# The Global Politics of AIDS

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LYNNE RIENNER PUBLISHERS
BOULDER
LONDON

Published in the United States of America in 2007 by
Lynne Rienner Publishers, Inc.
1800 30th Street, Boulder, Colorado 80301
www.rienner.com

and in the United Kingdom by
Lynne Rienner Publishers, Inc.
3 Henrietta Street, Covent Garden, London WC2E 8LU



**Library of Congress Cataloging-in-Publication Data**
The global politics of AIDS / edited by Paul G. Harris and Patricia D. Siplon.
p. cm.
Includes bibliographical references.
ISBN 13: 978-1-58826-467-1 (hardcover : alk. paper)
1. AIDS (Disease)—Political aspects. I. Harris, Paul G. II. Siplon, Patricia D.
RA643.8.G567 2006
362.196'9792—dc22

2006027913

**British Cataloguing in Publication Data**
A Cataloguing in Publication record for this book
is available from the British Library.

Printed and bound in the United States of America

The paper used in this publication meets the requirements of the American National Standard for Permanence of Paper for Printed Library Materials Z39.48-1992.

5 4 3 2 1

# Contents

# Preface

This book is a small effort to contribute to the world's understanding of the global public health crises arising from the spread of the human immunodeficiency virus (HIV) and the resulting pandemic of acquired immunodeficiency syndrome (AIDS). Rarely is it possible to compose a book that requires no justification at all owing to the profundity of its subject matter. If there is such a subject, the one to which this book is devoted may be it. Already, some 25 million people have died from AIDS—an average of one million people per year since the disease was first identified. The HIV/AIDS pandemic is a public health crisis of the greatest magnitude, albeit one that is taking place in a sort of slow motion that has resulted in halting and, all too often, inadequate policy responses.

Like so many other observers, we are humbled by the scale of suffering brought on by the spread of HIV/AIDS around the world. The stories of the people affected by the pandemic, and the efforts of those who seek to help them and to bring this scourge to an end, are frequently painful reminders that we have an obligation to do all that we can to fully understand this problem. Here, a small group of concerned scholars and practitioners seek to further that understanding. Ours is an attempt to give power to people living with HIV/AIDS, others affected by it, and those who wish to help to reduce and one day end the pandemic. We hope that the book will lead to positive results that build on and assist the efforts of enlightened individuals, organizations, and governments.

In a tiny effort to increase the benefits that the book might bring to those who suffer from HIV/AIDS, all royalties will be used to help people living with AIDS.

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The editors and contributors are grateful for very helpful comments and suggestions from anonymous referees. The editors wish to thank the contributors for joining this project and for persisting with it through peer review and revi-

sions. Our hearty thanks also go to Marilyn Grobschmidt of Lynne Rienner Publishers, who (along with her colleagues) saw the importance of this project and ushered it to final publication. The editors gratefully acknowledge funding from the International Joint-Research Program of the Centre for Asian Pacific Studies and the Centre for Public Policy Studies at Lingnan University, the Faculty Development Fund of Saint Michael's College, Rotary International University Teacher's Program, and the Fulbright Scholar Africa Regional Research Program. We also benefited from the able assistance of Kwok Kin Chan in preparing the index. Most of all, the editors would like to thank Kwok Kin Chan and Todd M. Watkins for their support and patience during the long period spent working on this project.

*—Paul G. Harris and Patricia D. Siplon*

# 1

# Global Politics and HIV/AIDS: Local, National, and International Perspectives

Paul G. Harris

> We're now marking the 25th anniversary of the detection of AIDS, and it has been a sad chapter in the history of humanity.
>
> —Nicholas D. Kristof[1]

A sad chapter indeed. Despite tens of millions of deaths from AIDS and widespread suffering by countless other people indirectly affected by the disease, the global response to this monumental pandemic has been slow and halting. The lack of power among most of those directly affected by AIDS has been a signature factor exacerbating it, but in some places the weakness of those with HIV/AIDS has started to shift in their favor, resulting in new policies that are finally starting to slow the pace of new infections and increase the number receiving effective treatments. This book explores this nascent change by examining the politics and power of HIV/AIDS at multiple levels of human activity, from individual sexual relations to corporate boardrooms to the centers of international power in Washington, Brussels, United Nations headquarters, and beyond.

