

HIV/AIDS AND HUMAN RIGHTS AS AN EVOLVING STRATEGY¹

Though the smallpox eradication campaign was successful, it occasionally stoked fears of a nefarious, malicious motivation. Its disregard for local structures and beliefs, occasionally heavy-handed tactics, and extensive surveillance requirements undermined the broader goals of international infectious disease control. Some people came to equate international infectious disease control with intrusions and a lack of respect.

HIV/AIDS was the next infectious disease to receive widespread international attention. The Joint United Nations Program on HIV/AIDS (UNAIDS) estimates that 33 million people worldwide are HIV-positive.² The AIDS epidemic presents one of the greatest challenges to public health systems around the world, straining national budgets and medical expertise worldwide. Not only is AIDS incurable, but it also disproportionately afflicts people in their early adult years. The very people who should be contributing to the economic, political, and social development of the state are instead falling ill and dying. This has huge social and economic cost. It also challenges governance structures and democratization processes.³

In response, the international community has taken an active role in providing access to treatment, education, and prevention programs. Its organizations provide financial resources and personnel to national governments and collect data about the disease's spread. Given the magnitude and effects of the AIDS epidemic, this is not surprising. What is surprising, though, is that, instead of predicating their actions simply on public health grounds, advocates for people living with HIV/AIDS (PLWHAs) increasingly argue that education programs and treatment access are matters of human rights. For example, UNAIDS declares,

The risk of HIV infection and its impact feeds on violations of human rights, including discrimination against women and marginalized

groups...Over the past decade the critical need for strengthening human rights to effectively respond to the epidemic and deal with its effects has become evermore clear. Protecting human rights and promoting public health are mutually reinforcing.⁴

The International Federation of Red Cross and Red Crescent Societies specifically advocates human rights as a cornerstone of its AIDS prevention programs. Protecting rights, it argues, will empower vulnerable groups to demand education, economic opportunities, and protection from violence. This, in turn, will reduce HIV transmission.⁵ Amnesty International notes that human rights abuses contribute to HIV's spread and undermine treatment efforts, and Human Rights Watch (HRW) finds that such abuses fuel transmission, which in turn leads to additional abuses and discrimination.⁶ Similarly, Physicians for Human Rights encourages medical professionals to both treat the disease and call attention to its underlying causes.⁷ In this approach, health care workers can use their public credibility to highlight violations of economic, social, and cultural rights and the ways in which those violations increase a person's vulnerability to infection.

Historically, disease containment has been more associated with "coercion, compulsion, and restrictions" than human rights.⁸ Reciprocally, diseases have not typically been the subject of human rights activism. Today's emphasis on human rights in HIV/AIDS treatment and prevention therefore represents a major and contentious shift in public health policy and human rights advocacy. Why did public health officials move away from traditional strategies and turn to human rights-based strategies for confronting AIDS? By examining these changes, we can see how the meaning of the area of human rights itself has evolved and how strong advocates in critical positions can catalyze change. It also shows how a human rights-based strategy attempts to balance the need for biopolitical surveillance for effective disease control with the desire to provide a GPG. It would far-fetched to argue that HIV/AIDS demonstrates the international community's wholesale embrace of human rights-based infectious disease control strategies, but it does demonstrate a marked shift.

Global health strategies that emphasize human rights as foundational seek to span the divide between a GPG provision and fears about biopolitical surveillance. They allow the international community to work together to combat the spread of infectious disease, but they also provide a modicum of reassurance to the people most

directly affected by the accompanying surveillance measures. A human rights-based strategy lets everyone know the basic ground rules by which the programs will operate and offer some recourse if people believe a program violates those rights. It lets people know that they will be surveilled, but that the surveillers are under international legal obligations to follow certain policies and procedures that respect and reaffirm the basic human dignity of the surveilled.

HIV/AIDS control bridges all categories of public goods. Its containment would certainly be a public good. Many of the treatment strategies, though, rely on finding mechanisms for providing private good (in this case, antiretroviral drugs) in some more public, less market-based manner. This could be through reimagining these drugs as either a club good, where access to these drugs is restricted to certain groups of people, or as a common good, whereby the drugs themselves are freely available to all but in limited quantities. A common good approach could potentially provide more people access to these drugs, but quantity restrictions could inadvertently exacerbate problems of drug resistance. A club good approach, on the other hand, requires continued and reliable access to these medicines, which either requires costly outlays for a long period of time or a domestic pharmaceutical industry (and potentially violating the intellectual property rights of other drug companies).

This chapter begins by identifying three human rights approaches to AIDS. The next section examines how advocates began promoting rights arguments against the public health orthodoxy of the mid-1980s. This effort started at the national level, led by public health officials and domestic AIDS activists particularly in the United States. It gradually worked its way up to the international level, at which point the international community promoted it to national governments around the world. As discussed in the third section, a few well-placed individuals brought rights-based approaches to AIDS to international organizations, most importantly Dr. Jonathan Mann, initial director of the WHO's Global Program on AIDS (GPA). Mann's advocacy faced stiff opposition from WHO bureaucrats imbued with traditional public health attitudes, but the battle in this key international organization helped inform the world about the advantages of integrating human rights into AIDS policy. In this context and under pressure from their own AIDS advocates, key states began adopting their own rights-based policies concerning the disease in the early 1990s, as discussed in the following sections on Brazil and South Africa. By the mid-1990s, conventional human

rights NGOs, initially reluctant to embrace AIDS as a rights issue, also began changing their attitudes.

