

CONFRONTING AIDS: Human Rights, Law, and Social Transformation

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How AIDS has been theorised has had profound implications, not only for how we understand the disease, but for our responses to it.

—Karen Lee & Anthony Zwi

This piece developed out of discussions between the authors at the 12th World AIDS Conference, held in Geneva in 1998. In the sessions on human rights, a number of delegates from Asia and Africa experienced some difficulty understanding how they could apply the primarily legal arguments of the UN's *HIV/AIDS and Human Rights: International Guidelines* to local conditions.¹ Particularly visible was a confusion about the relevance of international law as well as the difficulty associated with “downloading” a paradigm of human rights located in a Western legal framework into non-Western societies.

The piece asserts the enormous importance of human rights issues to HIV prevention and care. It looks fleetingly

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at the history and main features of the campaign for human rights during the AIDS epidemic, and it confirms that fighting for human rights is and remains an extremely important part of confronting AIDS. But it also aims to provoke a debate about the nature of rights, the role of law, and their respective capacities as agents for social transformation. We believe that this debate might help those who are committed to working for human rights and an end to the epidemic to think beyond the current impasse which, we feel, faces many HIV workers. This is particularly so in countries where poverty and inequality are the dominant realities for most people.

To the extent that there have been critiques of the discourses that have developed around AIDS, they have focused largely on the biomedical and neo-liberal biases of these discourses. Critical analysis of other areas of the response has been almost absent. The concept of human rights, particularly, has been treated as an uncontested monolith (except by those who oppose them). Within the broad church of the human rights camp the manifold and sometimes contradictory meanings of human rights have not been rigorously explored. We have not debated whether there may be a conservative view of human rights as well as a radical approach. Consequently there has been little discussion that allows for the possibility that even *bon fide* strategies for achieving "human rights" might reflect some form of appropriation that has blunted their transformative potential.

The link between the struggle for rights and the most effective HIV prevention and care is enormously important. In the words of Michael Kirby, reflecting on the role of Dr. Jonathan Mann, this linkage is "more than a moral imperative . . . it [is] an epidemiological necessity."² This article argues that during the 1990s, as Mann realized, changes in global society had outpaced the evolution of thinking—or alternatively exposed the lack of thinking—about human rights and AIDS. For Mann, "globalization" created an imperative for a reassessment and extension of our understanding of human rights. The delay in doing this has led many activists into a cul-de-sac from which they have been unable to significantly better the experience of people with HIV.

Today in countries where HIV infection has entered into the “general population” and is no longer confined to identified “risk groups,” poverty and inequality—rather than stigma and exclusion—are the primary determinants of the success or failure of attempts at curtailing new HIV infections. These have been categorized by one epidemiologist as “explosive,” “masked,” and “emerging.”³ According to the Joint United Nations Programme on HIV/AIDS (UNAIDS), they are “frankly out of control in many areas.”⁴ If those involved in AIDS work are to retain the ambition of ending this epidemic, rather than merely mitigating some of its worst effects, then the international human rights agenda will have to be redefined and reinvigorated. Strategies will have to be found that can effectively begin to challenge not just human rights violations, but human rights omissions, particularly those that exacerbate the vulnerability of millions of people in the developing world to HIV.

The Early Emergence of Human Rights in the AIDS Epidemic: North America

The emergence of AIDS as a political issue in the early 1980s in the United States immediately involved a strong emphasis on questions of individual rights and equality. Once the extent of individual vulnerability to HIV had been identified as being determined primarily by sexual behavior, activists sought to mobilize the gay community to convey messages about avoidance of AIDS/HIV infection. But AIDS also added to existing stigma against homosexuality, both male and female—just when some of the strongest prejudices seemed to be in retreat. The view of some American fundamentalists that AIDS was “God’s punishment” was echoed in many other countries and, in some cases, indirectly informed government responses, most often through neglect.

From the outset, therefore, fighting AIDS also meant combating prejudice against gay men. This required dealing with the mechanisms that had been adopted before AIDS as protection against abuse. Openness and anger were required. But, in the face of the new stigma of AIDS, rights to privacy (concerning HIV infection) and nondiscrimination (against

people with HIV) also assumed a new importance. In response to a new backlash against gay men, the early AIDS movement therefore promoted rights to confidentiality concerning HIV infection and protection against arbitrary discrimination, such as employers' dismissing people because of their HIV status.⁵ Not surprisingly, this emphasis was also adopted in other countries in which AIDS organizations grew out of gay communities.⁶ By contrast, in countries such as Uganda or Senegal, where early AIDS organizing was unrelated to any sort of gay movement, the early development of the political language around the epidemic was notably different.

Individuals and organizations based in the gay community in industrialized countries (particularly North America) used various forms of activism to draw attention to the social dimensions of the disease. Throughout the 1980s, American "AIDS activists" complained bitterly about inaction by the government and the medical research establishment, claiming that if this new disease had been affecting heterosexual white men, millions of dollars would have been poured into research immediately.⁷ Other groups were also affected by the stigma against AIDS, particularly drug users and sex workers, even though in rich countries the rate of infection among sex workers has rarely been particularly high. The gay/lesbian community was, however, by far the most visible, both as a target from conservative groups and as a source of political mobilization against the epidemic.

