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Gesundheit und Menschenrechte

HIV/AIDS and Human Rights revisited

Bringing HIV/AIDS policies and programs into line with international human rights law

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As the number of people living with HIV and with AIDS continues to grow in nations with different economies, social structures, and legal systems, HIV/AIDS-related human rights issues are not only becoming more apparent, but also increasingly diverse. Policymakers, program managers, and service providers must become more comfortable using human rights norms and standards to guide and limit government action in all matters affecting the response to HIV/AIDS; and those involved in HIV/AIDS advocacy must become more familiar with the practicalities of using international human rights law when they strive to hold governments accountable.

HIV continues to spread throughout the world, shadowed by increasing challenges to human rights both within countries and globally. The virus continues to be marked by discrimination against population groups: those who live on the fringes of society or who are assumed to be at risk of infection because of behaviours, race, ethnicity, sexual orientation, gender, or whatever social characteristics happen to be stigmatized in a particular society. In most of the world, discrimination also jeopardizes equitable distribution of access to HIV-related goods for prevention and care, including drugs necessary for HIV/AIDS care and the development of vaccines to respond to the specific needs of all populations, in both the North and the South. As the number of people living with HIV and with AIDS continues to grow in nations with different economies, social structures, and legal systems, HIV/AIDS-related human rights issues are not only becoming more apparent, but also increasingly diverse.

The interaction between HIV/AIDS and human rights is most often illustrated through the impact on the lives of individuals of neglect, denial, and violation of their rights in the context of the HIV/AIDS epidemics. This is equally the case, albeit in different ways, for women, men, and children infected with, affected by, and vulnerable to HIV.

People infected with HIV may suffer from violations of their rights when, for example, they face government-condoned marginalization and discrimination in relation to access to health, education and social services¹. In this context, the realization of rights by people living with HIV would require non-discriminatory access within a supportive social environment. People are affected by HIV/AIDS when their close or extended families, their communities and, more broadly, the structures and services that exist for their benefit are strained by the consequences of the pandemic and as a result fail to provide them with the support and services they need. These negative effects of the HIV epidemics on people's lives may be compounded by marginalization and stigmatization on the basis of such attributes as race, migrant status, behaviours, or kinship that may be perceived as risk factors for HIV infection.

Violations of many of the rights of people affected by HIV may involve restricted or denied access to health services, education, and social programs.² People affected with HIV may progress toward the realization of their rights and better health if the personal, societal, and other impacts of the HIV epidemics on their lives are alleviated. This requires policies and programs designed to extend support and services to affected families and communities. Children orphaned by HIV/AIDS illustrate this need.

Vulnerability to HIV is the lack of power of individuals and communities to minimize or modulate the risk of exposure to HIV infection. Even in populations where HIV has not spread widely, some individuals may be more vulnerable than others with regard to HIV. For example, gender differentials may impose on a monogamous woman that she engage in unprotected sex with her spouse, even if he is engaging in sex with others. Adolescent girls and boys may be vulnerable to HIV by the mere fact that they are denied access to preventive information, education, and services. A truck driver's vulnerability to HIV may be enhanced by peer pressure to engage in multiple unprotected sexual encounters. Sex workers may be at greater vulnerability to HIV if they cannot access services able to diagnose and treat sexually transmitted infections, particularly if they are afraid to come forward because of the stigma associated with their occupation. Vulnerability is enhanced by the denial of such rights as the rights to information, education, association, or to essential care. To reduce vulnerability requires actions that enable individuals and communities to make and effectuate choices in their lives and thereby effectively modulate the health risks to which they may be exposed.

The effects of discrimination, particularly in the forms of racism, gender-based discrimination, and homophobia, continues to exacerbate the impact of the pandemic on the lives of individuals and populations around the world. It is increasingly recognized that realization of human rights is critical to protecting the rights and dignity of those infected and affected by HIV/AIDS, and to decreasing the relative vulnerability of individuals and communities.