EARLY RESPONSES TO AIDS

When AIDS emerged on the public health scene in 1981, many of the initial proposals and policy responses emphasized overt surveillance, ostracism of the infected and those perceived to be at risk, and the potential use of quarantine. Fear motivated many of these discussions, as scientists and doctors were initially uncertain as to the disease's cause and means of transmission. As a result, policy responses proceeded from a perspective of being "under siege by an unrelenting, devastating, and somewhat unfathomable enemy."⁹ The American government introduced measures that required various groups to submit to mandatory HIV testing as a condition of employment—immigrants, ROTC students, Job Corps members, military personnel and recruits, Peace Corps members, and members of the Foreign Service.¹⁰ Some states stipulated that applicants for marriage licenses take a blood test for HIV and test negative for it. Going to the extremes, U.S. Senator Jesse Helms proposed a bill in 1987 that would mandate widespread and mandatory HIV testing and require quarantine for HIV-positive persons. "We did it [quarantine] back with quarantine, did it with other diseases, and nobody even raised a question about it," he asserted during a television interview.¹¹ William Bennett, the U.S. Education Secretary, concurred with Helms and argued that HIV-positive prisoners "who make threats to spread the disease" should have their sentences extended indefinitely.¹² While neither proposal officially became law, at least a dozen state governments isolated people with HIV "whose behavior posed a risk."¹³

Such responses were not confined to the United States. European countries like Sweden, Germany, and France threatened HIV-positive persons with jail time for failing to disclose their status to sexual partners or for failing to adhere to treatment regimens.¹⁴ The German state of Bavaria went even further, screening members of "high-risk groups" for AIDS simply by virtue of their group membership. This requirement initially targeted prostitutes and intravenous drug users, but later expanded to include applicants for civil service positions, foreigners from non-European Union countries seeking resident status, and prisoners.¹⁵ Some countries specifically tested foreign scholarship students, deporting those who tested positive. Baldwin describes the logic of these tests: "to keep scarce resources for those most likely to make productive use of them."¹⁶

Oftentimes, these tests specifically targeted students coming from sub-Saharan Africa.

Authorities in Iceland and Switzerland could place HIV-positive persons under house arrest for engaging in unsafe sexual practices, and some Canadian provinces mandated the quarantining of AIDS patients (and, in some instances, their contacts).¹⁷ The Cuban government instituted a formal quarantine program for AIDS patients¹⁸. The 1988 Public Health (Infectious Diseases) Regulations in the United Kingdom went so far as to ban wakes and open caskets for those who died of AIDS.¹⁹ The Kenyan government, for example, rounded up 275 women in 1986 on suspicion of prostitution and forced them to submit to HIV tests. If the test came back positive, they were subject to criminal prosecution.²⁰ The South African government initially saw AIDS as a tool for furthering and legitimizing apartheid. In a debate in Parliament in 1990, a Conservative Party member of parliament alleged that the ruling National Party was telling white South Africans not to worry about majority rule because "AIDS will be responsible for the large-scale elimination of the Black population, to such an extent that Blacks will in reality become a minority in South Africa within five years."²¹ Dr. E.H. Venter, the Minister of National Health and Population Development, denied these accusations. She responded that it was actually the Conservative Party that was at fault. She quoted Conservative Party Member of Parliament Clive Derby-Lewis, who stated, "If AIDS stops Black population growth, it would be like Father Christmas."²²

Some African governments, while conducting their own surveillance programs, perceived an intense and prejudicial surveillance being used against them by Western states. In the late 1980s, Kenyan officials bemoaned the loss of foreign direct investment and tourism because of the association between Africa and AIDS.²³ Focusing surveillance efforts on Africa reinforced the perception that it was a diseased continent that others should avoid. This, in turn, further dampened their economies and drove them deeper into debt. Thus, from the perspective of the Kenyan government, international surveillance had a very real and tangible economic cost.

With these policies, surveillance specifically singled out those deemed to pose a risk to the greater community. They marginalized and stigmatized members of particular groups merely for their group membership regardless of individual characteristics. In so doing, they often discouraged open discussion about appropriate responses to AIDS and dissuaded people from seeking out whatever therapeutic services might have been available. Surveillance became a tool of

oppression and persecution. Because of that, public health officials and policymakers lacked crucial information about the nature and scope of the disease's spread—information that could have assisted with crafting rational policy responses and encouraging people to seek out treatment options in a timely manner.

DEFINING A HUMAN RIGHTS APPROACH TO AIDS

What do human rights mean in the HIV/AIDS context? In the early days of the epidemic, advocates invoked human rights to argue against detention and isolation of those suffering from AIDS. Later, the rights frame was expanded to include equal access both to education about AIDS transmission and to palliative and later recuperative treatments. More recently, some activists have promoted a broader rights approach, demanding reductions in poverty and social inequality, which are seen as major risk factors for HIV infection.

These three approaches to human rights in the HIV/AIDS context are not mutually exclusive, but they have different policy emphases. The first two—opposition to detention and isolation, and equal access to education and treatment—reflect a pragmatic way of combating AIDS. Their advocates did not necessarily have an attachment to human rights *per se*. Instead, they saw rights norms as tools for effectively addressing the epidemic. For instance, when governments began placing HIV-positive persons into isolation and indefinite detention, advocates argued that such action frightened people away from testing and treatment, thereby spreading the disease.²⁴ To support these arguments, activists also appealed to human rights principles against arbitrary detention and restrictions on free movement, which are both part of the Universal Declaration of Human Rights (UDHR) and the International Covenant on Civil and Political Rights (ICCPR). Similarly, activists invoked the rights to information and education as a basis for disseminating basic facts about the disease, its spread, and treatment. Simple as these measures seem, implementing them often meant confronting deep aversions to openly discussing sexual practices (including homosexuality) and intravenous drug use. It also meant reaching out to marginalized communities such as commercial sex workers. Rights arguments provided an important basis for overcoming these societal taboos.