At present, about 40 million people worldwide are living with the human immunodeficiency virus (HIV), the virus that causes acquired immunodeficiency syndrome (AIDS).[2] More than 25 million people, predominantly in the poorest parts of the world, have died from AIDS-related diseases since the pandemic was first recognized in the early 1980s, most of them in the developing world, particularly the hard-hit countries of sub-Saharan Africa.[3] More than three million people, including half a million children, perished as a consequence of AIDS in 2005 alone.[4] About five million people (including three-quarters of a million children) were infected with HIV in 2005,[5] with millions

of people expected to be infected in the future as the virus increasingly spreads in regions where prevalence was relatively low until recently (e.g., the former Soviet states and south, southeast, and east Asian countries). Consequently, AIDS will almost certainly kill tens of millions more people in coming decades. Antiretroviral (ARV) therapy, the only effective means of treating HIV/AIDS (by preventing HIV from leading to full AIDS or reversing the infections that arise from it), is reaching barely more than one of every ten people who need it.[6] This is a public health crisis of monumental proportions; it is a personal tragedy for its victims, their families, and caregivers; and it is a monumental challenge for people, businesses, and governments almost everywhere but especially in the most vulnerable communities and societies across the globe. The need to understand the HIV/AIDS pandemic is utterly manifest.

Even though there is much that is remarkable about this crisis, two glaring attributes of the HIV/AIDS pandemic are clear—one frustratingly obvious, the other quite apparent when we examine the issue. The first is the depressingly slow response of governments (as compared to the much more rapid response, within their capabilities, of many affected groups of people), arising from what the Joint United Nations Program on HIV/AIDS (UNAIDS) has bluntly called "social discrimination and political indifference."[7] The second is the related degree to which *power relationships*, and power disparities and imbalances in particular, have defined this problem. In the first case, for too long governments turned a blind eye to HIV/AIDS, and in most cases continue to do too little, either because they lack the capability to act or the willingness to do so. In the case of power relationships, it is now clear that, as a general rule, those most adversely affected by HIV/AIDS are those individuals, groups, communities, and nations that lack power. Indeed, where there have been successes in resisting the spread of HIV and treating people with AIDS, it is very often those with power who have rallied support, either through self-help or by doggedly breaking down the barriers that still, in too many places, are preventing the implementation of solutions.

This book is a group effort to look at these two (and many related) attributes of the HIV/AIDS pandemic. We ask, what explains the slow response of governments? What explains the reactions of other actors? Which groups have been most affected and why? How have power relationships and disparities in power in particular led to and perpetuated this problem, and what is their role in ongoing and potential efforts to relieve and perhaps one day end the associated human suffering? We attempt to answer these and similar questions by adopting a global perspective on the politics and power of HIV/AIDS. We are interested in the pandemic's causes, impacts, and solutions at all levels of human activity, from individual people to global institutions and forces. HIV/AIDS predominantly exists because of behavior almost universal to people everywhere, notably sex and reproduction. It has been exacerbated by other vectors,



such as intravenous drug use, but most of all it has been spread—indirectly, but only barely so—by poverty and despair, discrimination, and the subservient position in which some groups, countless women, and even entire countries find themselves. The characteristics of the pandemic are not consistent globally, however: they are very much shaped by particular cultural, social, and political forces. For this reason, governmental and nongovernmental actors that want to help those infected—and affected—by HIV/AIDS must first address its local causes and consequences. At the same time, both the spread and containment of HIV/AIDS are international phenomena. Like all viruses, HIV does not respect national borders. The problem is also international because the world's rich countries have resources that can be, and slowly are being, mobilized to address the problems of HIV/AIDS that are disproportionately borne by poor countries and peoples.

Bearing these considerations in mind, this book brings under one cover a collection of sometimes provocative case studies of the local, national, and international politics of the HIV/AIDS pandemic. We seek to understand how particular affected communities and countries have dealt with HIV/AIDS; to compare these experiences in search of lessons that are (and are not) transferable to other groups, countries, and regions; and to examine how diplomacy and international relations affect, and are affected by, this extremely pressing global problem. It is important to note that the chapters highlight many key domestic and transnational actors, institutions, and forces (e.g., civil society actors, people and organizations affected by AIDS, state officials, transnational corporations, and other stakeholders) influencing responses to the pandemic. The book's overall approach to this issue is one that combines scholarship and analysis with sensitivity to, and awareness of, the suffering of those afflicted and the frustration felt by those seeking to bring about meaningful change that will mitigate this suffering and prevent its spread. Toward this end, contributors to the book include academics, practitioners, and activists who hope and expect that it will be a valuable resource for governments, stakeholders, nongovernmental organizations (NGOs), activists, and students interested in public health and HIV/AIDS in particular. The chapters that follow can also be informative for concerned global citizens seeking to understand the world's inadequate responses to the most deadly pandemic ever to face humankind—and the possible ways to provide more help to those suffering from it and to ultimately bring it to an end.

