

Report

UNAIDS: Human Rights, Ethics, and Law

Susan Timberlake

The UNAIDS Strategic Plan 1996–2000 noted that “a special joint programme, bringing together UN organizations with complementary mandates and expertise, was thought to be warranted by the epidemic’s urgency and magnitude, its complex socioeconomic and cultural roots, the denial and complacency still surrounding HIV and its routes of transmission, and the discrimination and human rights violations faced by those infected or threatened by HIV.”¹ In response to this need for a more comprehensive, coordinated, and expanded response to HIV/AIDS, the Joint United Nations Programme on HIV/AIDS (UNAIDS) was established in January 1996. UNAIDS is a unique UN entity in that it is a United Nations program cosponsored by six UN-system agencies: UNDP, UNESCO, UNFPA, UNICEF, WHO, and the World Bank. The objectives of UNAIDS are to “foster an expanded national response to HIV/AIDS particularly in developing countries, to promote strong commitments by governments to an expanded response to HIV/AIDS, to strengthen and coordinate UN action on HIV/AIDS at the global and national levels, and to identify, develop and advocate international best practice.”²

At the global level, UNAIDS is the HIV/AIDS program of its cosponsors. At this level, UNAIDS works towards an effective and expanded UN response to HIV/AIDS; towards

Susan Timberlake, JD, LL.M., was formerly Human Rights Advisor and is now Policy Advisor at the Joint United Nations Programme on HIV/AIDS (UNAIDS). Please address correspondence to Susan Timberlake, UNAIDS, 20 Avenue Appia, 1211 Geneva 27, Switzerland.

creating a body of knowledge on policies, best practices, and tools to use in responding to the epidemic; and towards mobilizing and informing governments, donors, the media, civil society, and those living with HIV/AIDS.³ For 1998-1999, UNAIDS will focus on five broad areas of key outputs. These are:

- national strategic plans for countries and integrated workplans on HIV for the UN system;
- an extensive collection of best practice and policy advice;
- technical resource networks for identifying, collecting, and disseminating best practices and providing technical assistance;
- advocacy; and
- accurate and up-to-date monitoring and information on the epidemic.⁴

At the country level, UNAIDS works through UN Theme Groups on HIV/AIDS to support governments and communities in their fight against HIV/AIDS. The Theme Groups, supported by UNAIDS Country Program Advisers (CPAs) and Inter-Country Technical Teams, also ensure that the UN response at the national level avoids duplication and eliminates gaps. In financial terms, UNAIDS assists national AIDS programs by supporting fundraising activities and providing training in resource mobilization. In programmatic terms, UNAIDS provides expertise and assistance in technical areas to governments. This structure allows the UN system's support to national responses to be tailored to the specific needs and realities of each country.

UNAIDS has an annual budget of approximately 60 million US dollars and employs a staff of some 93 persons in Geneva (including two full-time human rights advisers), 45 country program advisers, and 30 inter-country technical advisers. Though the program is a relatively small UN program, it is one that is able to leverage the resources and expertise of its cosponsors and to work with and through them toward common goals. This brief description of the goals, structure, and resources of the program provides the context in which UNAIDS human rights activities are carried out.

UNAIDS and Human Rights

In June 1996, the UNAIDS Programme Coordinating Board (PCB) discussed the program's workplan for 1996–1998.⁵ The workplan included "human rights, ethics and law" as one area in which UNAIDS would identify, develop, and advocate best practices that had proven to be technically, ethically, and strategically sound and that were considered necessary as part of the expanding response to the epidemic.

Even though human rights, ethics, and law already formed an integrated part of the UNAIDS workplan, the PCB strongly emphasized the importance of human rights by adding human rights to the cross-cutting themes of the program.⁶

Other forums, as well, had urged that UNAIDS include human rights as an important part of its work. At the Paris AIDS Summit in December 1994, representatives of 42 governments committed themselves to the protection of human rights in the context of HIV/AIDS.⁷ They also gave the new program responsibilities to pursue in this area.⁸ Furthermore, the UN Commission on Human Rights, comprising representatives of 56 governments, had called for States to promote and protect HIV-related human rights and for UNAIDS to build a strong human rights component into all its activities.⁹ In this regard, the Commission requested that the UN Secretary-General prepare a progress report on development of the human rights component of UNAIDS.¹⁰ Reinforcing calls by the Commission were similar appeals by the Sub-Commission on Prevention of Discrimination and Protection of Minorities urging that the new program incorporate human rights into its activities.¹¹ UNAIDS had also benefited from a long history of human rights-related work by the WHO Global Programme on AIDS (GPA).