The third meaning of human rights in the AIDS context represents a further shift in thinking. Using rights language and treaties, it calls for fundamental socioeconomic changes to reduce vulnerability to exploitation and disease. For instance, instead of promoting informational campaigns about AIDS prevention and treatment, this

approach seeks to alter the social conditions placing people in peril of infection. Dr. Paul Farmer, a physician and medical anthropologist who teaches and practices both at Harvard Medical School and in Haiti, is one of the most vocal advocates of this position. The NGO he founded, Partners in Health, uses human rights arguments to challenge the “structural violence” that increases individual disease risk. In this view, “HIV transmission and human rights abuses are social processes and are embedded, most often, in inegalitarian social structures.”²⁵ Thus, human rights norms are not just tools for reducing AIDS but a foundation for achieving health for all.

In an essay published after his death in 1998, Jonathan Mann wrote, “[F]or the first time in history, preventing discrimination toward those affected by an epidemic became an integral part of a global strategy to prevent and control and epidemic of infectious disease.”²⁶ With this recognition, international programs to combat the spread of AIDS paid special attention to issues of discrimination and social vulnerability. Instead of focusing solely on individuals, these programs began to integrate a social dimension. They looked at issues of vulnerability within a broader context. Instead of assuming that members of certain groups faced a higher risk of infection, they asked *why*. Traditional public health strategies often see disease epidemics as dynamic events within a static societal arrangement.²⁷ This new awareness of discrimination and human rights instead saw disease epidemics as dynamic events within potentially changeable societies and sought to understand the societal fault lines that allowed for the disease’s spread.²⁸

Proponents also argued that a human rights approach was superior to one based on individual behavior change because it better understood human motivations and realities. An exclusive focus on *individual* behavior obscures the role of social relations and forces that influence behavior in the first place.²⁹ Acknowledging the relationship between AIDS and human rights “means taking full account of the very real difference that shape our lives, while giving full respect to our common humanity.”³⁰ Social factors so profoundly influence personal behavior that separating them is impossible. By the same token, any program designed to combat AIDS will be created within and constrained by larger social forces that inevitably influence their reception. Instead of focusing on personal behavior, we should understand societal vulnerability, or the contextual factors that define and constrain personal and programmatic vulnerability. We cannot understand “high-risk” behaviors or why some individuals engage in them without understanding the social context in people and groups find themselves. A human rights approach takes this into account by

offering a framework for understanding expectations and deprivation. This recognition forced programs to shift tactics, broaden their scope, and reconceptualize how they approached risk reduction.

The question remains, why does societal vulnerability increase the risk of contracting HIV? Mann et al. argue that states rarely recognize health problems that afflict socially marginalized groups and offer these groups few (if any) health services.³¹ What's more, violating the human rights of a group through discrimination or the denial of necessary information almost inevitably has a negative impact on health. The AIDS epidemic exposes the fractures and strains that exists within societies and demonstrates the links between poverty and disease. Denying the dignity of the members of a group also violates the standards set forth in the UDHR.³² "The mutual interdependence of public health and human rights is becoming increasingly clear. Substantial progress in resolving public health problems will require improvements in respect for human rights and dignity. Similarly, improvements in health create conditions which favor the full enjoyment of human rights and dignity."³³

Finally, some have argued that embracing a legalistic human rights framework reflected the political realities of the international community. Political discourse, especially those in the United States, does not offer much space for addressing questions of social and economic inequalities. However, space may exist for addressing these issues through the framework of human rights and the legal obligations established by signing various international treaties. Government leaders understand discourse about rights, though they may not understand discourse about structural violence and widespread inequality. In such a case, a human rights framework could provide a backdoor way to address issues of social vulnerability without explicitly acknowledging them.³⁴ However, the United States actively prevented the integration of human rights into AIDS prevention programs in early stages of such programs. In the late 1980s, American officials opposed what they perceived as the "politicization of UN specialized agencies, especially WHO."³⁵ For these officials, resolutions that specifically protected the rights of people with AIDS did just that. Rumors began to circulate that the United States would withdraw its financial contributions to the WHO if the GPA took too strong a stance on AIDS and human rights.³⁶ The United States and Saudi Arabia both vigorously opposed any resolutions, which would strongly condemn discrimination against people with AIDS because of fears that it would set a "dangerous precedent by linking health and human rights issues."³⁷ This early

experience demonstrated some of the resistance to linking AIDS and human rights.

Over time, though, awareness of the links between human rights and AIDS grew, and international organizations started to explicitly recognize this connection. Many of these resolutions and actions were rooted in the UDHR. Though not a legally binding document, actions taken by international organizations and individual states have given it a great deal of international legitimacy.³⁸ The UDHR itself does not explicitly guarantee a right to health. Within the UDHR, though, many of the articles can be interpreted in such a manner that connects the provision of health care with human rights. Article 26, Section 1 of the document guarantees that everyone has the right to an education, whereas Article 19 states that everyone has the right to receive and impart information and ideas through any media. Many persons have seized upon the languages in these two articles, arguing that these include the public health information contained within AIDS education programs. AIDS prevention programs cannot effectively operate if governments restrict the information available to their citizens about disease treatment and avoidance. Similarly, many have argued that Article 9, which bans arbitrary detentions, directly contradicts the use of forced isolation or quarantine without recourse to the court system.³⁹ More significantly, advocates for connecting AIDS and human rights point to Article 25, Section 1 of the UDHR. It reads, "Everyone has the right to a standard of living adequate for the health and well-being of himself and his family, including food, clothing, housing, medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age, or other lack of livelihood circumstances beyond his control." This passage does not unambiguously argue that people have a right to *health* per se. It does, however, intimate that people require a certain level of health in order to appreciate and take advantage of their rights as humans. If human rights specify the minimum requirements for a satisfactory life, then this passage implies that health care is necessary for achieving those minimum requirements. Within these interpretations of the UDHR, the advocates for a more robust response to AIDS found support for their programs as basic human rights. Governments need to provide health care to HIV-positive persons, allow AIDS prevention education campaigns, and ensure access to information about transmission and protection—not as a matter of public health, but as a matter of human rights. In this view, failure to do so constitutes a human rights violation.