The book is divided into two parts that follow the introductory chapters. Each chapter examines the HIV/AIDS policy process, including key actors, institutions, and forces, and many of the power relationships among them. As a prelude to the case studies in Parts 1 and 2 of the book, in Chapter 2 Patricia D. Siplon highlights the absolutely central, crosscutting, and often determinative role that is played by *power*, *power relationships*, and *power disparities and imbalances* in the spread of HIV and the resulting scourge of

AIDS. As Siplon reminds us, at its most fundamental level, politics is about who gets what, when, and how; it is about power. Like politics generally, HIV and AIDS are also fundamentally about power. Siplon's chapter shows how, at all of the levels that we analyze—individual, group, community, state, or international—power relationships can strongly influence and even dictate the spread of HIV/AIDS. Power, or the lack of it, often dictates who engages voluntarily or, as often happens, involuntarily in risky behaviors, and when. It is important to note that lack of power also contributes to the compromised overall health status of individuals within many risk groups, particularly the very poor, which makes infection upon exposure more likely. Groups within countries compete for power to shape the rules of society that structure human relationships and in turn the pandemic, and they fight for control of scarce national resources that impact the course of HIV and AIDS. Power also matters at the international level, where strong states often dictate to weaker ones and where powerful states at least have sway over how the human, technological, and financial resources of international organizations are or, quite often, are not deployed to address the causes and consequences of HIV/AIDS. As Siplon puts it, "in all of these cases, it is power—whether the ability to make one's own choices or the ability to make other actors behave in accordance with one's wishes—that determines what will and will not happen and whether HIV/AIDS will take hold and spread human suffering."

All of the case studies that follow, to varying degrees, are demonstrations of the power relationships highlighted by Siplon. Often the stories are sad demonstrations of what we might call the "failures of politics" to allocate resources and remedies as we might normally desire. Sometimes, however, especially in depictions of more recent events, there are success stories, examples of things changing for the better. It is to understanding both these failures and these successes, and how we might see more of the latter, that the following chapters turn.

## Part 1: Domestic Politics and Policy

The chapters in Part 1 describe and analyze HIV/AIDS in domestic and comparative perspective. Here we are interested in highlighting and understanding experiences by people and groups *within* specific countries, in the process garnering lessons that may be transferable to other local and national circumstances or, alternatively, understanding experiences that clearly are not transferable to other countries (so that governments and other actors can avoid wasting time on them). Although HIV can infect anyone, certain populations have disproportionately borne the virus and its impacts. Some of these groups have been affected by certain risky behaviors common to the group, such as



illicit injection drug users. Others have suffered the effects that HIV/AIDS has had on those closest to them, such as widows and orphans. Some proactive groups have been empowered by organizing and engaging in activism, whereas others have been held back, hampered by cultural and economic obstacles, overpowering discrimination, or a shortfall in information and skills. To better understand the global pandemic, we look at some of these groups in order to understand the internal power dynamics that affect the spread of and the suffering caused by HIV/AIDS. Many of the dynamics working at the local level also affect interactions at the national and international levels (as the case studies in Part 2 of the book show). We examine cases from both developed and developing countries, including those considered to have successfully addressed HIV/AIDS and others regarded as having undertaken inadequate or even counterproductive efforts. By looking carefully at country cases and comparing their experiences, we highlight valuable lessons that can help those formulating HIV/AIDS-related public health policies in other countries not specifically analyzed in this book.

Our case studies of domestic politics and policy begin in Chapter 3 with André de Mello e Souza's analysis of Brazil's successful effort to "defy" the forces of globalization through HIV/AIDS policies premised on self-reliance. He examines Brazil's National HIV/AIDS Program and its antiretroviral treatment program. This ARV program, which was among the first to give free AIDS therapies to all patients, has been successful but also highly controversial. It was controversial because it defied conventional wisdom regarding public health policy and international agreements intended to protect the patents of multinational pharmaceutical companies. De Mello e Souza shows that Brazil's ARV policy grew out of changes in the country's political system in the 1980s, notably a new conception of health care as a constitutionally protected right that was at odds with prevailing neoliberal approaches to public policy. He argues that the ARV program resulted from the emergence of AIDS NGOs as Brazil democratized and as government officials subsequently took the demands of these organizations seriously. The program's success relied on Brazilian manufacture of generic ARV medicines in order to make the cost of treatment affordable for the government. This capability to produce generic medications also allowed Brazil to credibly negotiate with major multinational pharmaceutical companies, which gave it substantial discounts on patented drugs, although the companies—with the backing of the US government—strongly protested. By mobilizing all of its diplomatic resources and by having the backing of transnational advocacy networks, Brazil was able to resist those pressures. In so doing it also "defied established health policy beliefs upheld by authoritative and politically influential international organizations, funding agencies, and health research centers, according to which antiretroviral treatment [was considered to be] unfeasible in developing countries." Chapter 3 is

thus a case study of how developing countries can, through determination at the national level, defy international political and economic forces to effectively respond to HIV/AIDS.