In this charged context, there was little space and considerable unwillingness to consider how vulnerability to HIV might also relate to class or race. What was also atypical about the early social struggles around AIDS was that generally it fell upon a cadre of relatively affluent middle class white men to try to expose the institutionalization of discrimination in the delivery of services and allocation of money. In the 1960s the civil rights movement in the U.S. had fought exclusion based upon race. In the 1980s AIDS compelled gay men to challenge discrimination and exclusion based on sexuality.

In the face of totally unexpected increases in mortality and the absence of any effective treatments, the initial polit-

ical questions revolved primarily around demands for government and private sector investment in research and prevention appropriate to the size of the problem. It was not until the 1990s, when the AIDS Coalition to Unleash Power (ACT UP) emerged in a few U.S. cities, that the idea of individual “rights” to health care and concurrent obligations on government to subsidize treatments for people living with HIV/AIDS became central to the rhetoric of AIDS activism. (Other industrialized countries that were affected had universal health insurance, which was one reason why the anger around AIDS and direct activism was less important there than in the U.S.)

It seemed essential in the early days of the epidemic to stress the need for protection of individual rights. Rights to privacy and confidentiality were a first line of defense. If successfully defended, they offered protection against other forms of discrimination. In the U.S. and elsewhere, however, the importance of these rights grew from community struggles. They were often a logical extension of existing political demands in the same way as the creation of the concept of “persons living with HIV/AIDS” grew out of the gay liberation idea of “coming out.”

Internationalizing Rights: The Global Programme on AIDS

In 1986, with the potential global dimensions of the AIDS epidemic increasingly apparent, the United Nations system responded by establishing the Global Programme on AIDS (GPA) as part of the World Health Organization (WHO).⁸ In large part because of the personal commitment of the founding director of GPA, Dr. Jonathan Mann, the human rights principles that had become integral to HIV/AIDS activism in industrialized countries also became the stock-in-trade of the international response to HIV. Thus, for example, a 1988 resolution of the World Health Assembly titled Avoidance of Discrimination in Relation to HIV-Infected People and People with AIDS urged Member States “to protect the human rights and dignity of HIV-infected people” and to ensure confidentiality of HIV testing.⁹

It is important to note, however, that there were several rationales for this. At the outset, rights to confidentiality and nondiscrimination were promoted primarily for “public health” reasons; progressive epidemiologists had warned governments that discrimination drove “risk groups” away from health care providers and was therefore counterproductive in preventing the epidemic. These arguments were marshaled in response to the many governments that had begun to respond to AIDS by placing draconian restrictions on people with HIV and AIDS, or people thought to be especially at risk of HIV infection (a decision that was usually based upon pre-existing stigma).¹⁰

Mann and Kirby et al. used the GPA and other international forums to warn against these restrictions and publicize the paradox that:

One of the most effective laws we can offer to combat the spread of HIV is the protection of persons living with AIDS, and those about them, from discrimination. This is a paradox because the community expects laws to protect the uninfected from the infected. Yet, at least at this stage of the epidemic we must protect the infected too.¹¹

The success of this campaign is evident from the steady move by most governments away from resorting to unfairly discriminatory laws to combat the epidemic, a change in approach that began by the early 1990s and continued until recently. In 1998, for example, Peter Piot, the Executive Director of UNAIDS, praised Jonathan Mann, noting that without him,

the world’s approach to combating AIDS would surely have been very different; [it] would have had much less to do with human rights issues and might very well have gone towards quarantine.¹²

As the global focus on HIV/AIDS developed, there were systematic attempts to link it to existing frameworks of international human rights. A series of international consultations on AIDS and human rights helped move the debate firmly into the terrain of international law. Eventually, through this process, a more comprehensive

theoretical framework was established to link human rights to HIV prevention. While the *raison d'être* remained primarily epidemiological (rather than moral or ideological), the language in which these rights were expressed was increasingly that of law and ethics. Thus, confidentiality, privacy, and bodily autonomy were now described in the language of the international human rights movement as "civil and political rights." Questions around access to health care were pushed back into the murky terrain of social and economic rights.

Although it has taken a long time to be recognized, the "one model fits all approach" that emerged at an international level was not entirely successful and has had several long-term negative (even if unintended) consequences. First, although equally important to social transformation, rights, law, and ethics all have very different functions. Blurring these functions impacts negatively on their individual power, as well as their relations with each other. Second, in the minds of people directly affected by HIV, the hierarchy of rights issues in developing countries is different from the one dominant in industrialized countries, although it is important to recognize that there are significant class distinctions in the experience of HIV even in rich countries. Though all rights are rooted in concepts of "human dignity" and "equality," the rights that most immediately impact on these states of being are different. In a country with a high standard of living, privacy and confidentiality may be seen by infected people as central to dignity and autonomy. In a poor country, dignity depends equally on economic needs; in the case of AIDS it means access to treatment and care, which includes basic shelter and sustenance. This is borne out by a survey of the issues considered most important for an advocacy campaign carried out by the Southern African Network of AIDS Service Organisations (SANASO). The two issues ranked as the most important by over 80 respondents were: (1) access to care and treatment and (2) measures to protect the dignity of children directly or indirectly affected by AIDS.¹³

As the center of gravity of the AIDS epidemic shifted from industrialized to developing countries, and as social

and economic rights related to development arguably became the human rights issues with the greatest influence on the epidemic, the human rights model that was increasingly being enshrined in international declarations began to encounter political difficulties in providing a unifying framework in the Third World. It has not been able to encompass the full range of social, political, and cultural factors involved in vulnerability to HIV and responses to AIDS. This is not to deny its importance, but only to point to the larger range of issues to which the dominant Western understanding of human rights, which often unconsciously privileges individual civil and political rights, was unable to respond.