Building off the rights enunciated in the UDHR, numerous later human rights documents and international treaties explicitly guarantee the right to health. These include the 1961 European Social Charter, the 1966 International Covenant on Economic, Social, and Cultural Rights, the 1981 African Charter on Human and Peoples' Rights, the 1985 United Nations Convention on the Rights of the Child, and the 1988 Additional Protocol in the Area of Economic, Social, and Cultural Rights to the American Convention on Human Rights, among others. While these later treaties do call for an explicit right to health, prominent advocates of a human rights-based approach to AIDS like Jonathan Mann and Peter Piot, the executive director of UNAIDS from 1995 to 2009, identify the UDHR the foundation for their advocacy. The UDHR set the stage upon which these later documents were built, so they root their advocacy of human rights in this earliest document.

Between 1987 and 1990, nearly every UN agency took some action on limiting the spread of AIDS and its impact on societies and individuals.⁴⁰ These efforts ranged from eliminating HIV tests as a precondition for employment with the agency to calling upon governments to respect the human rights of those with HIV. The World Summit of Ministers of Health adopted the London Declaration on AIDS Prevention in late January 1988. The London Declaration calls on all states to educate their citizens about AIDS, facilitate the free exchange of accurate information about the disease and its spread, and protect the human rights and dignity of HIV-positive persons. This document explicitly recognizes the connections between human rights and AIDS and justifies the connection through international human rights treaties. The WHA, an annual meeting of WHO member-states, passed a resolution May 13, 1988 against discrimination against people living with HIV and AIDS. The United Nations General Assembly passed resolutions in 1990 and 1991 calling upon all nations to respect human rights as an integral aspect of their campaigns to prevent the spread of AIDS.⁴¹ The UN Commission on Human Rights appointed a Special Rapporteur in 1990 to focus solely on issues of discrimination and human rights abuses related to HIV infection status.⁴² These early actions all highlighted the connection between discrimination, marginalization, stigmatization, and a lack of respect for human rights on the one hand and heightened vulnerability to health problems like HIV on the other.⁴³

In 1998, the United Nations' Office of the High Commissioner for Human Rights and UNAIDS released a set of 12 international guidelines for states for incorporating human rights into their national AIDS prevention strategies. These guidelines crystallize ideas about the connections between AIDS and human rights into concrete policy

actions for governments to implement. The guidelines suggest that member-states:

1. Establish effective national frameworks to coordinate and implement HIV/AIDS policies and programs.
2. Develop community partnerships and consulting with community groups in all phases of policy design, implementation, and evaluation.
3. Ensure that national public health laws are consistent with international human rights law and not applied to HIV/AIDS in an inappropriate manner.
4. Ensure that national criminal laws and penal systems are consistent with international human rights law and not applied to HIV/AIDS in an inappropriate manner.
5. Enact and strengthen antidiscrimination laws to protect PLWHAs.
6. Regulate HIV-related goods and services to ensure high quality and affordable prices.
7. Implement legal support systems to educate people about their rights regarding HIV and develop expertise on HIV-related laws within appropriate government offices.
8. Promote a supportive environment for women, children, and vulnerable groups, and collaborate with them in setting and implementing policy.
9. Use creative education techniques and the media to change discriminatory attitudes and eliminate stigmatization.
10. Work with the private and public sectors to develop and implement codes of conduct regarding HIV/AIDS that put human rights principles into practice.
11. Monitor and enforce the protection of human rights for PLWHAs.
12. Cooperate through the United Nations and UNAIDS to share information and provide mechanisms for protecting human rights.⁴⁴

This 12-point framework offers a comprehensive and wide-ranging set of recommendations, especially given the relative lack of experience of most international public health agencies and most international human rights organizations in working with one another. This framework went beyond simple resolutions and provided more concrete strategies for actually implementing the ideas contained in the various resolutions previously passed. It not only represented the collective will of the international community, but also offered the

international community the necessary tools to put their ideas into practice. It provides for surveillance, but within limits that still allow for the provision of this global public good.

Crafting this framework was no easy task. Those advocating a link between AIDS and human rights faced intense skepticism from public health officials, who perceived human rights as irrelevant to health concerns and too far outside their realm of expertise, and human rights organizations, which lacked experience with health concerns and were unsure if it fell under their purview. To achieve successes like the 12-point framework above, advocates had to show that traditional public health strategies were actually counterproductive for treating AIDS, craft a convincing rhetoric to link two seemingly unrelated concepts, and demonstrate the efficacy of such a connection.

FAILURES OF TRADITIONAL PUBLIC HEALTH STRATEGIES

Public health strategies for containing communicable disease like isolation and quarantine traditionally placed little emphasis on human rights. Isolation refers to separating those who are exhibiting signs of illness from the rest of the population. Quarantine functions more as a preventative measure. It involves separating those exposed to a disease from the rest of the population, even though they may not be exhibiting any signs of illness. If individuals infected with or considered susceptible to a disease, they are separated from the rest of the population in hopes of preventing the further spread of the disease. Although such strategies have certain logic, their implementation has traditionally ignored individual rights. Fidler notes, “Historically speaking, infectious disease control measures have never been kind to individuals. Quarantine practices had long been notorious for their ill-treatment of and cruelty to travelers.”⁴⁵ Quarantine strategies often reflected popular prejudices and were applied in an arbitrary manner. Dispossessed and “undesirable” groups were often blamed for the spread of disease, as they were thought to be “dirty.”⁴⁶ This then gave officials license to forcibly remove groups from cities and institute discriminatory measures. Historically, for example, the spread of bubonic plague was blamed variously on Jews, Roma, Africans, and Asians. As a result, members of these groups were forced from their homes, had their possessions burned, lost their jobs, and were barred from traveling—all in the name of protecting public health.