Recognition of the relationship between Human Rights and HIV/AIDS

In the 1980s, the relationship of HIV/AIDS to human rights was only understood as it involved people infected with HIV and AIDS and the discrimination to which they were subjected.³ For HIV-infected people and people with AIDS, the concerns included mandatory HIV testing; restrictions on international travel; barriers to employment and housing, access to education, medical care, or health insurance; and the many issues raised by named reporting, partner notification, and confidentiality. These issues are serious, and almost 20 years into the epidemic they have not been resolved. In some ways, the situation has become even more complicated, as old issues crop up in new places or present themselves in new and different ways. For example, in certain settings, access to employment used routinely to be denied to people infected with HIV. Even in places where this situation has improved, HIV-positive individuals now run the risk of finding themselves excluded from workplace health insurance schemes, with considerable impact on their health and, therefore, on their capacity to work. There are also new issues, with tremendous human rights implications, that have been raised for HIV-positive people in recent years, including the large and growing disparities and inequities regarding access to antiretroviral therapies and other forms of care.⁴

The 1980s were extremely important in defining some of the connections between HIV/AIDS and human rights. In fact, by the end of the decade the call for human rights and for compassion and solidarity with people living with HIV/AIDS had been explicitly embodied in the first WHO global response to AIDS.⁵ This approach was motivated by moral outrage but also by the recognition that protection of human rights was a necessary element of a worldwide public health response to the emerging epidemic. The implications of this call were far-reaching. By framing this public health strategy in human rights terms, it became anchored in international law, thereby making governments and intergovernmental organizations publicly accountable for their actions toward people living with HIV/AIDS. The groundbreaking contribution of this era lies in the recognition of the applicability of international law to HIV/AIDS – and therefore to the ultimate responsibility and accountability of the state under international law for issues relating to health and well-being.⁶ The strong focus in the 1980s on the human rights of people living with HIV/AIDS helped pave the way for increased understanding in the 1990s of the importance of human rights as a factor in determining people's vulnerability to HIV infection and their consequent risk of acquiring HIV infection and chances of accessing appropriate care and support.⁷ It is only very recently, however, that human rights have also come to be understood to be directly relevant to every element of the risk/vulnerability paradigm.

Government responsibilities for Human Rights in the context of HIV/AIDS

Given the reality of violations that continue to occur in the context of HIV/AIDS, it is useful to consider the specific human rights responsibilities of governments. Governments are responsible for not violating rights directly, as well as for ensuring the conditions that enable people to realize their rights as fully as possible. It is understood that, for every human right,

governments have responsibilities at three levels: they must respect the right; they must protect the right; and they must fulfill the right.⁸ As an illustration, consider governmental obligations in the context of HIV, using one right – the right to education:

Respecting the right means that states cannot violate the right directly. This means that the right to education is violated if children are barred from attending school on the basis of their HIV status.

Protecting the right means that a state has to prevent violations of rights by non-state actors – and offer some sort of redress that people know about and have access to if a violation does occur. This means that a state has to ensure, for example, that groups motivated by extremist ideologies are not successful when they try to stop adolescents from accessing reproductive-health education.

Fulfilling the right means that states have to take all appropriate measures – legislative, administrative, budgetary, judicial, and otherwise – toward fulfilling the right. If a state fails to provide essential HIV/AIDS prevention education in enough languages and mediums to be accessible to everyone in the population, this in and of itself could be understood to be a violation of the right to education.

In most countries, resource and other constraints can make it impossible for a government to fulfill all rights immediately and completely. The mechanisms responsible for monitoring governmental compliance with human rights obligations recognize that, in practical terms, a commitment to the right to basic education is going to require more than just passing a law. It will require financial resources, trained personnel, facilities, textbooks, and a sustainable infrastructure. Therefore, realization of rights is generally understood to be a matter of making steady progress toward a goal. This principle of “progressive realization” is fundamental to the achievement of human rights. This is critical for resource-poor countries that are responsible for striving toward human rights goals to the maximum extent possible; but it is also important because it imposes an obligation on wealthier countries to engage in international assistance and cooperation.⁹

Using human rights concepts, one can look at the extent to which governments are progressively respecting, protecting, and fulfilling their obligations for all rights – civil, political, economic, social, and cultural – and how these government actions influence the patterns of who is getting infected and what is being done about it.¹⁰