HIV/AIDS and Human Rights: International Guidelines

Throughout the 1990s, a model essentially derived from Western experiences was used to justify the promotion of the human rights of people vulnerable to and infected with HIV. It can be detected in numerous national and regional charters and in declarations made at the international AIDS conferences.¹⁴ The growth in currency of human rights in relation to HIV/AIDS has culminated in the drafting of *HIV/AIDS and Human Rights: International Guidelines*, which was endorsed by the Executive Director of UNAIDS and the UN High Commissioner for Human Rights.¹⁵ In 1998 these *International Guidelines* were also adopted by the International Council of AIDS Service Organisations (ICASO), which decided to focus its human rights advocacy around the *Guidelines* at an international level.¹⁶ The promotion and acceptance of human rights appeared to have reached its zenith.

In an appendix to the *International Guidelines* that looks at the "History of the Recognition of the Importance of Human Rights in the Context of HIV/AIDS," however, it is noted:

Although some positive measures at a national level to promote and protect human rights in the context of HIV/AIDS are in place, a dramatic gap exists between professed policy and implementation on the ground. It is

hoped that these Guidelines, as a practical tool for States in designing, co-ordinating and implementing their national HIV/AIDS policies and strategies, will assist in closing the gap between principles and practice. . . .¹⁷

At the 12th World AIDS Conference (1998), many delegates attending an NGO networking meeting thought the *International Guidelines*, while an extremely important addition to the armory of AIDS activists, were not filling this gap. Some commented that the *Guidelines* were not well known, that they were difficult to use in everyday struggles, or that governments were ignoring them, and that UNAIDS was not campaigning for them with sufficient vigor.

The reasons for this, as well as for the “dramatic gap . . . between . . . policy and implementation” of other instruments and declarations, are profound. We will focus on the *International Guidelines* because they are indicative of many of the problems facing AIDS activists internationally in that:

- They reflect an excessive reliance on legal frameworks that mean little in practice for many populations of the First and Third World who are most affected by HIV.¹⁸ Moreover, changes in laws are meaningful only to the extent that they are actually implemented.
- They place excessive responsibility on governments to preempt and prevent unfair discrimination, ignoring the real power of large corporations, international agencies, and local ethnic, tribal, and religious power brokers.
- They illustrate and reinforce the practical separation of “civil and political rights” from “economic and social rights”—a paradigm that has been inherited from mainstream approaches to human rights in the post–World War II period. This separation is increasingly difficult to justify.
- They stress combating the individual’s experience of discrimination and prejudice, arguably to the detriment of fighting the social discrimination and inequity that create vulnerability to HIV infection for millions of people.

An example of this stress on the individual is the growing emphasis on the need for HIV-positive people to be “open” and take a public role in the epidemic. While moves to empower people living with HIV/AIDS should be strongly supported, it is also worth noting that many HIV-positive people do not wish to make their sero-status a mark of identity. In addition, the idea of “coming out” as positive has very different meanings and implications in less individualistic cultures than those in which a U.S.-style gay movement has been most successful. The 1998 murder of South African activist Gugu Dlamini because of her public declaration of her HIV status should illustrate this point. In societies where there is extreme hostility to people with HIV/AIDS, the assertion of civil and political equality implied by “openness” also necessitates the existence of social mechanisms to protect people with HIV from violence—in Gugu’s case, a sympathetic police force. Here, as we will illustrate more fully later, is another example of the blurring of civil/political and economic/social issues.

The Limits to Legal Enforcement of Rights

The reasons for linking strategies to realize human rights so firmly to international and civil law are complicated to unravel. They are also not unique to AIDS.

It might be argued that the reliance on law, rather than other institutions, to legitimate and further human rights was influenced, at least in part, by the ideological crisis that overtook many of the proponents of social activism—including AIDS activism—at the end of the 1980s. This was, after all, the time of the much-heralded “end of socialism” and the Pyrrhic victory of the advocates for an unrestricted market and the minimum of social intervention to protect the marginalized and vulnerable. One of the consequences of the collapse of the allegedly socialist states was that many of the organizations traditionally associated with promoting and protecting human rights (including trade unions, political parties, and left-leaning governments) faced uncertainty about what could be achieved in the “new world order.” For a time, it seemed to many as if the traditional avenues to advance human rights had been

blocked. The desire to gain legitimacy for the “AIDS paradox,” therefore, led its advocates into the realm of international law and the institutions that were once intended to enforce it.

As Dr. Jonathan Mann discovered as head of the GPA, however, once the struggle for human rights in the context of HIV/AIDS was placed within the domain of the UN system (first with the GPA, under WHO, and later through UNAIDS), it encountered structural factors inhibiting active (or effective) campaigns—particularly campaigns targeted at removing the underlying social and economic causes of the AIDS epidemic. These structural factors, which today undermine the UN’s development as a genuine center for global governance, include the dominance of industrialized nations, the attachment to national sovereignty shared by many lesser powers, and the lack of mechanisms to enforce key aspects of human rights documents. Unfortunately, the rhetoric of rights created expectations among activists that the international recognition of human rights would translate into respect for the same rights at a governmental level. It did not. In one of his last articles, Mann warned:

Precisely because they are embedded in the status quo, it would be unrealistic to expect official organizations, whether at national or international levels, to provide strong and sustained support for concrete human rights-based action (as opposed to rhetoric). This problem is not restricted to HIV/AIDS, nor to the health-related United Nations organizations; the entire UN system is riven by the conflicting pressures of respect for national sovereignty (often the defender of the status quo) and the promotion of universal human rights norms. Support for human rights-based action to promote health (to reduce vulnerability to HIV/AIDS) at the level of declarations and speeches is welcome, and useful in some ways, but the limits of official organizational support for the call for societal transformation inherent in human rights promotion must be recognized.¹⁹

In addition, linking the attainment of human rights so closely to international law (which has its roots in the legal history of Europe and the United States) had the unexpect-

ed disadvantage of creating a dependency on civil and international law in an historical period that has witnessed the de-legitimizing of “Western” law in many ex-colonial countries. This is a consequence of the growth of religious movements, the desire to be free from colonial trappings, and the cynicism and social disintegration that have left many parts of the world beyond the “rule of law.”

Some of the implications of the collapse of civil law in many countries in Africa and the strengthening of customary/ethnic law are analyzed by South African academic Mahmood Mamdani.²⁰ Discussing the civil war in the Democratic Republic of the Congo, Mamdani contrasts some of the different forms of “citizenship” and civic identity that have re-emerged in the 1990s. He points out that many African governments have adopted Western notions of law and of the legal entitlements that accrue to citizenship, usually evident in their Constitutions. The weakness of these governments, however, has generally led their citizens to look to other social institutions for the realization or protection of these rights.

Hence, Mamdani writes:

Civic citizenship is a consequence of membership of a central state; it is specified in the Constitution, and is the basis of rights—mainly individual rights in the political and civil realm. In contrast, ethnic citizenship is a consequence of membership of the native authority; it is the source of a different category of rights, mainly social and economic.²¹

Civic citizenship, the meanings and entitlements of which are usually elaborated in law, is an extremely fragile notion. Mamdani observes that, for millions of people, economic and social entitlements—which should be the core of citizenship and which assume added importance amongst impoverished peoples—can no longer be claimed from governments. Generally they can be attained only through individual access to a range of diverse systems of ethnic or religious patronage. This insight should caution human rights activists against repeating the mistake they have made in the pursuit of civil and political rights—that

is, placing all demands for social betterment on governments.

In reality, in many countries in the world, the powers wielded by civic governments have been drastically weakened over the last two decades. Their power to improve the environment in which people live is minor in comparison to the power over resources and resource allocation held by international monopolies and First-World governments.

Compounding this problem is the cynicism about human rights that exists among governments in many developing countries. Because the U.S. and other members of the G-8 (Group of 8 Industrialized Nations) ignore their obligations under international law in relation to social and economic rights, redefining these obligations as acts of beneficence that can be switched on and off at will, corrupt Third-World governments from Zimbabwe to Malaysia are able to rationalize their own gross human rights violations. They argue that those industrialized countries that do claim to uphold civil rights generally have a regard for international law only to the extent that it suits their own purposes and cements their own power. For example, on International Human Rights Day, 1998—ironically, also the 50th anniversary of the signing of the Universal Declaration of Human Rights—Zimbabwe's government-controlled *Herald* newspaper carried a scathing editorial contrasting Western concerns for civil and political rights, particularly for gay men and lesbians, with their neglect of economic and social rights:

In the din of today's parades, demonstrations and discussions, we urge all interested parties . . . to work in the true spirit of the theme: All human rights for all! Not just human rights for the foreign-funded, privileged few. Not just human rights for vocal urban-based elites. Not just human rights for homosexuals and lesbians.²²

There are numerous other examples (many, of course, from rich countries) of the ways in which the language of human rights is used to deny their applicability to unpopular minorities or to appeal to anti-democratic prejudices.

The Possibilities for the Legal Enforcement of Rights

There is an important relationship between law and human rights, but to achieve the full potential of both, we must unpack their respective meanings. Law should—but does not always—represent the high-water mark of civilization, enshrining and protecting values that have been deemed worthy of human beings and have arisen through the history of morality, science, medicine, and philosophy. It should be a regulating mechanism. Law, however, does have limitations. In the words of Edwin Cameron:

It is not the law or lawyers who generate wealth. Nor do lawyers or the law provide the resources essential to secure submission to the law. It is not the construction of elaborate edifices of legal principle that ensures law enforcement, or that attends to the difficult, dangerous and drab business of follow up and follow through. The law, in the end, can only be an adjunct social agency.²³

Law should be seen as an adjunct to rights. Rights, like international law, have only been partially achieved. In the context of HIV/AIDS, rights must both depend on existing law, seek to create new law, and find agencies for the universal enforcement of law. The first value of rights in confronting HIV/AIDS is that they are a standard that can be deployed by both majorities and minorities as, in the words of Carl Stychin, “a socially transformative instrument.”²⁴ This role is encapsulated in the following statement by Chris Jochnick:

Rights rhetoric provides a mechanism for reanalyzing and renaming “problems” as “violations,” something that needn’t and shouldn’t be tolerated. . . . Rights make it clear that violations are neither inevitable or natural, but arise from deliberate decision and policies. In their demands for explanations and accountability, human rights expose the hidden priorities and structures behind violations. Thus, the demystification of human rights, both in terms of their economic and social content, and their applicability to non-state actors, constitutes a critical step towards challenging the conditions that create and tolerate poverty.²⁵