During these early years of the AIDS pandemic, little international coordination on containing the spread of HIV existed. Most

campaigns focused solely on informing the public how HIV was (and was not) transmitted. Widespread fear and misinformation inhibited international coordination, as few states were willing to take an active role on an issue that was largely framed as one of individual responsibility and morality. Human rights were not even on the agenda initially.

This changed in the mid-1980s as activists and officials started to argue that existing policies failed to stop the epidemic's spread and perhaps even exacerbated it. In this view, threats of quarantine, isolation, and discrimination made people unwilling to be tested or counseled.⁴⁷ In the United States in particular, activists took to the streets to challenge government policies that promoted stigmatization of HIV-positive persons. AIDS Coalition to Unleash Power (ACT-UP) took the lead in these demonstrations. Founded in 1987 in New York largely by gay activists, ACT-UP channeled the frustration many HIV-positive persons felt about the lack of public education and treatment options available to them. The group took nonviolent direct actions to call attention to the plight of those with AIDS and to humanize its victims.⁴⁸ ACT-UP sought to counter American politicians such as Jesse Helms, who introduced legislation to deny funds for safer sex education programs aimed at gay men, and journalists such as William F. Buckley Jr., who called for tattooing the buttocks of HIV-positive gay men and the arms of HIV-positive IV drug users.⁴⁹ ACT-UP charged that government policies failing to protect rights, provide accurate information, or offer effective treatments were genocidal.⁵⁰ The group also agitated for a quicker review process for AIDS drugs.

In response to this activism, public health policies in the United States and elsewhere slowly changed, with punitive and discriminatory elements replaced by policies that respected individual rights and liberties. Notably, however, this shift occurred for pragmatic reasons—to better stem the epidemic—not because of an ideological commitment to human rights.⁵¹ Moreover, neither the public health nor the human rights communities uniformly welcomed this new approach. Elements within both communities greeted calls for connecting AIDS and human rights with skepticism or hostility. The next two sections highlight the battles within each.

PUBLIC HEALTH BATTLES OVER AIDS AS A HUMAN RIGHTS ISSUE

While traditional public health strategies do not necessarily emphasize respect for human rights, certain public health officials were

among the most forceful proponents of integrating human rights into AIDS prevention work. This clash led to significant discord within the public health community. These disagreements played themselves out at the international level through the experiences of Jonathan Mann and the GPA.

The international community initially reacted to AIDS with apathy. Because it was first discovered in the United States and other Western states, many observers believed that AIDS was a disease of the rich and largely confined to these states.⁵² Some in the international community even expressed relief that the disease emerged in these states. An internal WHO memo from 1983 on AIDS argued that the WHO did not need to involve itself in the issue. AIDS, its author noted, “is being very well taken care of by some of the richest countries in the world where there is the manpower and know-how, and where most of the patients are to be found.”⁵³ Between 1981 and 1985, scientists scrambled to find the causative agent of AIDS and understand how the disease was transmitted, while paranoia and discrimination grew. Many public health officials saw AIDS as another infectious disease that could be addressed using traditional public health strategies for disease containment like quarantine and isolation.

Between 1985 and 1990, a shift occurred toward a period of “global mobilization.”⁵⁴ The international community discovered not only how widespread the disease was but also how vital international cooperation was for effectively combating the disease. Instead of being associated with wealth, AIDS quickly became associated with poverty as more and more cases were discovered in developing states.⁵⁵ Discussions about an international response to AIDS formally began in April 1985 when the WHO held a special consultation about how best to respond to the disease. The following year, the WHO declared AIDS to be a global health priority and committed the WHO’s resources to combat AIDS.⁵⁶ The WHO began some programs devoted to HIV and AIDS in the mid-1980s, but it quickly became obvious that an international response to the disease required a more coordinated effort. In February 1987, the WHO officially launched the GPA.

The GPA’s initial approach to AIDS largely followed traditional public health approaches used to fight infectious diseases such as cholera and smallpox. It encouraged states to develop national AIDS programs and sought donations from developed states to target states that were especially in need of assistance. Within a year of the program’s founding, 170 countries requested assistance in forming and coordinating the activities of their own national AIDS programs. The

GPA initially provided technical and organizational guidance and small amounts of funding (less than \$1 million) to 151 countries.⁵⁷ Starting with a small budget and one secretary, Mann eventually turned the GPA into the WHO's largest single project with a staff of more than 200 persons under his leadership.⁵⁸

The story of Dr. Jonathan Mann's tenure at GPA embodies the conflicts over how best to address the AIDS epidemic. Upon GPA's founding in 1987, Mann was appointed to lead the organization. Mann came to GPA after directing AIDS programs in Zaire and was widely respected for his medical skills and charisma. His experiences in Zaire convinced him that treating AIDS required compassion and respect, not discrimination and stigma. Upon joining GPA, Mann immediately started meeting with government officials and members of the press from around the world to raise the profile of GPA and encourage the active involvement of as many states as possible. Mann's personal diplomacy, for example, inspired the Swedish government to increase its voluntary donations to GPA from \$1.8 million in 1986 to \$10.5 million in 1987.⁵⁹ Mann's efforts received widespread praise not just for elevating AIDS to a high place on the international agenda but also for putting WHO back on the international map. While his actions won praise from many, Mann also invited jealousy among his colleagues in less well-funded WHO programs.⁶⁰

Because GPA was housed entirely within the WHO, its approach initially adopted traditional public health strategies. These were the techniques with which the WHO was familiar, and few saw any reason to deviate from them. Mann, though, started to argue publicly that any AIDS prevention efforts needed to place respect for human rights front and center—even though this might deviate from traditional strategies. Tensions rose within the organization. The original three objectives of GPA's global AIDS strategy were to prevent HIV infection, reduce the personal and societal impacts of HIV infection, and mobilize national and international efforts to combat the disease. In 1991, GPA undertook an effort to assess the applicability of these objectives to the epidemic as it was then unfolding. While not rejecting its original objectives, GPA added six clarifying points: emphasizing adequate health care coverage, expanding treatment for STDs, reducing women's vulnerability to infection through increased education, eliminating cultural and social impediments to discussing matters of sexuality, planning for the anticipated socioeconomic impact of AIDS, and communicating the public health rationale for eliminating discrimination against those with HIV.⁶¹ This list shows the tension between traditional public health strategies on

AIDS and new strategies that emphasize human rights. Traditional strategies focusing on individual risk reduction play a prominent role, but the GPA called for access to information and socioeconomic changes that allow people to realize their full range of human rights. The human rights framework was working into GPA's arsenal, but it uncomfortably shared space with other strategies. Mann's personal pragmatic interest in human rights as an AIDS prevention strategy often clashed with the WHO leaders who oversaw the program and believed in the traditional strategies.