Thus, since its inception, UNAIDS has included human rights as one essential aspect of its commitment to a multifaceted response to HIV/AIDS. In this sense, the program is part of the growing awareness, some of which is promoted by this journal, of health as a complex condition dependent upon social, economic, and political factors, including protection of human rights.

The UNAIDS Strategic Plan highlighted the importance of an ethical and human rights response to HIV/AIDS. It noted that "HIV tends to spread along the pre-existing fault lines of

society, fueled by societal and structural factors such as poverty, disorder, discrimination and the subordinate status of women," and cited human rights as a core value and guiding principle of the new program.¹² Since then, UNAIDS has repeatedly stressed in various forums, particularly in the UN human rights bodies such as the Commission on Human Rights and its Sub-Commission, that the human rights framework is essential for protecting people in the context of HIV/AIDS.¹³

Thus, there has been strong support for a human rights component in UNAIDS, both from within and outside the program. The importance of this commitment is emphasized by the fact that 15 years into the epidemic, a rights-based response to HIV/AIDS is neither widespread nor necessarily translated into effective human rights promotion and protection at national and community levels. A comprehensive review of HIV/AIDS and human rights found that "despite the fact that this pandemic has generated more interest and effort on behalf of human rights, particularly the rights of infected persons, than for any other infectious disease," there is "widespread governmental noncompliance with many of the primary injunctions of the international efforts to promote a rights-oriented approach to the pandemic."^{14,15}

Given the fact of continuing human rights violations in the context of HIV/AIDS, which both result from infection and increase vulnerability to infection, UNAIDS seeks to build on what has occurred and help to overcome resistance by many States, as well as by non-State actors, to a rights-based response to HIV/AIDS. Towards this end, the UNAIDS workplan for 1998-1999 commits UNAIDS to the identification and promotion of best practices, the development of technical resource networks, and the provision of technical assistance with regard HIV-related human rights, ethics, and law.

HIV/AIDS and Vulnerability

UNAIDS is particularly concerned about the heightened vulnerability of certain groups and their human rights situation.¹⁶ UNAIDS has characterized vulnerability to HIV/AIDS as "exercising little or no control over one's risk of acquiring HIV infection or, for those already infected with or affected by HIV, to have little or no access to appropriate care and

support. Vulnerability results from the interplay among many factors, both personal (including biological) and societal. While everyone is vulnerable in some way at some point in his or her life, vulnerability is magnified by societal factors such as marginalization or discrimination...and by economic policies and other structural factors that hinder sustainable human development."¹⁷

Vulnerability differs widely across groups, within countries, and across continents. Depending upon relevant social and legal factors and the nature of the epidemic, groups of concern can involve women, children, minorities, indigenous populations, migrants, refugees, men having sex with men, sex workers, injecting drug users, and prisoners. In human rights terms, reducing this vulnerability involves two key components: overcoming existing discrimination in access to social benefits and services; and overcoming social and legal factors that limit the autonomy and support necessary for one to exercise personal and social choices beneficial to economic, social, and physical well-being. As the UNAIDS Strategic Plan states: "...in the context of people's lives, many of our key AIDS messages and services may be irrelevant. Billions of men, women, and children live in a societal context in which they would not be able to exercise prevention and care options even if these were available to them."¹⁸

To clarify and articulate the link between vulnerability and human rights, UNAIDS seeks to examine the relationship between HIV/AIDS and the following: laws, policies, and regulations concerning marital, family, and property relations; reproductive health/populations programs; and migration, sex work, homosexuality, drug use, and prison policy. UNAIDS will also seek to support and join current efforts to improve human rights protection of these groups and to promote HIV-related concerns among them.

These efforts will occur in the context of ongoing debates on critical issues concerning application of human rights principles in the context of HIV/AIDS. These issues include:

- the content of the limitations of human rights in the forms of "public health" and the "rights and freedoms of others," including who decides—and under what scrutiny—the meaning of privacy and integrity of the

person, in terms of testing, confidentiality, and informed consent;

- the meaning of sexual autonomy, particularly for women, adolescents, prisoners, sex workers and their clients, people having same sex relationships, and transgendered people;
- the minimum standard for steps to be taken and resources to be allocated to achieve the right to health, including *inter alia*, the right to HIV-related information, education, means of prevention, treatment, drugs, and support;
- the effect of legal status on human rights protection, including the rights to health and nondiscrimination, particularly for drug users, sex workers, prisoners, people of the same gender having sex;
- the content of prohibition of discrimination on the grounds of "other status," now interpreted to include health, including HIV/AIDS;
- protection against human rights abuse occurring in the private sphere against women and people living with HIV;
- the rights of people living with disabilities in relation to the rights of people living with HIV/AIDS; and
- children's rights regarding access to HIV-related information, education, means of prevention, care, and support, as well as their right to be key actors in HIV-related programs for children, and to reduce their vulnerability to sexual exploitation and other marginalizing conditions, including being orphaned by HIV/AIDS.¹⁹

These issues must be further articulated both in terms of human rights and the protection of dignity, and in terms of achievable, effective public health goals.