National and international law can play a critical role in

combating human rights violations. In addition, there is unquestionably still a strong public health argument for supporting and promoting civil and political rights and using the law for this purpose, in countries where this is possible. Significant human rights struggles utilizing the law have been undertaken in a number of countries, and legal battles have been won on issues around the protection of privacy and guarantees against discrimination, violence, criminalization, etc.²⁶ In Latin America, India, the Philippines, and South Africa, AIDS groups and gay groups have been imaginative and effective in their use of legal and human rights arguments to win basic gains in respect for those infected and affected by HIV. In Costa Rica, Venezuela, and Argentina, NGOs have been able to mount arguments and win legal battles about socioeconomic rights, particularly to treatment.²⁷

Ultimately, however, human rights advocates must balance the possibilities and limitations of the law as an instrument that can be used to bring about a sustained improvement in human rights. There is a need for other campaigns to ensure that individual legal decisions (e.g., on issues such as confidentiality or access to treatment) are implemented and generalized. Activists must therefore be realistic about the limits to what can be achieved through international law. International conventions must be used to remind signatory governments of their obligations, but the conventions must also be subject to rigorous criticism of their inadequacies, as well as the inadequacies of the system intended to oversee their progressive realization. In the foreseeable future, their moral authority will still far outweigh their actual power.

International law in relation to the right to health is a case in point. In 1946 health was defined in the WHO Constitution as "a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity."²⁸ According to the International Covenant on Economic, Social and Cultural Rights (ICESCR), everyone has the right to enjoy "the highest attainable standard of physical and mental health," although this right can be achieved progressively by developing countries according to their "available resources."²⁹ But during the life of the ICESCR, public health has at best fluctuated and in many

countries deteriorated. Despite adoption of a General Comment on the Right to Health in May 2000, there is still no definition of “the highest attainable standard” or a mechanism to ensure that there is a progressive realization of this right.³⁰

The HIV/AIDS experience continues to remind us that it is wrong to understand or measure health only—or even largely—in terms of access to hospitals, clinics, and medicines. The social environment is the major determinant of vulnerability to HIV/AIDS. The diseased nature of the social environment is largely due to the lack of progress (indeed, regress, in many parts of the world) in changing the determinants of HIV infection: rights to education, employment, and gender equality, among others. Therefore, to insist—as we must—that basic human rights include the right to “the highest attainable standard of physical and mental health” raises many hard questions about what this means in the context of radically different resources.

Social and Economic Rights?

A 1998 article in *The Economist* states:

Claims for economic goods are not justiciable. A court of law, even in a poor country, can determine when civil and political rights are being violated by the government, but it cannot, by a mere legal judgment, summon the resources to meet social and economic goals.³¹

In the early stages of the AIDS epidemic in industrialized countries, there was a clear link between individual vulnerability to HIV and unfair discrimination, primarily with regard to the civil and political rights of gay men but also those of sex workers and drug users. This forced activists to combat covert and overt homophobia in the allocation of resources for confronting the epidemic. However, in poor countries (and increasingly in the Third-World parts of industrialized countries, e.g., among Aboriginal people in Australia, First Nations peoples in Canada, or African-Americans in the U.S.) the most important connection between human rights and vulnerability to HIV is through poverty.

According to UNAIDS, for most of the 1990s,

The fastest growing epidemics have been among the most socio-economically disadvantaged populations within and across countries. In low-income countries, greater human insecurity and social inequalities have led many individuals to resort to coping strategies (e.g., migrant labour, commercial sex) under conditions which have placed them at risk of HIV infection.³²

Recently, this recognition has grown in importance. Under the sub-heading "What Drives the Epidemic," the December 1998 *UNAIDS Update* states:

There are several factors which clearly influence the shape of the epidemic. People [may be] on the move—escaping from abuse, or even just leaving their families in search of work. . . . People whose daily existence is stressful and dangerous may not care about the long term risks posed by HIV. . . . People in conflict and refugee situations may have little control over their exposure to HIV, indeed even to sex.³³

In the context of HIV/AIDS, this confirms the argument by the United Nations Development Programme (UNDP) that:

Poverty and sustainable livelihoods are closely linked to human rights. Indeed, poverty is a violation of human rights. Poverty and inequality can undermine human rights by fueling social unrest and violence and increasing the precariousness of social, economic and political rights. . . .³⁴

Perhaps the most surprising confirmation of the statement above is to be found in a 1997 World Bank report that presents empirical evidence that low per capita income and unequal distribution of wealth within a country are strongly associated with high HIV infection rates.³⁵ The World Bank, always attracted to the quantifiable, argues that "for the average developing country a \$2000 increase in per capita income is associated with a reduction of about 4 percentage points in the HIV infection rates of urban adults." The report states:

A country that improves per capita income and reduces inequality, for example, by implementing investment policies that generate jobs and raise its economic growth, will reduce its risk of suffering an AIDS epidemic or help to minimise an epidemic already under way. If, in addition, the country acts to close the literacy and urban unemployment gap between men and women, HIV would have even more difficulty spreading.³⁶

But for the average developing country, such significant increases in per capita income, job creation, and literacy are proving extremely difficult—and little help is forthcoming from the international community. When governments attempt to carry out even modest social reform programs, they are often forced to retreat in the face of the demands of the global economy.

From the mounting evidence of the links between poverty and explosive AIDS epidemics, it should be apparent that the approach to human rights and HIV/AIDS must, from now on, attach equal and increasing importance to campaigns to bring about rapid improvements in social and economic conditions.