Tensions over the appropriateness and relevance of human rights to AIDS increased in 1988 with the election of Dr. Hiroshi Nakajima as the director general of WHO. Nakajima had previously served as the regional director for the Western Pacific and the chief of Drug Policies and Management unit at WHO. He was also viewed as a more traditional and conservative leader—a contrast to his predecessor, Dr. Halfdan Mahler, an advocate of the “Health for All by 2000” strategy.⁶² Nakajima and Mann quickly clashed over GPA's organizational autonomy vis-à-vis WHO and how best to raise and spend GPA's funds.⁶³ They disagreed about the prominence given to GPA relative to other WHO programs, GPA's embrace of nontraditional tactics, and GPA's embrace of projects that fell outside traditional public health bounds. Mann and Nakajima also clashed over access to AIDS drugs in developing states. Nakajima called for a retrenchment of GPA's budget and activities and cut the organization's budget by \$35 million in 1990 when donations to the program fell short. He also resisted Mann's efforts to broaden the focus of GPA to encompass issues of human rights and delayed or cancelled joint initiatives between GPA and other UN organizations.⁶⁴ The constant squabbling undercut GPA's effectiveness, as outsiders could not be certain that GPA initiatives would actually be implemented.

The disagreements eventually became too much for Mann. In March 1990 he resigned as the head of GPA. In a strongly worded letter to Nakajima, Mann noted, “There is a great variance between our positions on a series of issues which I consider critical for the global AIDS strategy.”⁶⁵ He lambasted Nakajima's attitude, stating, “Dr. Nakajima's attitude is that AIDS is not such a big problem. The figures say otherwise.”⁶⁶ Mann's replacement, Dr. Michael Merson, had previously headed the Diarrheal Disease Control and the Acute Respiratory Infections Control programs of WHO. He, like Nakajima, was viewed as more of a traditionalist but was faulted for his lack of imaginative leadership.⁶⁷ His tenure at GPA's helm coincided with a period of complacency. Contributions to GPA, and AIDS programs

in general, plateaued, as donor states showed little inclination to continue to support the efforts of GPA. Rumors also circulated during Merson's tenure that top WHO officials ordered GPA staffers to remove quotations from and references to Mann in its materials. The campaign, which Merson vigorously denied, sought to exorcise Mann's influence and bring the GPA back in line with other WHO programs.⁶⁸

Many of the conflicts over the appropriate response to AIDS came to a head at the Eighth International Conference on AIDS, held in Amsterdam in 1992. Press reports noted a severe fissure between competing camps. On the one hand, Merson and his allies argued that the international AIDS control regime should focus its energies on promoting condom usage and treating venereal disease. By encouraging changes in behavior, they argued, the disease could be stopped. Mann led a competing faction, arguing that the fight against AIDS required an all-out assault on discrimination and inequality because it was these two factors that gave rise to the epidemic in the first place.⁶⁹ An emphasis on behavioral change assumes that those infected with HIV have willingly entered into the behaviors that exposed them to the virus. Those advocating a human rights-based approach countered that poverty and inequality put people in positions in which they could not freely exercise the choice to avoid putting themselves in harm's way.

In the 1990s, Mann and his followers continued their efforts through publishing, speaking, and lobbying governments to recognize the link between AIDS (and other health issues) and human rights. In 1993, Mann helped launch the Francois-Xavier Bagnoud Center for Health and Human Rights at Harvard University, the first academic center with such a focus. The following year, he cofounded *Health and Human Rights*, a journal that speaks to both academics and practitioners interested in the issue. These platforms allowed Mann to maintain his public advocacy, eventually winning over some of his foes. For instance, by 1993, Merson was calling for AIDS prevention programs that recognized and respected human rights.⁷⁰ In 1998, Mann died in an airplane crash en route to Geneva to consult with UNAIDS officials. Obituaries and remembrances highlighted Mann's efforts to call attention to human rights and public health. One noted that the Harvard School of Public Health gave its graduates a copy of the UDHR along with their diplomas at his suggestion.⁷¹

Ultimately, Mann's rights-based approach to AIDS prevailed at the international level. At the 1994 World AIDS Summit in Paris,

delegates agreed to disband GPA and replace it with UNAIDS. This new organization combined the resources and expertise of various organizations within the UN system to coordinate international AIDS programs, with human rights approaches as a central strategy.⁷² This rights-based approach remains dominant today.

HUMAN RIGHTS ORGANIZATIONS AND THE BATTLES OVER AIDS

Linking human rights and AIDS control was not easy. WHO traditionalists were not the only ones resistant. Major international human rights organizations such as Amnesty International and HRW initially expressed skepticism at including AIDS, or any international infectious disease control campaign, within the pantheon of human rights issues. Writing in 1992, Gruskin and colleagues, specifically chastised human rights NGOs for failing to involve themselves with HIV/AIDS issues. They argued that this undermined attempts by public health officials to encourage governments to take seriously the human rights of those with HIV. Without the public campaigns in which human rights NGOs frequently engage, international organizations lacked neutral, nongovernmental sources about country practices toward AIDS patients. Local AIDS service organizations tried to fill this gap, but they rarely had the resources or expertise to provide this information effectively.⁷³ Seeing little action on AIDS from established human rights NGOs, Mann called for the creation of “an Amnesty International-style organization for people who are discriminated against because they have [AIDS].”⁷⁴

Major human rights organizations like Amnesty International and HRW initially shied away from HIV/AIDS because it was too distant from their previous campaigns and strategies. Amnesty International’s mission, for instance, largely focused on political and civil rights violations against particular individuals. Protecting human rights in the context of AIDS fell too far outside its mission. Not only did AIDS affect large numbers of people, but also its human rights implications centered primarily on social and economic rights.