Ethics

UNAIDS is also concerned with ethics, including: (1) general principles that should guide the international, national, community, and individual response to HIV/AIDS, such as compassion, solidarity, responsibility, tolerance, and empowerment; and (2) ethical principles that should guide

policy formulation and professional conduct in implementation of HIV-related research and delivery of services, including well-being and beneficence; equity and distributive justice; autonomy and respect for persons; confidentiality and informed consent; and duty to treat.²⁰

Given continuing controversy, ignorance, and disparate application concerning these ethical principles in the context of HIV/AIDS, they require further articulation and elaboration.

From Concept to Action

In its mission statement, UNAIDS states that “as the main advocate for global action on HIV/AIDS, UNAIDS will lead, strengthen and support an expanded response aimed at preventing the transmission of HIV, providing care and support, reducing the vulnerability of individuals and communities to HIV/AIDS, and alleviating the impact of the epidemic.”²¹

Therefore, UNAIDS is committed to the protection and promotion of those human rights necessary to reduce vulnerability to HIV infection, as well as to those necessary to reduce the impact of HIV/AIDS. Indeed, most human rights are crucial to this endeavor. They include: nondiscrimination and equality before the law; life and health; liberty and security; freedom of expression; freedom from inhuman or degrading treatment or punishment; freedom of movement; privacy; marriage and family; education and work; adequate standard of living; social security; assistance and welfare; seeking and enjoying asylum; sharing in scientific advancement and its benefits; and participating in public and cultural life. There are also the specific rights of women and of children, including issues of nondiscrimination and participation. The importance of these rights in the context of HIV/AIDS has been articulated in much literature and in many forums.²²

Reducing vulnerability to infection would involve such rights as nondiscrimination, privacy, liberty, and security of person.²³ It would also involve rights related to the content and availability of services, including HIV-related education, information, and health. Only if these rights are sufficiently implemented by the State will there be adequate education and information about STDs and reproductive health services,

as well as will means of prevention, such as condoms and clean needles, reach those in need of them.

Reducing the impact of HIV/AIDS on those already infected would involve the rights necessary both to protect their dignity and to enable them to withstand the disease's physical, psychological, social, and economic consequences. Discrimination in health care, reproductive rights, marriage, employment, education, social security and assistance, movement, and political asylum all disable those living with HIV/AIDS. Protection from discrimination based on HIV/AIDS status is critical. Such discrimination not only compounds the difficulties and anguish of living with HIV/AIDS, but also increases its social and economic impact. HIV/AIDS is also forcing the issue of the content of the right to health—including its nondiscriminatory application, and States' obligations to implement it—as it magnifies the glaring inequities between rich and poor in accessing drugs and treatment. One key goal of UNAIDS is to promote greater access to drugs and treatment in developing countries.²⁴

Even though a great deal has been studied and written about the relationship between human rights and HIV/AIDS, more needs to be researched about the linkages between the two. UNAIDS supports action-oriented research that will show in concrete and compelling ways how specific human rights protection will result in specific quantifiable and qualitative gains, both in terms of health and individual, family, and community coping mechanisms. Working with others currently exploring the link between health and human rights, UNAIDS hopes to help establish and support research that will clarify this link and indicate effective programmatic responses that can be replicated in the field.²⁵

To promote this agenda, UNAIDS will work through its own structure, and will collaborate with various partners, including: all branches of government; UNAIDS' cosponsors; AIDS service organizations (ASOs) and community-based organizations (CBOs); other nongovernmental organizations (NGOs) including human rights NGOs; UN human rights bodies; networks of people living with HIV/AIDS (PLWHAs); academic, research, and professional communities; the private sector; and religious groups.

At the national level, UNAIDS advocates “for political commitment, multisectoral involvement and the development of policies and environments conducive to effective responses to HIV/AIDS, emphasizing human rights and dignity and international best practice.”²⁶ Primary mechanisms for such advocacy are the UN Theme Groups on HIV/AIDS.

The Theme Groups must be fully briefed by governments, by NGOs, and by their own agency staff to identify critical HIV-related human rights and ethical issues. The UNAIDS Country Program Advisers (CPAs) and focal points should be instrumental in stimulating and coordinating these briefings, by identifying and ensuring that a wide range of concerned and affected groups participate in them.²⁷ After identifying the critical human rights and ethical issues, the Theme Groups should ensure that the policies and practices of their own programs address these issues.