This too requires a change in emphasis: while it is frequently stated that all human rights are universal, indivisible, interdependent, and interrelated, rights activism in relation to HIV/AIDS has consistently emphasized civil and political rights. Admittedly, resolutions of the Commission on Human Rights have repeatedly drawn attention to the social factors that heighten vulnerability to HIV.³⁷ The United Nations Committee on Economic, Social and Cultural Rights (CESCR) has even stated that the “suggestion that the full realisation of economic, social and cultural rights will be a direct consequence of, or will automatically flow from the enjoyment of civil and political rights is misplaced.”³⁸ Yet in practice this recognition has rarely been more than a rhetorical postscript, leaving the key economic and social issues that govern vulnerability largely neglected. By asking too much of the concept of human rights we risk undermining its importance, and thus setting back both the struggle against HIV and the battle for human rights themselves.

NGOs as a Vehicle for Campaigning for Social and Economic Rights

The dilemmas and difficulties faced by NGOs attempting to tackle human rights violations or omissions that are economic or social in origin are captured in Chris Jochnick's comments on the human impact of oil development in the Ecuadorian Amazon: "There was little sympathy for the legal nuance that private companies are technically immune to human rights claims, that they don't sign Covenants. . . . [I]nsisting solely on governmental obligations would obscure the true nature of the violation. . . ."39 These dilemmas are also evident in the ongoing debate in the policy field about how to define, promote, and monitor social and economic rights, with the most recent contribution to this being the Maastricht Guidelines on Violations of Economic, Social and Cultural Rights.⁴⁰

In the context of HIV/AIDS, it is important for activists to improve the response to individual cases of stigma, exclusion, and unfair discrimination. But this work must be linked to an understanding that the AIDS epidemic itself will not be brought into abeyance unless its root causes are confronted. The UNAIDS strategic plan warns:

[I]n 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.⁴¹

This is a stunning admission. In the face of the UN's incapacity to effectively address poverty, it amounts to a prior admission that its best efforts to manage the AIDS epidemic will be defeated.

Moreover, advocacy for civil and political rights while ignoring or excluding economic and social rights may actually compound some people's vulnerability to HIV. This lopsidedness is an obvious characteristic of the policies pursued by the World Bank and the International Monetary Fund (IMF), whose lending is predicated upon the democratization of the "civil state" but is combined with economic policies that prevent the genuine exercise of democratic

rights and further impoverish and marginalize millions of people. Richard Cornwell of the Institute for Security Studies in South Africa has argued:

The contradictions between the imperatives of democratisation and structural adjustment have become apparent: at the very moment when democratisation stimulates popular demand for better social and welfare services, structural adjustment requires that this be denied. In broad terms this has played a significant part in further undermining the state's claim to legitimacy in the eyes of its own citizens.⁴²

But if the connection between civil/political and economic/social rights is often overlooked in international rhetoric, it is even less apparent to nongovernmental organizations (NGOs) and community-based organizations (CBOs) in developing countries that, faced with deep structural inequalities, develop strategies to promote civil and political rights but are uncomfortable with integrating them with campaigns for social and economic rights.

In some instances this places human rights NGOs in strange dilemmas. For example, in parts of Africa, women's inequality is deeply entrenched in customary law and traditional practice. In countries where men and women cannot exercise their civil and political rights as equals, and where the burden of poverty falls disproportionately on women, some rights can become a tool in the hands of the powerful (in this case, men) that reinforces the vulnerability of the disempowered (in this case, women) to other human rights violations. For example, the right to confidentiality and privacy, when it is exercised by men in the context of inequality of women, can increase women's vulnerability to HIV infection. The guarantee of privacy can also discourage behavior changes by men that might reduce the risk to the female partner.

On this basis, some women's organizations in Zimbabwe have argued that the ethical and legal obligation of doctors and counselors to protect confidentiality further disempowers women and entrenches sexual inequality. In a recent study of vulnerability to infection, 100% of the 759 female participants reported that they had been abused by a sexual

partner, and 77.5% had an STD. But whereas 90% of the women said they would inform their partner if they had an STD, only 19% believed their partners would inform them. These inequalities translate into unequal risks of HIV infection. Thus it is that 80% of young people under 20 who are HIV-infected are women.⁴³ The implication must be that in the absence of the power to decide if, when, and how to have sex, partner notification has a different meaning for these women than it may have had in the debates that have taken place around partner notification and confidentiality in industrialized countries.

Clearly, the answer is not to discard fundamental rights to privacy or the protection of civil and political rights more generally. This would not help the many women who, the same research reveals, would not have had the power to insist on safer sex even if they had been informed of their lovers' HIV status. But the repeated postponement of massive and targeted social investment in women and the social conditions that determine their lives does leave women with a terrible vulnerability to HIV infection. Often a woman's willingness to exert her reproductive rights will depend solely upon the extent of her economic and social independence from a man. In situations of poverty-induced dependence this power evaporates. Thus, while women wait for the "progressive realization" of their social and economic rights, they are hoisted on the petard of men's greater knowledge and greater power to utilize their civil and political rights.

The modern approach to rights must therefore be all-embracing if it is not to risk making a mockery of equality. The separation of civil and political from economic and social is entirely artificial. Women's civil rights will not be attained separately from social improvement. Dignity is not just a civil construct, but also an economic one. Genuine democracy depends upon economic development and corresponding social progress. Failure to recognize this means that human rights campaigners will celebrate only Pyrrhic victories. In South Africa, for example, the civil and political rights entrenched in the Constitution have not slowed down the AIDS epidemic, because the major factor fueling the epidemic is the social conditions under which people live.