Brazil has been hit hard by HIV/AIDS, to be sure, as have other countries in Latin America. Their suffering is surpassed, however, by that experienced in sub-Saharan Africa, the epicenter of the pandemic. We devote two chapters to this important region. In Chapter 4, Bernard Haven and Amy S. Patterson explore the relationship—which they refer to as the "disconnect"—between the public health objectives of government and those of NGOs in Ghana: Haven and Patterson analyze how civil society organizations, specifically local HIV/AIDS-specific NGOs, have faced difficulties in influencing public health policy. Their case study highlights several major obstacles confronting HIV/AIDS organizations in Ghana. They have limited resources, they find it difficult to coordinate their activities with one another, and they are excluded from most national institutions that design and implement HIV/AIDS policy. More generally, Ghana's social and political environments are not amenable to the work of AIDS-related organizations, and their work lacks widespread support from the public. The case study in Chapter 4 shows that NGOs that are institutionalized into the policy process can have greater impact, albeit at the expense of their own public health objectives. The HIV/AIDS-specific NGOs have assets—their passion and direct experience with the pandemic—but they also have problems inherent in their membership. When the people with AIDS who make up the NGOs see activists and members die, it saps their morale and institutional memory and also poses profound practical problems for their operations. Overall, Haven and Patterson's case study demonstrates, sadly, that stigma, poverty, and marginalization can severely limit the power of AIDS organizations to influence public health policy and that efforts to address HIV/AIDS must simultaneously reduce these weaknesses if those efforts are to be successful.

Our second chapter dedicated to sub Saharan Africa is by Patricia D. Siplon and Kristin M. Novotny. In Chapter 5, Siplon and Novotny look at the goals of and solutions to an HIV/AIDS epidemic sought by a "triply oppressed group": widows of AIDS victims who themselves have HIV/AIDS. The authors interviewed women in Tanzania suffering simultaneously from severe resource deprivation, discrimination, and HIV/AIDS. One key concept underlying Siplon and Novotny's case study is that of *autonomy*, especially personal autonomy, which can potentially enable women in Tanzania to effectively confront the difficulties and challenges they have been forced to face as a consequence of HIV/AIDS. The chapter traces the conceptual development of autonomy in Western (particularly feminist) political thought, showing how a lack of it, combined with gender discrimination, has increased the already disproportionate burden that AIDS has created for women and girls. The disease has not only infected the women studied in this chapter, but it has made them widows as



well. A bitter brew of personal tragedy, anger, and a total lack of resources to meet their own and their children's material needs has motivated these women to collectively mobilize in the hope that doing so might enable them to survive the epidemic in their communities. Siplon and Novotny look at how these Tanzanian women have attempted to overcome tremendous adversity to increase their personal autonomy, in the process challenging Western assumptions about autonomy and offering African perspectives as an alternative. In their words, these women "strive to realize control over their lives in a way that invokes Western conceptions of autonomy but without (1) the resources that are necessary to realize these goals and (2) stereotypical Western assumptions that autonomy is the product of an isolated self." They note that these women, despite the multiple obstacles in their paths, have remarkable clarity in their visions of their own autonomy goals and now are collectively seeking empowerment, in the form of resources and opportunities, in an attempt to realize these visions.

With a population of those living with HIV/AIDS exceeding five million,[8] India has the unfortunate distinction of joining South Africa as the two countries worst affected by the pandemic, although so far India's per capita exposure is much lower than in a number of African countries. Millions of Indians have already died from AIDS, and many millions more will do so at an increasing rate unless urgent action is taken very soon. In Chapter 6, Marika Vicziany looks at one aspect of India's pandemic: HIV and AIDS resulting from heterosexual intercourse, the predominant means of transmission there (although there are other important vectors in India, notably through the sharing of contaminated drug-injection needles). Vicziany argues that HIV has entered India's general population due to the universal practice—and even duty—that all Indians enter marriages, meaning that men who have sex with men will usually marry and "become family men." These same men, with a new sexual revolution in India, will seek out sex (usually unprotected) that is not available in their premarital social groups, thereby further spreading the virus. Much as has happened in other countries, the government's attitude toward HIV/AIDS has been characterized by indifference followed by a "coercive response that victimizes sexual minorities who continue to be falsely regarded as the root cause for India's epidemic." It was only in late 2003 that the government's AIDS body, the National AIDS Control Organization (NACO), recognized this problem. But HIV infection rates continue to rise, showing, according to Vicziany, that the Indian government's policies have "failed dramatically." The official response to the pandemic in India has been simplistic, focusing on high-risk *groups* (e.g., homosexuals) rather than stressing high-risk *behavior* and conditions that foster transmission. The chapter shows that, unless public health policy in India is refocused, the prospect for controlling HIV/AIDS there "looks grim." Vicziany's case study also suggests that NACO, despite being "generously funded" by the World Bank, has been grossly incompetent, wasting money and failing to effectively create and utilize an infrastructure for addressing HIV/