Together with the CPAs and focal points, the Theme Groups should further ensure that means are established to engage in regular and meaningful dialogue with governments so that concerns can be raised and effective collaboration achieved. This should involve dialogue with all concerned government entities such as ministries of justice, education, employment, welfare, interior, finance, and health, as well as parliamentary and legislative committees reflecting the full spectrum of political representation. The Theme Groups should also promote channels of communications to encourage dialogue between government and nongovernmental partners on these issues.

Finally, CPAs and Theme Groups should help mobilize and/or direct resources, to governmental and nongovernmental partners, that would support activities to achieve a rights-based and ethical response to HIV/AIDS. This would include resources for necessary administrative and legal reform; legal support services for people living with AIDS; information and education campaigns to combat discrimination and stigma; and financial support for nongovernmental partners working toward an ethical and rights-based response to HIV/AIDS, particularly in the areas of support groups, advocacy, networking, and capacity-building.

UNAIDS believes that law should be utilized to provide a supportive framework for the national and local response

to the epidemic and to protect vulnerable groups and PLWHAs. Unfortunately, law is often over-used, in that too many expectations are placed on it, or it is misused, being employed to provide coercion or abuse. Though many areas of law affect the nature of the response, key areas for reform include laws regarding public health, anti-discrimination, disability, crime, information, regulation of goods and services; marital, property, and custody rights of women; and the regulation of sexual behavior, sex work, and drug use. UNAIDS works with States to promote law reform in these areas so as to create a legal framework that reduces vulnerability to HIV infection and protects those living with HIV/AIDS. UNAIDS works with governments in drafting legislation, officially commenting on draft legislation, providing examples of positive legislation, and identifying legal resources, expertise, and collaboration.

Much positive change can also be achieved through administrative reform. This is particularly relevant in the context of HIV/AIDS, where much governmental policy and practice is dictated not by law, but by regulation, including that promulgated under public health law. UNAIDS urges governments to review such administrative practice and regulation to ensure that it does not burden human rights and ethical principles.

While legislative and administrative reform are important for promoting a rights-based response, they can also be problematic. Promulgation of positive law and regulations can require a great deal of time, resources, and political will. Also, legislation or legal reform occurs in a political or social context and can be influenced by fear, ignorance, and overreaction. Furthermore, law and regulation do not have much significance in societies where legal and governmental structures are weak, inaccessible to much of the population, and of little educative or normative influence.

Other means of securing a rights-based response at national and local levels involve: (1) promoting or supporting means of dialogue in communities; (2) focusing on ethical capacity-building among government and private sector entities; (3) promoting information and education campaigns designed to address discrimination and intolerance; and (4) using nonformal and creative means by which to change dis-

criminy and stigmatizing attitudes. Such activities are not mutually exclusive and take varied forms across countries.

Dialogue can be stimulated and supported in many ways. States may be encouraged to establish and fund a formal process of dialogue. For example, in Australia, a legal working party was established "to examine the legal issues related to all major areas of HIV/AIDS and to make recommendations on future legislation that might affect the course of the epidemic and the welfare of those affected by it."²⁸ This working party was established as a subcommittee of the Intergovernmental Committee on AIDS and was made up of legal policy specialists from the Commonwealth, State, and Territory Departments of Health, and Attorneys General, and the Australian National Council on AIDS. It produced discussion papers on a number of key legal issues (e.g., public health, homosexuality, intravenous drug use, sex work, employment, civil liability for transmission of HIV), sent these out for public comment, and received numerous submissions from organizations and individuals. Based on these, final recommendations for legal reform were made in the final report.²⁹

A second example of a formal process of dialogue is the Joint Network/Canadian AIDS Society Project on Legal and Ethical Issues Raised by HIV/AIDS. This project, initiated by the NGO community, involves extensive consultation with a variety of groups and individuals, development of discussion papers on priority legal and ethical issues, convening of workshops across Canada to discuss the issues, and finally, production of comprehensive resource documents.³⁰

Another forum for dialogue is the establishment and support, at national and regional levels, of networks on HIV-related ethics, human rights, and law. Networks bring together those concerned about these subjects, and comprise an open-ended spectrum of participation, including health care workers, ASOs, CBOs, PLWHAs, as well as representatives of academia, the legal professions, religious communities, and government. Such networks involve mutual support and information-sharing on issues related to human rights, ethics, and law; promotion of policy and legislative initiatives; and community dialogue and consensus-building on critical and controversial issues. The most important work of these net-

works occurs at the national level. However, it has also been useful for them to link at regional levels so that valuable experience, knowledge, and skills can be shared across regions and among countries. UNDP has been a major sponsor of national networks in Africa, Asia, and Latin America.³¹ The strengthening of these networks at national and regional levels is a priority for UNAIDS.