The Powers of Government?

Implicit in much of the language we use to discuss human rights around AIDS, and explicit in the international human rights documents, is the presumption that even the weakest and poorest receive some assistance from an impartial state that is capable of and interested in enforcing basic protections on behalf of its populace. This is not true, as has been recognized by the UN Committee on Economic, Social and Cultural Rights.⁴⁴ In 1994, Elizabeth Reid, addressing a meeting of the Africa Network on Ethics, Law and HIV, warned:

The response [to AIDS] in Africa to date has been based on the concept of nation states. It has *assumed* an effective reach of centralized bureaucracies and formal institutions, *including the law*. There has been no acknowledgement of their limitations because the epidemic and its response has been seen as addressable from outside by technological interventions: a drug, a condom, a test kit. There has been little thought given to *the limit of governmental action* in attitudinal and behavioral change, yet these latter lie at the heart of an effective response (emphasis added).⁴⁵

While the crisis of governance is at its most extreme in Africa, it is being experienced in other parts of the world as well. For example, Anatol Lieven has written:

Russia in the 1990s has repeated the experience of many other weak states under the lash of the free market: they have not reformed but crumbled; and the collapse of the traditional order has led neither to democracy nor to economic progress, but to the rule of corrupt elites whose effect has been precisely to stifle both real democracy and economic efficiency.⁴⁶

In the words of South African activist Zackie Achmat, "governments have become the prisoner of many different social forces."⁴⁷ Similarly, Solomon Benatar points to the disjunction between the international economy and the state:

[M]ultinational corporations, unfettered by the democratic requirement of accountability, wield great economic and political power. . . . Their formidable economic power and transnational mobility increasingly undermine the

ability of national governments to provide the legal, monetary or protective functions necessary for a well-working economy.⁴⁸

The draft Universal Declaration of Human Responsibilities represents one of the first significant departures from the state-centric approach to human rights by international leaders.⁴⁹ This declaration addresses itself to the global community and identifies the responsibility of governments, business, NGOs, and individuals to protect human rights.

But the implications of these insights about the diminishing powers of governments (which are patently obvious to people “working on the ground”) have still not been fully internalized in the realm of health or by human rights activists linked to the struggle against AIDS. Thus, when the *International Guidelines* pitch most of their recommendations at states, they imply a level of both authority and resources that many governments in Africa, Asia, Latin America, and the former Soviet Union and Yugoslavia no longer possess. Their focus on governmental obligations also risks obscuring the role and responsibility of business, which often has more control than governments over living conditions and economic development. A sustained improvement in public health is now an ideal that escapes the control of most governments, even the few that are committed to genuinely bettering public health. AIDS is thus a crude expression of modern disparities and inequalities.

This is the context in which the arguments by bodies such as UNDP and UNAIDS that governments should be more accountable, both in terms of democratic control and performance (i.e., responsibility in decision-making), must be understood. Governments are the most legitimate and potentially most democratic form of social organization that human beings have devised. But for this potential to be realized, activists must campaign to reassert the powers of governments against non-accountable “market forces” and strengthen the ability of governments in developing countries to pursue the well-being of their citizens, an impossible task in the face of crippling debt and uncontrollable currency flows.⁵⁰

The relevance of the actual power of governments vis-à-vis multinational corporations, and the impact this may have on the implementation of public health programs, including HIV prevention programs, can be illustrated with the example of Nigeria. For decades a succession of military governments in Nigeria were shored up by multinational oil companies such as the Shell Oil Company. Despite the overt corruption of these governments and their obvious lack of legitimacy among the Nigerian population, they remained responsible for the lives of 110 million people. Warnings about the possible explosive character of HIV in Nigeria appeared in the early 1990s. Until 1998, however, the first draft of Nigeria's national AIDS plan was kept secret, although it has since been published as part of the moves toward democratization under the post-Abacha regime.⁵¹

Human rights violations that arise from acts of omission, such as the failure to initiate a national program to provide information and resources for HIV prevention, ultimately reflect back not only on corrupt government officials, but also on those whose actions and policies allowed them to remain in power. If we accept this, the duty to provide a remedy for human rights violations must also extend beyond government. Since 1998 a process of democratization has taken place in Nigeria. But surely the new government should not be solely responsible for finding the resources to manage an HIV/AIDS epidemic, whose seriousness is due precisely to the collusion of multinational companies with a series of governments that privileged the interests of economic and political elites over those of the population. To what fate then does this leave the Nigerian population? UNAIDS estimates that, by 1999, there were already 2.7 million people in Nigeria living with HIV and there had been 250,000 AIDS-related deaths.⁵² What obligations are placed on the international community to combat the epidemic if the Nigerian government cannot?

Toward a New Agenda

The combination of circumstances outlined here will eventually undermine efforts to realize human rights for

people with AIDS and to reduce vulnerability to HIV infection for people whose fundamental civil, political, economic, or social rights are neglected or violated. Even though important struggles have been waged and won over the last 17 years, it has been difficult to generalize or sustain these victories at a national or international level.

Modern-day inequality, and thereby vulnerability to HIV, has become inextricably bound up with the powers of privately-owned multinationals, international capital flows, and, to some extent, the state. Finding ways to address inequalities that could not be easily challenged or removed by the use of civil and constitutional law was the leap the U.S. civil rights movement could not make. Bridging this divide will be far more difficult outside the boundaries of a single nation-state. But it is a leap that must be made by the movement for human rights in relation to AIDS.