AIDS. This has been manifested by the continued difficulty most people face in acquiring condoms and the woeful lack of education about HIV/AIDS, especially in rural areas. Indeed, NGOs fighting HIV/AIDS at the grassroots are still subject to attacks by India's police forces, which see even the possession of condoms as evidence of illicit prostitution. These policies are largely a result of social stigma and bureaucratic sclerosis, although it is possible that India's current, more secular, government could eventually make a difference, especially if there is additional funding, antidiscrimination legislation, educational reform, and improvements in the healthcare infrastructure.

Turning from southern to eastern Asia, in Chapter 7 Susanne Y.P. Choi and Roman David present a case study of law, public health, and AIDS prevention in China. Choi and David note how HIV/AIDS has become—very slowly at first, but much more rapidly recently—a major public health issue within China. As they point out, according to a joint survey conducted by the Chinese government, the World Health Organization, and UNAIDS, China officially had about 650,000 people infected with HIV and about 75,000 people living with AIDS. The actual number of people infected with HIV by January 2006 in China was widely assumed to be much higher, however, with the UN predicting that it could reach 10 million by the end of this decade.[9] Despite the Chinese government's very slow response to the pandemic, recently the government and the country's top political leaders have publicly acknowledged the problem, and they have shown a greater commitment to combat it, as evidenced by official issuance of "China's Action Plan for Reducing and Preventing the Spread of HIV/AIDS (2001–2005)." Ethnographic research, as described in Chapter 7, suggests, however, that the central government's efforts to address the HIV/AIDS pandemic may be seriously undermined by the strategies of law enforcement officials at the local level. Using data collected from in-depth interviews and focus group sessions with intravenous drug users in Sichuan Province, Choi and David show how tactics employed by the police may prevent high-risk populations from practicing harm reduction, such as minimizing the exchange of contaminated needles and increasing their use of condoms during sexual intercourse. Mirroring some of the lessons learned from the case study of India in Chapter 6, Choi and David highlight the importance of finding a balance between law enforcement and public health needs. Because those populations most vulnerable to HIV/AIDS are often lacking in power, socially marginalized, and subject to serious discrimination, Choi and David argue that this task must be accomplished through collaboration of many government agencies at the central, provincial, and local levels, accompanied by assistance from international donors and the active participation of NGOs (heretofore frowned upon in China).

Moving on from our case studies of HIV/AIDS policy in the economically developing world, Part 1 concludes with two chapters looking at HIV/AIDS policy in France and the United States. France is the subject of Michael J. Bosia's case study in Chapter 8. The major themes in Bosia's chapter include activism of NGOs, namely the group Act Up Paris (which was inspired by the AIDS Coalition to Unleash Power [ACT UP] in the United States); the politics of identity; and the notion of accountability for those who exacerbated the epidemic in France. Bosia argues that a battle over who is responsible for AIDS there is what defines activism and shapes the identities of those people affected by it. Going further than the aggressive rhetoric of its counterparts in the United States (see Chapter 9), Act Up Paris lodged *criminal* complaints against government officials, accusing them of allowing HIV to spread in France, particularly through infected blood products used by hemophiliacs. Some government ministers were in fact tried in special courts, although they were condemned less by those courts than by public opinion. What is more, AIDS NGOs in France worked to overcome labels that associated HIV/AIDS with homosexuality, forging a common identity with all affected groups and using narratives "that reinvented many established values associated with French citizenship," thereby showing that people with HIV/AIDS are "members of the national community." According to Bosia, French activists were able to unite identities based on race, class, gender, and sexuality, thereby resisting the political marginalization previously experienced by affected groups. Bosia describes this strategy as having been successful, with "a large and growing segment of the public and the establishment accept[ing] the transformation of homosexual and AIDS activists into legitimate citizens through concerns framed as common interests with a strong commitment to solidarity," in the process making the politics of identity surrounding HIV/AIDS compatible with a "popular [French] republicanism"—even to the point at which a gay socialist was able to win the race for mayor of Paris. From a power perspective, this case also demonstrates how activists may be able to use coalition building and linking of issues to commonly held values to increase the power of affected groups. Ultimately, French activists were able to transform HIV/AIDS from a question of government policy alone to one of national values and government responsibility as well, resulting in more accountability for those responsible for exacerbating the pandemic in France, and more effective policies for combating it.