Dialogue via networks can have critical results: it brings HIV/AIDS out of the conspiracy of silence; it provides space for focus on difficult social, legal, and ethical issues that require ongoing discussion and reflection; it involves many different voices and perspectives, including those most affected by HIV/AIDS; it allows consensus to be reached in nonconfrontational settings; it builds a sense of understanding, ownership, and solidarity; and it promotes positive and strategic responses, in both the private and public sector, including the government and parliament. UNAIDS supports all such processes that help foster sufficient space for dialogue and that support a critical mass of concerned individuals who can be leaders in constructing a rights-based and ethical response to HIV/AIDS.

Ethical capacity-building among government and the private sector is another approach. Many societies either do not have a tradition of establishing explicit ethical standards, or if they do, have not yet fully articulated these in terms of their application to HIV/AIDS. UNAIDS works with professional groups, such as health care workers, lawyers, the judiciary, corrections staff, police, welfare administrators, business leaders, employers, trade unions, and the press, to encourage them to develop, within the context of their professions and professional societies, ethical codes of conduct, including the means to disseminate and enforce such codes of conduct. These should result from dialogue and consensus-building within professions and should provide clear guidance on professional and personal behavior in the context of HIV/AIDS.

UNAIDS also promotes local and national capacities for ethical review of research, including HIV-related research. This should lead to establishment and/or strengthening of national and local ethical review committees so that meaningful review of HIV-related research is ensured at the na-

tional level. UNAIDS has established an Ethical Review Committee to provide “ethical assessment of research projects and proposals being considered by UNAIDS for financial and/or technical support, where the research involves human subjects or biological material obtained from human subjects.”³² Part of its mandate is also to “develop and/or review, as necessary, UNAIDS ethical guidelines for specific research issues.”³³ It is intended that this committee will effect greater attention to, and dialogue about, the application of ethical principles in the context of HIV-related research.

Much of the world has already been saturated with HIV/AIDS information outlining modes of transmission and means of avoiding infection. Unfortunately, this information has not necessarily translated, at the intellectual or emotional level, into a nondiscriminatory and nonstigmatizing response. Information and education campaigns that are explicitly designed to address discrimination and intolerance are needed and will be promoted by UNAIDS.

Apart from promotion of human rights standards and ethical principles through formal means (law, ethical codes of conduct, monitoring and reporting systems, UN human rights bodies), UNAIDS wishes to promote more informal, creative activities by which to change attitudes and to destigmatize HIV/AIDS. These would involve information and education campaigns explicitly focusing on HIV-related human rights and ethics and on tolerance and inclusion, as well as use of the arts (theater, films, videos, public-service announcements, painting, music, poetry) to address these issues. Such activities will involve partnerships with the media, including the film and advertising industries, and with arts communities. It should also include greater participation of people living with HIV/AIDS as spokespeople and leaders in promotion of human rights and the destigmatizing of HIV/AIDS.

Second International Consultation on HIV/AIDS and Human Rights

Many of these areas for action were confirmed as priorities at the Second International Consultation on HIV/AIDS and Human Rights, jointly organized by UNAIDS and the United Nations High Commissioner for Human Rights/Cen-

tre for Human Rights and held in September 1996. It was attended by 35 participants selected because of their experience and expertise in HIV/AIDS and human rights—representatives from governments, human rights NGOs, ASOs, academia, networks of PLWHAs, and UN-system agencies and programs.

The objective of the consultation was to set out concrete, action-oriented guidelines for governments that could be applied to promote and protect HIV-related human rights.³⁴ The consultation confirmed that protection of human rights in the context of HIV/AIDS is essential for protecting human dignity, saving lives, and reducing suffering.

Strategies proposed by the guidelines can be categorized under three main activity areas: (1) institutional responsibilities and processes; (2) law review, reform, and support services; and (3) promotion of a supportive and enabling environment. The consultation outlined strategies that involve creation of an effective national framework for the HIV/AIDS response, including: government support for community organizations and activities; reform of public health law and criminal law; enactment of anti-discrimination laws that cover HIV/AIDS; improved regulation of goods and services, including information and education, concerning HIV/AIDS; implementation of legal support services for those living with HIV/AIDS; the empowerment of women, children, and vulnerable groups by improving their social and legal status; changing of discriminatory attitudes through education, training, and media; development of ethical public and private-sector professional standards; and the monitoring and enforcing of human rights in the context of HIV/AIDS.