It is sometimes asserted that to raise concerns about poverty and global inequality as issues of human rights might stretch to the breaking point what has been considered possible under this rubric. But these concerns have also begun to be expressed by many NGOs, AIDS service organizations, and developing-country governments. In 1998, South African President Nelson Mandela made a veiled attack on the global capitalist system and neo-liberal institutions when he complained that "the very right to be human is every day denied to hundreds of millions of people as a result of poverty." Mandela pointed out that "the unavailability of food, jobs, water and shelter, education, health care and a healthy environment" is "not a pre-ordained result of the forces of nature or the product of a curse of the deities." It is "the consequence of decisions which men and women take or refuse to take, all of whom will not hesitate to pledge their devoted support for the Universal Declaration of Human Rights."⁵³

The dramatic collapse of apparently booming economies in southeast Asia in 1998, and the resulting misery, underlines the importance of this critique. There are reports of the economic turndown in both Indonesia and Thailand affecting resources available for even such basic programs as screening of donated blood.⁵⁴

The Way Forward

It is one thing to recognize that a paradigm must be changed. It is another to make concrete proposals. Renegotiating Third-World debt and changing inequities in the global control of resources, production, and consumption are central to attaining human rights and dignity for all. But unlike the case of civil and political rights, it is difficult to create political mobilization around these “macro” issues. Addressing these issues will require new strategies and tactics and a willingness to critically assess and extend the model inherited by the present generation of human rights activists. Either we can argue for a broader definition of human rights, one that genuinely places social and economic rights on the same level as civil and political rights (or does away with this division entirely), or we can argue for a multi-pronged approach, stressing that fighting AIDS requires both a commitment to human rights and a commitment to greater socioeconomic equality. It is important to note that the equal stress on both factors separates us from the exponents of traditional cultural rights or “Asian values”—who would claim that the economic and social equality of a nation should take precedence over individual political and civil rights—and from liberal free-marketeers (such as the World Bank and the IMF) who insist on government adherence to civil rights while promoting policies that undermine social rights. We would put forward the following principles for discussion:

- Any definition of human rights must recognize that a core content of socioeconomic rights is fundamental to human dignity.
- The universality of rights and the worldwide presence of forces that undermine rights demand universal action. In mobilizing around the AIDS epidemic, there must be greater unity of purpose between First-World and Third-World activists and organizations. There must also be better links between organizations in the Third World.
- Campaigns must continue to focus on individual rights, but they must also seek to bring about major

shifts towards greater social, economic, and political equality, recognizing the gender dimensions within all of these factors.

- A much broader range of players must be rapidly recruited to the campaign against AIDS and its causes. Fighting AIDS requires effective alliances between those whose main commitment is to civil rights and those committed primarily to socioeconomic equality and development. For example, AIDS prevention and the call for “dignity for all” should have been a central part of the Jubilee 2000 campaign for Third-World debt relief.
- It is necessary to understand what role bodies like UNAIDS can and cannot play. Many in the present generation of human rights activists concerned with HIV/AIDS have come to expect UNAIDS to be the leader of the international campaign on human rights understood in its broadest sense. UNAIDS cannot occupy this position because it is a very small program dependent on its seven UN cosponsors and on rich donor countries, and effective advocacy requires confrontation with the existing international system. Speaking in 1998 in South Africa, Peter Piot challenged notions that “UNAIDS could behave like an NGO.” He also agreed that, while socioeconomic inequities have a huge influence on HIV prevalence in the developing world, UNAIDS “could not be about poverty alleviation,” and it is important for NGOs to campaign to put these issues on the political agenda.⁵⁵

These principles, of course, do not make the linkages between human rights and law any less important. But they remind us that the struggle to establish a nondiscriminatory legal environment is only half the battle; indeed, many of the gains of legal battles will be implemented only if other changes are achieved simultaneously. The Costa Rican victory on access to treatment, which used human rights arguments to win government funding for anti-retroviral AIDS medications for four individuals, was possible because of constitutional provisions that do not exist in the great

majority of countries. Where such constitutional provisions do not exist, they must be fought for.

It is for these reasons that we advocate a new approach to AIDS and human rights, one which more fully recognizes that HIV is inextricably entangled with basic questions of social, economic, and political justice. This is most obvious in poor countries, but it is increasingly true of the epidemics in the First World as well. The 1980s and 1990s taught us that the most effective means of HIV prevention with stigmatized groups in industrialized countries involves community development and peer education. In most parts of the world, where states tend to fluctuate between weakness and authoritarianism, and where power is often arbitrary or in the hands of multinational corporations, only major structural change can effectively control HIV and improve conditions for those already infected.

This approach does not imply that it will be impossible to do effective HIV prevention or offer care for people with AIDS without thorough social transformation. Neither does it deny the need for focused programs. But it does mean that any human rights analysis must remember that:

AIDS is compounding a vicious circle whereby socioeconomic factors create vulnerability and HIV infection then creates new inequality. This prevents the social organization and development of peoples to take their place as citizens who may actively strive for the promotion and observance of all rights.⁵⁶

Such a recognition may even mean incorporating the unfashionable terms "exploitation" and "capitalism" into the human rights discourses we embrace if we are to honestly and effectively explain and challenge the structural inequalities on which HIV thrives.

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