HIV/AIDS, Public Health, and Human Rights in Practice

Advocacy and accountability

Governments are responsible for promoting and protecting both public health and human rights. None of the human rights treaties specifically mentions HIV or the rights of individuals in the context of HIV/AIDS, yet all the international human rights mechanisms responsible for

monitoring government action have expressed their commitment to exploring the implications of HIV/AIDS for governmental obligations. This may be of critical importance for bringing HIV/AIDS and human rights together in practical and concrete ways. In addition, governments have made political commitments at international conferences such as the Cairo International Conference on Population and Development and the UN Fourth World Conference on Women, stating their responsibility for ensuring the rights of individuals in the context of HIV/AIDS.¹¹ Resolutions of the UN Commission on Human Rights and the 1998 International Guidelines on HIV/AIDS and Human Rights provide both advocates and policymakers with useful tools for helping to ensure increased attention to both HIV/AIDS and human rights.¹² The consensus document that will come out of the UN General Assembly Special Session on HIV/AIDS scheduled for June 2001 may become a critically important document for advocacy and accountability in relation to HIV/AIDS and human rights.

Human rights in HIV/AIDS policy and program design

Recognizing human rights in the design, implementation, and evaluation of health policies and programs can help point the way toward more effective action. Human rights are governmental obligations toward individuals; because these obligations include the protection of public health, they are relevant to the design, implementation, and evaluation of health policies and programs. ¹³ Based on these obligations, governments can be understood to be legally responsible for instituting policies and programs that can reduce the spread and impact of HIV/AIDS.

Examining public health through a human-rights lens means looking not only at the technical and operational aspects of public health interventions but also at the civil, political, economic, social, and cultural factors that surround them.¹⁴ These factors may include, for example, gender relations, religious beliefs, homophobia, or racism. Individually and in synergy, these factors may influence the extent to which individuals and communities are able to access services or to make and effectuate free and informed decisions about their lives and, therefore, the extent of their vulnerability to HIV/AIDS, including accessing needed care and support once HIV infection has set in.

HIV/AIDS policies and programs can be improved by a systematic review of how and to what extent interventions are both respectful of human rights and of benefit to public health. The following questions can be used by policymakers and public health and other government officials to help in the development, implementation, and evaluation of more effective HIV/AIDS policies and programs. They can also be used by nongovernmental organizations and other concerned actors as an advocacy tool to hold governments accountable for the ways they are and are not in compliance with their international legal obligations to promote and protect both public health and human rights. They are intended only to serve as a starting point:¹⁵

What is the specific intended purpose of the policy or program?

- What are the ways and the extent to which the policy or program may impact positively and negatively on public health?
- Using the international human rights documents for guidance, what and whose rights are impacted positively and negatively by the policy or the program?
- Does the policy or program necessitate the restriction of human rights?
- If so, have the criteria/preconditions been met?
- Are the health and other relevant structures and services capable of effectively implementing the policy or program?
- What steps are being taken to progress toward the optimal synergy between the promotion and protection of health and rights in relation to the issue?
- What system of monitoring, evaluation, accountability, and redress exists to ensure that the policy or program is progressing toward the intended effect and that adverse effects are acted upon?

A Framework for action

An agenda for action can be created by recognizing the convergence of the three situations in which people live in a world with HIV/AIDS – infected, affected, and vulnerable – and the three levels of government obligations that exist for every right: respect, protect, and fulfill. This approach has the power to bring about the incorporation of human rights promotion and protection into the diversity of responses designed to bring the pandemic under control and mitigate its impact.*

Conclusion

People living with HIV/AIDS, their friends and relatives, their communities, national and international policy- and decision-makers, health professionals, and the public at large all, to varying degrees, understand the fundamental linkages between HIV/AIDS and human rights. The importance of bringing HIV/AIDS policies and programs into line with international human rights law is generally acknowledged but, unfortunately, rarely carried out in reality. Policymakers, program managers, and service providers must become more comfortable using human rights norms and standards to guide and limit the actions taken by or on behalf of governments in all matters affecting the response to HIV/AIDS. This requires genuine attention to building their capacity to recognize and promote the synergy between health and human rights, and to more fully appreciate the gains to be achieved when health interventions are guided by human rights principles. Those involved in HIV/AIDS advocacy must become more familiar with the practicalities of genuinely using international human rights law when they strive to hold governments accountable. For human rights to remain relevant to legal and policy work in HIV/AIDS, the contact between the conceptual work being done on the linkage between HIV/AIDS and human rights and the realities being faced by those working in

advocacy and in policy and program design must be constant. It is the mutually supportive – although occasionally mutually challenging – interaction between these that will help keep this work vital and useful.

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Notes

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