The finalized guidelines were sent to the 1997 session of the UN Commission on Human Rights and were issued by UNAIDS and the Centre for Human Rights as a report, translated into the six UN languages, and widely disseminated to States, intergovernmental organizations, and NGOs.³⁵ UNAIDS is committed to promotion of the guidelines, and expects the guidelines to form a large part of the basis on which UNAIDS will work with States in order to translate human rights norms into reality in the context of national HIV/AIDS responses.

UNAIDS and the International Human Rights System

As part of its work with States to achieve specific national and community-based responses, UNAIDS seeks to build strong partnerships with critical collaborators in the area of ethics, human rights, and law, including human rights NGOs and the UN human rights bodies.

The relevant UN human rights bodies include: (1) those established by the UN Charter—the Commission on Human Rights, the Sub-Commission on the Prevention of Discrimination and Protection of Minorities, and the Commission on the Status of Women; and (2) those that derive their existence and mandates from the various human rights treaties: the Human Rights Committee, the Committee on Economic, Social and Cultural Rights, the Committee on the Elimination of Discrimination against Women, the Committee on the Rights of the Child, the Committee against Torture, and the Committee on the Elimination of Racial Discrimination. There are also the Special Rapporteurs, Special Representatives, and Working Groups working under these bodies.³⁶

In terms of fashioning an expanded response to HIV/AIDS, these UN human rights bodies are critical to tackling the human rights aspects of the epidemic. They have the human rights mandates and expertise to further articulate the relationship between human rights and HIV/AIDS, to advocate the protection of rights related to HIV/AIDS, to monitor State compliance with these rights, and to work with States to secure their implementation. The human rights bodies, particularly the charter-based bodies, have shown interest in the human rights aspects of HIV/AIDS and have done important work in this area.³⁷ However, much more work needs to be done, including full integration of HIV-related human rights issues into their work.

In particular, UNAIDS will continue to encourage the treaty-based bodies to include HIV-related issues in their dialogue with governments.³⁸ This is crucial if States are to accept HIV/AIDS as a human rights issue that requires a human rights response. Currently, too many States continue to characterize HIV/AIDS solely as a health issue and include very little, if any, reference to the human rights aspects of HIV/AIDS in the context of their State reports to the UN treaty bodies.³⁹ This means that there is little dialogue be-

tween governments and the treaty bodies on HIV-related issues. In 1997, UNAIDS issued a *UNAIDS Guide to the United Nations Human Rights Machinery* which is intended to encourage and assist ASOs, people living with HIV/AIDS, and others working in the area of HIV/AIDS and human rights to access the UN human rights bodies and engage in advocacy and information-sharing on HIV-related human rights issues in these forums.⁴⁰

Monitoring and Responding

In order for the treaty bodies to be appropriately apprised of the HIV-related human rights issues in a given country, a means is needed for collecting information and monitoring HIV-related human rights at the country level. This extends beyond the involvement of the UN system. More than 15 years into the epidemic, there is still no systematic collection or reporting of HIV-related human rights information at the country level—neither with regard to human rights abuses by public and private actors, nor with regard to success stories involving strategies and programs that have led to human rights protection. What information does exist is largely anecdotal, and though there are indications that abuse is widespread, there is little that is well-documented in terms of the extent, nature, and locales of the abuse.⁴¹ Human rights NGOs, ASOs, and networks of PLWHAs have critical roles to play in collecting and reporting HIV-related human rights information. UNAIDS will encourage such activities by supporting human rights capacity-building among ASOs and networks of PLWHAs, through training seminars and development of training materials, communications, and databases. UNAIDS will also encourage human rights NGOs to learn about HIV-related human rights issues, share their expertise and experience with ASOs and networks of PLWHAs, and include HIV/AIDS in their monitoring and advocacy activities.

The systematic collection and monitoring of HIV-related human rights information will help indicate where action is needed, what the priorities are, and what level of input is required. It should benefit the activities of ASOs and human rights organizations at local and national levels, in terms of giving a focus for advocacy and action, and it should help

galvanize governments and international bodies to address these issues.

Conclusion

This paper has outlined the substantive concerns of UNAIDS in terms of human rights and ethics, as well as UNAIDS's programmatic activities in this area. It is an ambitious agenda: to succeed, UNAIDS will work with many and diverse partners—from community-based organizations to people living with HIV/AIDS to human rights activists to national AIDS programs to the cosponsors of UNAIDS and the UN human rights bodies. All are needed for a truly expanded response to HIV/AIDS. Such a response must consider the complexities and controversies of HIV-related human rights and ethics. While States, international organizations, and NGOs increasingly recognize the human rights and ethical dimensions of HIV/AIDS, these still have not taken their full place on the agenda. Within its resources and in partnership with others, UNAIDS will seek to put them there.

