond to such requests leaves the donors, their supporters, and their critics unable to engage in meaningful discussion of funding in support of AIDS work. The major lessons of the funding survey are that development assistance resources, including those for HIV/AIDS, are not increasing and should not be expected to increase significantly in the short term. Expenditures on HIV/AIDS–related projects are extremely difficult to track, and results of aid projects are very difficult to measure.

As the United Nations AIDS Programme (UNAIDS) undertakes to enhance the capacity of developing countries to coordinate their international aid allocations, it will be critical that both donor and recipient countries improve their financial accountability. If the financial resources assigned to HIV/AIDS programs remain difficult to track—and thus to critically evaluate—they will likely continue to decline, at least in proportion to needs, if not in absolute terms.

REFERENCES

1. J. Mann, D. Tarantola, and T. Netter, eds., "Funding the Global AIDS Strategy," in *AIDS in the World* (Cambridge, MA: Harvard University Press, 1992):511–535.

2. "Kindness of Strangers," editorial, *Economist* (May 7, 1994):19.
3. Organisation for Economic Cooperation and Development, *Efforts and Policies of the Members of the Development Assistance Committee 1993* (Paris: OECD, 1993):7.
4. "Kindness of Strangers," editorial, *Economist* (May 7, 1994):19.
5. *Ibid.*
6. Global AIDS Policy Coalition, "International Financing of AIDS Programs, A Survey of Official Development Agencies," conducted for *AIDS in the World* (Cambridge, MA, 1993).
7. *Ibid.*
8. World Bank, *World Development Report 1993: Investing in Health* (New York: Oxford University Press, 1994).
9. R. Feachem, P. Musgrove, and A. E. Elmendorf, "Comment from the World Bank," *AIDS*, 9 (1995):982–983.
10. "Kindness of Strangers," editorial, *Economist* (May 7, 1994):19.
11. Organisation for Economic Cooperation and Development, *Efforts and Policies of the Members of the Development Assistance Committee 1993* (Paris: OECD, 1993):131.