It was not until 2001 that Amnesty International broadened its organizational mission to include abuses of economic, social, and cultural rights. With this change, the right to information and freedom from discrimination came under Amnesty’s purview.⁷⁵ Amnesty situated its AIDS efforts within its broader campaign to promote health as a human right. This includes instrumental efforts in linking human rights and AIDS, such as ensuring access to accurate information and

expanding treatment options. It also includes broader efforts to combat social and economic disempowerment.

HRW has long focused its energies on major violations of established political and civil rights. Concerns about social vulnerability to disease did not fit within this framework. By 2002, though, HRW's attitude changed, and the organization established a program to document human rights violations based on HIV status, advocate for legal protections for HIV-positive persons, and produce research on AIDS-related human rights abuses.⁷⁶ Part of the motivation for instituting such a program arose from a new appreciation for the indivisibility of human rights. Though AIDS-related rights abuses generally arise from violations of economic, social, or cultural rights, HRW now holds that these rights are mutually reinforcing with the political and civil rights with which they have traditionally been concerned.⁷⁷ Violations of human rights fuel HIV infection and a person's HIV-positive status can lead to further human rights violations. Sexual violence and lack of information can spread the virus, and those infected with the virus may then be subject to discriminatory laws and social stigma. Joseph Amon, the head of HRW's AIDS campaign, writes, "Because human rights abuses fuel the HIV epidemic, HIV/AIDS programs must explicitly address, and find ways to mitigate, these abuses."⁷⁸ By drawing on its expertise documenting and exposing human rights violations, HRW has found a role for itself in combating HIV/AIDS.

Despite their recent inclusion of AIDS within their missions, human rights organizations have faced continuing criticism. Paul Farmer has been the most outspoken, excoriating NGOs such as Amnesty International and HRW for being too conservative. He calls their approach overly legalistic, ignoring the daily realities of the vulnerable populations whom they are trying to help. New laws or treaties are rarely enforced, and they cannot help people find jobs, take control of their bodies, or be integrated into the larger national community. Compiling reports and holding press conferences will do little to change the fundamental economic, political, and social dislocation that makes a population vulnerable to HIV infection in the first place. These tactics, Farmer explains, are too passive and do too little to reduce "structural violence" in societies.⁷⁹ To use a medical analogy, Farmer charges human rights NGOs with constantly treating symptoms without addressing the underlying disease.

Recent developments suggest that human rights NGOs may be heeding Farmer's criticisms. For example, Larry Cox, who took over as the executive director of Amnesty International USA in May 2006,

has pledged to better integrate social and economic rights with the organization's traditional focus on political rights.⁸⁰ Farmer, for his part, seems cautiously optimistic about Cox's pledge, but he has also worked to empower new human rights NGOs.⁸¹ He serves on the board of directors of the National Economic and Social Rights Initiative (NESRI), a new human rights organization that works to realize human rights to health and education. He sees NESRI as a tool for challenging the "orthodoxy in health and human rights" by fostering the development of a more expansive human rights culture.⁸² As a new organization, NESRI may also lack the institutional structures of more established human rights NGOs and therefore be in a better position to adapt its programs to integrating health and human rights.

AIDS AND HUMAN RIGHTS IN PRACTICE

The international community transmits and diffuses its ideas to national governments. As international organizations came to see the wisdom of human rights-based strategies to combat HIV/AIDS, they encouraged national AIDS control programs to adopt this framework. Brazil and South Africa provide two examples in which organizations used a human rights perspective to encourage and promote provision of the GPG of AIDS control. In both cases, grassroots organizations rallied public support and attracted international attention by calling for their governments to respect human rights as part of the AIDS fight. Interestingly, AIDS activists in both countries had participated in national democratization movements and applied the techniques they had learned to their new cause. Both show how drawing on international human rights can strike a balance between providing public health services and maintaining oversight.

Brazil

After years of military rule, democracy returned to Brazil with the adoption of a new constitution in 1988 and the inauguration of a democratically elected president in 1990. One of the major players in the prodemocracy movement was the "sanitary reform movement." This loose affiliation of health care workers and academics promoted health as a human right. Thanks in part to this group's activities, Brazil's 1988 democratic constitution recognized health as a fundamental individual right and charged the government with ensuring it. The constitution also called for an active and ongoing dialogue

between the government and civil society groups on how best to uphold human rights.⁸³

Using this legal framework and the lessons learned through the prodemocracy movement, PLWHAs have formed numerous legal aid groups. These groups ensure that HIV-positive persons know their rights, how to obtain treatment, and where to go if they experience discrimination. The legal aid groups have also pressured Brazilian public health officials to treat AIDS as a human rights issue.⁸⁴ More broadly, Brazilian AIDS policy has moved beyond a focus on individual behavior to address the larger social context in which people make decisions about sexuality.⁸⁵ Many programs now recognize that the socially vulnerable may make different decisions regarding sexuality than the privileged. Finally, some of the local NGOs have been active in international meetings and networks.⁸⁶

The success of local AIDS activists is most apparent regarding provision of antiretroviral drugs (ARVs). ARVs have shown remarkable promise in treating HIV-positive persons, prolonging and enhancing lives. However, these drugs are expensive. When first released in the 1990s, one year's supply cost more than \$10,000—too expensive for most Brazilians. Activists pressed pharmaceutical companies to reduce prices and encouraged the government to produce generic versions under a compulsory licensing scheme. Significantly, the campaign framed access to ARVs as a human right. In this view, to uphold the constitutionally guaranteed right to health, the government needed to ensure that all Brazilians had access to these drugs, regardless of their ability to pay.⁸⁷ To make this argument, activists sued the Brazilian government for free and universal treatment. They achieved their goal in 1996, and the government has remained committed to providing ARVs ever since—despite pressure from the World Bank to abandon the policy.⁸⁸ This has had broader repercussions. Free AIDS treatment demonstrates to marginalized groups that the government cares about them, increasing their use of all forms of preventative health care.