References

1. See UNAIDS Strategic Plan 1996-2000 (Revised December 1995), pp. 5, 6, and 13, wherein is recognized the importance of contextual factors that increase vulnerability to HIV/AIDS, including existing discrimination against certain groups, and where human rights are cited as core values and guiding principles for UNAIDS' mission.
2. See UNAIDS Workplan, 1996-1997, p. 4.
3. See UNAIDS Proposed Programme Budget and Workplan for 1998-1999, Joint United Nations Programme on HIV/AIDS, Geneva, March 1997, p. 28.
4. Internal UNAIDS document "Translating the Strategic Vision Into Action: Organizing Around Our Priorities," Geneva, Switzerland, January 28, 1998.
5. The Program Coordinating Board is the governing board of the Joint United Nations Programme on HIV/AIDS. It has ultimate responsibility for all policy and budgetary matters and meets at least once a year.
6. The other cross-cutting themes being gender, young people, and the greater involvement of people living with HIV/AIDS. See Report of the Third Meeting of the Program Coordinating Board of UNAIDS, Geneva, Switzerland, June 10-11, 1996; UNAIDS/PCB(3)/96.10, August 19, 1996, pp. 4, 21.
7. The Declaration of the Paris AIDS Summit *inter alia* included a declaration by those participating of their "determination to ensure that all persons living with HIV/AIDS are able to realize the full and equal enjoyment of their fundamental rights and freedoms without distinction and

under all circumstances." They also undertook in their national policies to "protect and promote the rights of individuals, in particular those living with or most vulnerable to HIV/AIDS, through the legal and social environment" and to step up international cooperation by seven initiatives one of which is to "strengthen national and international mechanisms that are concerned with HIV/AIDS related human rights and ethics." The Declaration stated: "[T]he scope of each initiative should be further defined and developed in the context of the joint and co-sponsored program and other appropriate fora."

8. Ibid. The signatories to the Paris AIDS Summit called upon "all countries, the future joint and co-sponsored United Nations program on HIV/AIDS and its six member organizations and programs to take all steps possible to implement this Declaration."

9. Commission on Human Rights Resolutions 1995/44 and 1996/43.

10. See Commission Resolution 1995/44. For Report of the Secretary-General on Human Rights and HIV/AIDS submitted in accordance with Commission Resolution 1995/44, see E/CN.4/1996/44, January 10, 1996.

11. Sub-Commission Resolutions 1994/29 and 1995/21.

12. UNAIDS Strategic Plan, see note 1.

13. See various UNAIDS statements to the Commission and Sub-Commission, 1995 and 1996 sessions, available on request from UNAIDS. See also Keynote Address by the UNAIDS Executive Director to the National Council for International Health Symposium, "HIV/AIDS: International Perspectives on Legal Issues and Human Rights," Arlington, VA, USA, June 28-29, 1995.

14. R.L. Siegel, "AIDS and Human Rights," *Human Rights Quarterly* 18(3) (1996):618.

15. Ibid.

16. See also "Assessing Vulnerability to HIV Infection and AIDS," in: *AIDS in the World*, J.M. Mann, D.J.M. Tarantola, T.W. Netter (eds.) (Cambridge: Harvard University Press, 1992), pp. 577-602, and "From Vulnerability to Human Rights," in: *AIDS in the World II*, J.M. Mann and D.J.M. Tarantola (eds.) (New York: Oxford, 1996), pp. 463-476.

17. UNAIDS Strategic Plan, see note 1, p. 4.

18. Ibid. For more on vulnerability see "Expanding the Response," UNAIDS Key Material, UNAIDS 98.1, Geneva, Switzerland, 1998.

19. See UN Commission on Human Rights Resolution 1995/44 and 1996/43; Sub-Commission Resolutions 1994/29 and 1995/21.

20. For further reading, see "Declaration at Dakar," United Nations Development Programme (UNDP), 1994; International Ethical Guidelines for Biomedical Research Involving Human Subjects, Center for International Organizations of Medical Sciences (CIOMS), 1993; and "The Rights and Humanity Declaration and Charter on HIV/AIDS," Rights and Humanity, 1992.

21. UNAIDS Workplan, 1996-1997, p. 4.

22. J.M. Mann et al., see note 16.

23. François-Xavier Bagnoud Center for Health and Human Rights, Harvard School of Public Health, and International Federation of Red Cross and Red Crescent Societies, *AIDS, Health and Human Rights: An Explana-*

tory Manual, 1995.

24. UNAIDS, in partnership with WHO, has launched an initiative to improve access to HIV/AIDS related medicines through communities and health systems. It will focus on overcoming problems of access that arise from selection, supply and rational use of HIV-related medicines in countries.