In Chapter 9, Benjamin Heim Shepard describes and assesses the history of HIV/AIDS policy in the United States, which he portrays as transitioning through three identifiable stages: "gay plague," "national priority," and "social control." Shepard's chapter describes a history of HIV/AIDS advocacy in the United States, particularly (1) community organization and mobilization during the 1980s, (2) breakthroughs in treatment and legislation achieved in the 1990s, and (3) the "imposition of social control" that followed "in which people with HIV/AIDS and community-based service providers struggle for autonomy while attempting to preserve the remains of a US social

safety net and welfare state." He points out that owing to breakthroughs in the 1990s, such as the availability of highly active ARV therapy, the story of AIDS in the United States changed from one of tolerance to one of intolerance. Shepard argues that HIV/AIDS policy in the United States can be understood only by bearing in mind social and economic macrotrends that affect the allocation of public funds and other resources. Despite conservative politics in the United States, AIDS activists have been surprisingly successful in garnering public resources for their cause even when other interest groups have suffered cuts.[10] HIV/AIDS policy has been subject to broader policy trends, however (e.g., privatization of welfare, income inequality, unaffordable health care, and discrimination), and it is "still enacted with a moralizing approach aimed at social control." This suggests that HIV/AIDS policy continues to be shaped, at least to a substantial degree, by prejudicial attitudes, not yet being part of mainstream health policy—except insofar as it is likely to suffer from future budget cuts as Washington attempts to trim spending on social welfare and public health.

## Part 2: International Politics

What happens within domestic communities is greatly affected by the policies and actions of other countries, their governments, and the international community. Sometimes suffering at the local or national level has been exacerbated by international politics and the global trade regime; at other times assistance has come from the international community. With this in mind, Part 2 of the book moves beyond individual countries to explore relationships among governments, international organizations, and other transnational actors. It builds on the preceding chapters by exploring the politics of AIDS at the international level. The case studies in Part 2 examine the ways that governments, communities, international institutions, and other actors are interacting across national boundaries to address the problems created by HIV/AIDS. They include studies of specific policy conflicts, such as struggles over the uses of scarce international aid resources and the fight for affordable treatment in developing countries. Part 2 also looks at HIV/AIDS in the context of international trade, national security, and human rights and describes how global institutions are attempting to meet new challenges posed by the AIDS pandemic.

HIV threatens those infected with it, and AIDS threatens the very survival of those who suffer from it, particularly in the many places where effective ARV therapies remain out of most people's reach. The pandemic is also a threat to the security of the societies and even the nation-states in which its sufferers reside. That is, suffering from HIV/AIDS threatens more than those with HIV in their bloodstreams; the impacts of the disease also reverberate throughout



domestic communities, threatening livelihoods and broader human well-being. HIV/AIDS also threatens the national security of states as it erodes economies and exacerbates existing social and political problems that can lead to domestic conflict, possibly contributing to interstate rivalries. It is not surprising, then, that HIV/AIDS has been a major concern of the United Nations. In Chapter 10, Amy S. Patterson describes the response to the HIV/AIDS pandemic by the UN and affiliated international organizations and their attempts to build an international regime around a global commitment to health. Actions by the UN during the early 1980s, when the world started to recognize the pandemic, were relatively limited; initiatives and actions came mostly from governments and domestic actors, notably groups such as ACT UP in the United States. By the mid-1980s, however, the World Health Organization had formed the Global Program on AIDS, which helped develop standardized diagnoses and promoted international deliberations on HIV/AIDS that emphasized "empowerment and participation." During this period HIV/AIDS was portrayed as a medical issue requiring technical solutions and involvement of organizations representing people living with HIV/AIDS.