South Africa

In South Africa, activists, most prominently the Treatment Action Campaign (TAC), have incorporated human rights into the AIDS fight. TAC was founded on December 10, 1998 (International Human Rights Day) with a mission of building a racially diverse, grassroots movement to gain greater access to ARVs. The group's founders initially believed that their primary target would be the

multinational pharmaceutical companies that produce ARVs. However, after the government refused to make ARVs available despite a Constitutional Court ruling that compelled it to do so, TAC began to focus its energies on changing government policies.⁸⁹

Many TAC activists derive inspiration from their backgrounds in the antiapartheid movement. Zackie Achmat, the group's founder and chairperson, cites Nelson Mandela as his model.⁹⁰ Prior to founding TAC, Achmat directed the AIDS Law Project and established the National Coalition for Gay and Lesbian Equality (NCGLE). Working with the African National Congress (ANC) in the early 1990s, Achmat helped ensure that sexual orientation would be included in South Africa's postapartheid Bill of Rights.⁹¹ These experiences not only provided Achmat with knowledge of the antiapartheid movement but also fostered a network of committed activists who shared these understandings.

TAC draws heavily on the antiapartheid movement, using similar language, symbols, and songs.⁹² The group uses such tactics as civil disobedience, mass protests, and litigation in an effort to put pressure on the national government. These public actions further TAC's mission of educating South Africans about their rights in the context of AIDS.⁹³ Drawing on the legacy of the antiapartheid movement also increases TAC's legitimacy and allows the group to counter accusations that it is unpatriotic or "un-African."⁹⁴

With the ANC-led government being sensitive to charges of rights abuses, TAC has brought legal cases charging violations in such venues as the Constitutional Court, Human Rights Commission, and Commission on Gender Equity. The cases are grounded in part in the human rights guarantees contained in the South African Constitution and Bill of Rights. These documents charge the government with specific positive obligations to uphold a pantheon of individual rights, including the rights to equality, dignity, and access to health care.⁹⁵ TAC also draws on international human rights treaties to justify its positions. For instance, in criticizing the government for failing to implement a comprehensive AIDS program including access to ARVs, TAC cited Article 25 of the UDHR (on the right to an adequate standard of living for health and well-being), Article 16 of the African Charter of Human and Peoples' Rights (on the right to health and the government's responsibility to ensure it), the Rome Statute of the International Criminal Court (on crimes against humanity including the denial of medicine), and Section 27 of the South African Constitution (on the right to health care services and the government's responsibility to provide them).⁹⁶

TAC does not limit its activities to South Africa. The organization has built alliances with AIDS service organizations (ASOs) and activist groups around the world, lending its credibility to these groups while presenting a united transnational front to the international community. Doctors without Borders, the Gay Men's Health Crisis of New York, and ACT-UP have collaborated with TAC to pressure both the South African and American governments.⁹⁷ Achmat calls on fellow activists to cajole wealthy governments around the world to provide monies for treatment and to ensure that human rights are upheld for all PLWHAs.⁹⁸

CONCLUSION

The recasting of AIDS as a human rights issue, rather than simply a public health concern, is an important example of the struggle for "new" human rights. Initially, a pragmatic response to the epidemic's severity and the failures of traditional public health approaches, human rights approaches have become far more than that. Today, in fighting AIDS, access to information and treatment are central issues, underpinned by national and international human rights norms. Some advocates also raise broader human rights arguments about the pernicious effects of "structural violence" in creating social vulnerabilities to the disease.

Key players in this unprecedented transformation from disease to human rights issue include national-level AIDS activists, particularly in the United States. Well-placed individual advocates, notably Jonathan Mann, were also critical to raising international consciousness about rights-based approaches to AIDS. As a result, powerful organizations such as the GPA and UNAIDS promoted human rights approaches to AIDS and opened the door to broad acceptance of such policies internationally. In turn, this has affected local AIDS activists in the developing world, who drew on their own experience in domestic democratization movements to call attention to shortcomings in purely public health strategies to AIDS.

Major human rights NGOs such as Amnesty International and HRW have not been leaders in promoting the link between AIDS and human rights. Issues of disease and infection were too alien to the NGOs' long-standing focus on violations of civil and political rights. However, in the 1990s, the human rights NGOs came under pressure from national and international AIDS advocates. With this lobbying and with the United Nations' embrace of human rights approaches to AIDS, the human rights NGOs have recently begun to

work on limited aspects of the AIDS issue. This has not satisfied those such as Paul Farmer who believe that tackling the disease requires fundamental societal change. But it does represent a significant expansion in the cultures and missions of these organizations, one that mirrors public health institutions' earlier and equally contentious move to adopt rights-based approaches to AIDS.

HIV/AIDS presents a case where a human rights-based approach has evolved, and continues to do so, to balance the competing needs of providing a GPG and biopolitical surveillance. Although this approach is not universally accepted, it does appear to be gaining increasing acceptance by the international community. The AIDS pandemic emerged almost simultaneously with the recognition of human rights as an essential element of international public health. The following chapter examines the SARS outbreak of 2002 and 2003 and shows how this framework operated when the human rights framework was more firmly entrenched within the international community.