25. UNAIDS, see note 6, p. 20.

26. UNAIDS, see note 6, p. 9. This one of the activities that comprises the content of UNAIDS' country support.

27. Country program advisers are to assist the Theme Groups in their work. In countries where there is no CPA assigned, the cosponsors will designate a UNAIDS focal point, a percentage of whose time will be allocated to UNAIDS. UNAIDS, see note 6, p. 10.

28. "The Final Report of the Legal Working Party of the Intergovernmental Committee on AIDS," Department of Health, Housing and Community Services, Australia, November 1992, p. 2.

29. *Ibid.* See pp. 1-9 for description of the process.

30. See R. Jürgens, *Legal and Ethical Issues Raised by HIV/AIDS: Project Report* (June 1 – October 15, 1995), Montreal, Canadian AIDS Society and Canadian HIV/AIDS Legal Network, 1995.

31. For more information on the networks on HIV-related ethics, human rights and law, contact UNDP HIV and Development, New York. Also see R. Glick (ed.), *Law, Ethics and HIV, Proceedings of the UNDP Inter-country Consultation*, Cebu, Philippines, May 3 – 6 1993, UNDP; *African Network on Ethics, Law and HIV, Proceedings of the Inter-country Consultation*, Dakar, Senegal, June 27 – July 1 1994, UNDP; D.C. Jayasuriya (ed.), *HIV Law and Law Reform, Asia and the Pacific*, September, 1995, UNDP; see also "Newsletter of the African Network on Ethics, Law and HIV," No. 1, June 1996, UNDP Regional Project on HIV and Development, Dakar, Senegal.

32. UNAIDS Ethical Review Committee Provisional Terms of Reference and Procedures (available from UNAIDS).

33. *Ibid.*

34. The need for such guidelines was considered at the First International Consultation on AIDS and Human Rights held in 1989. Since then, guidelines have been called for in a number of resolutions by the UN Commission on Human Rights and the UN Sub-Commission on Prevention of Discrimination and Protection of Minorities. See Commission Resolutions 1995/44 and 1996/43. See Sub-Commission Resolutions 1994/29, 1995/21 and E/CN.4/Sub.2/1996/L.21, August 22, 1996.

35. Second International Consultation on HIV/AIDS and Human Rights, Geneva, Switzerland, September 23-25, 1996, Report of the Secretary-General, E/CN.4/1997/37; see also *HIV/AIDS and Human Rights, International Guidelines* (New York and Geneva: United Nations, 1998), HR/PUB/98/1.

36. For an example of integration of HIV/AIDS issues into the work of a Special Representative, see report of the Special Representative of the Secretary-General for Human Rights in Cambodia, Mr. Michael Kirby, submitted pursuant to Commission Resolution 1994/61, E/CN.4/1995/87/Add.1, February 13, 1995.

37. See Commission on Human Rights Resolutions 1990/65;1992/56;1993/53; 1994/49; 1995/44 and 1996/53. See Sub-Commission Resolutions 1989/17;1990/118; 1991/109; 1992/108; 1993/31; 1994/29; 1995/21 and E/CN.4/Sub.2/1996/L.21, August 22, 1996. See also the reports of the Special Rapporteur on Discrimination against HIV-infected People and People Living with AIDS to the Sub-Commission: Preliminary - E/CN.4/Sub.2/1990/9; Progress - E/CN.4/Sub.2/1991/10; Review of Further Developments - E/CN.4/Sub.2/1992/10; Final Report - E/CN.4/Sub.2/1992/10; and Conclusions and Recommendations - E/CN.4/Sub.2/1993/9.

38. The World Health Organization Global Programme on AIDS (GPA) sent a series of letters to some of the key treaty bodies: the Human Rights Committee, the Committee on Economic, Social and Cultural Rights, the Committee on the Elimination of Discrimination against Women, and the Committee on the Rights of the Child. These letters detailed the HIV-related issues arising under the provisions of each of the treaties in question. The GPA asked that the Committees use these as basis to question States on measures they are taking to comply with the treaty in terms of HIV-related issues. UNAIDS will follow up on this initiative.

39. Usually the only reference to HIV/AIDS is statistics on numbers infected.

40. See the UNAIDS Guide to the UN Human Rights Machinery (Geneva: Joint United Nations Programme on HIV/AIDS, 1997).

41. See papers prepared as background documents for the Second International Consultation on HIV/AIDS and Human Rights (available on request from UNAIDS). These papers, commissioned from the International Council of Women Living with HIV/AIDS, the Global Network of People Living with HIV/AIDS, the African Network of People Living with HIV/AIDS, ALTERLAW (Philippines), and Colectivo Sol (Mexico), all detail widespread abuse in their respective regions and areas of concern.