By the mid-1990s it became apparent that more cooperation among the UN and other international organizations was needed to effectively address the pandemic. Consequently, in 1996 UNAIDS was created. It went beyond the Global Program's advocacy (by both governments and NGOs) of national and international responses to the pandemic by prioritizing the building of political commitment to combating the disease. This was manifested in the 2001 UN General Assembly Special Session on HIV/AIDS. It is important to note that, unlike the Global Program, UNAIDS coordinates the HIV/AIDS-related programs of UN agencies. Its mission "reflects a broader framework . . . in which the disease is linked to concerns over human rights, underdevelopment, and gender empowerment." The UN also created the Global Fund to Fight AIDS, Tuberculosis, and Malaria, which garners major financial support for national action on HIV/AIDS (along with malaria and tuberculosis). Patterson concludes that a "realization that health and politics are interrelated is crucial not only for policymaking on HIV/AIDS but also for the development of a larger commitment to public health," with participation of political leaders being crucial, and she points out that there is a need for an *international* forum where political leaders can work together. The UN is serving as that forum, in the process also helping to coordinate action among governmental and nongovernmental actors.

Like so much else in a globalized world, the HIV/AIDS pandemic is intimately connected to and caught up in the global economy. Asia Russell examines these connections in Chapter 11. She points out that one of the factors conspiring to prevent people from getting access to treatment for HIV and AIDS is the prohibitively high cost of medicines. As she portrays it, this has led to one of the greatest preventable health tragedies of modern times, one

that disproportionately affects people in the poorest parts of the world. The advent of effective ARV treatments in the developed world happened to roughly coincide with the creation in 1995 of the World Trade Organization (WTO). The prices charged for ARV treatment at the time (on the order of $15,000 per year) were unaffordable for the vast majority of people with HIV/AIDS. Russell argues that the inability of these people to get access to ARV treatments resulted from a campaign by wealthy countries (e.g., the United States, Japan, and members of the European Union) to use the WTO to integrate the world economy, in the process imposing patent-protection regimes on poor countries that might otherwise find ways to get access to the medications (see the response of Brazil depicted in Chapter 3). Russell describes the intellectual property protections that were negotiated in the Agreement on Trade-Related Aspects of Intellectual Property Rights that accompanied the creation of the WTO and their impact on HIV/AIDS treatment in the developing world. Her chapter focuses largely on the efforts of the United States and its "allies in the pharmaceutical industry" to exploit bilateral relations and the WTO, thereby preventing or limiting the use of much less expensive generic ARV medicines manufactured in developing countries. Russell takes an important look at the efforts of activists and other civil society actors to highlight the unfairness of the system promoted by the United States and the drug makers, and the recent successful efforts of those activists to place the right to health, and ARVs in particular, on a par with the commercial interests of pharmaceutical producers. Indeed, by mid-2005 the US government was touting its approval of generic ARV combination therapies for use in US-funded programs overseas.

All of the chapters in this book highlight moral questions related to HIV/AIDS. In our final two chapters the pandemic is analyzed in the context of normative standards of human rights, cosmopolitan ethics, and international obligations between rich and poor countries. In Chapter 12, Joanne Csete looks at some of the human rights implications of the HIV/AIDS pandemic. One of her arguments is that violations of human rights exacerbate the pandemic, and in turn those people with HIV/AIDS suffer from violations of their human rights, creating a vicious and unjust cycle. As Csete notes, "any disease that started out with the name 'gay-related immune deficiency' would be likely to have some human rights challenges built in." She argues that the history of HIV/AIDS has been substantially shaped by the fact that many of the people most likely to be living with HIV/AIDS, especially in the early years (e.g., sex workers, intravenous drug users, prison inmates, migrant workers, and gay and bisexual men), were politically unpopular and disempowered. This posed a special challenge for those hoping to heighten the political salience of these people's rights. Although Csete notes that protecting human rights is increasingly recognized by international organizations and many governments as important for fighting HIV/AIDS, human rights considerations and the "stigma and discrimination" that underlie HIV/AIDS are nevertheless not adequately considered by policymakers and not sufficiently implemented in public health programs. This is especially true with regard to the ambivalence of many governments (e.g., the United States and Middle Eastern countries) toward protecting the rights of many of those people most vulnerable to HIV/AIDS. Women—women with HIV/AIDS most profoundly—also routinely face discrimination, especially in parts of the world where the pandemic is most severely entrenched (see Chapter 5). Thus, although much lip service is paid to protecting human rights, Csete finds a wide gap between rhetoric and practice. Reinforcing lessons learned in other chapters, she concludes that the pandemic is "unlikely to be turned around until state-sponsored harassment and persecution of persons with AIDS and those at risk are addressed, along with subordination based on gender, repression of information, and discrimination related to HIV/AIDS. . . . As long as people living with, at risk of, and otherwise affected by AIDS are abused and persecuted, this most destructive of epidemics will have the upper hand."



Our final case study looks at HIV/AIDS from the perspective of global ethics. In Chapter 13, Paul G. Harris and Patricia D. Siplon ask what obligations the world's wealthy countries have to help poor countries and their people to address the HIV/AIDS pandemic, and the extent to which the wealthy countries have fulfilled these obligations. Harris and Siplon highlight some of the ways in which HIV/AIDS presents the world with profound moral challenges. For example, the pandemic is one of the most severe and widespread manifestations of human suffering in history, especially in the poorest countries where the majority of the world's people live. Despite the extent of this suffering, the global response to HIV/AIDS, notably by the world's rich countries, which are most capable of taking action, has been severely lacking relative to the scale of the problem. Even though the governments of economically developed countries have acknowledged the problem and started to provide aid to those suffering from it, their actions are far less than they are capable of providing, recent increases in funding and attention (particularly from the United States) notwithstanding. Harris and Siplon argue that this "needs to—and ought to—change." They provide several ethical justifications (i.e., utilitarian ethics and considerations of responsibility for harm) for demanding that developed countries do more to help poor countries in their efforts to combat HIV/AIDS and to care for those who suffer from it. Harris and Siplon believe that doing so would "dramatically reduce the amount of human suffering caused by AIDS, and it would do so at very little cost to those providing the aid. This alone is enough justification for action." One important point made in Chapter 13 is that the economically developed countries (some more than others, of course) bear some responsibility for the suffering from HIV/AIDS in the developing world because they ignored the problem and the conditions that foster it for too long. A more direct accusation is that

at times they actively worked to prevent the worst affected countries from providing treatment for sufferers by keeping ARVs and other medicines unaffordable (see Chapters 3 and 11). According to Harris and Siplon, "this adds to the moral burden of the world's wealthier countries and peoples." This is especially the case because in today's world it is generally assumed that rich countries should provide aid to poor ones when they are in great need (as when aid is provided, often as a matter of routine, during major famines). Harris and Siplon point out that the fact that

> the world's poor are in need in this case is undeniable, and provision of aid is possible. Hence, we must conclude that further delay not only runs counter to the interests of all those who suffer from HIV/AIDS, as well as those indirectly affected all over the world, but that it is immoral and contradicts a desirable historical trend toward more care by the world's wealthy for the world's suffering poor. The case for denying aid is now very hard to make; the case for doing *much* more is very strong.

This is not to say that the rich countries have entirely failed to fulfill their obligations. Although their response has been slow, the United States and some other countries have pledged substantial aid and have started to provide it, and some privately funded organizations have teamed with the UN and others to provide more aid for HIV/AIDS prevention and care. What is more, many of the blatant efforts to prevent the spread of affordable (usually generic) ARVs have stopped. Having said that, not only is more aid needed, but conditions on existing aid (e.g., US restrictions on programs that advocate condom use or that fund organizations associated with abortion) diminish its benefits, and obstacles to ARVs remain in the fine print of free-trade agreements. Harris and Siplon thus acknowledge that the willingness to provide aid has increased over time, but they also argue that it has not gone nearly far enough. For reasons of morality (among others), the halting trend toward greater aid from rich to poor in the context of HIV/AIDS ought to be greatly accelerated.

## Conclusion

Our case studies on local and domestic politics of HIV/AIDS demonstrate how power relationships have been and remain drivers of HIV/AIDS policies in both developing and developed countries. During the early days of recognition of the disease in developed countries, insofar as HIV/AIDS was about homosexuality, the prejudices against gays determined how policy activists mobilized and to what end. In reality, of course, the pandemic is by definition not about gays; it is affecting an increasing number of groups and communities, with the most impact and suffering among those people—women, children, the poor, and the world's many "untouchables"—with the least power in their own national communities. When they have somehow been empowered, whether through their own efforts or with help from domestic and international actors, suffering and the spread of the disease have been lessened. Slowly—very slowly in many countries, including some of those most affected—HIV/AIDS is starting to be seen for what it really is: a scourge on a number of groups in society *and* upon society itself. If this gradual shift in attitudes continues, more effective policies already practiced in some countries will garner additional support, thereby at least lessening the impact of the disease. Alas, the trend in many places, notably China and especially India, is not very promising, with more people being infected and affected and with human suffering likely to increase on a grand scale unless more action is taken very soon.



Our case studies on international dimensions of the HIV/AIDS pandemic show how power relations between and among states, intergovernmental organizations, NGOs, and multinational corporations have material impacts on the scale of the pandemic, affecting whether policies to deal with it are encouraged and implemented and influencing the degree to which those policies are effective. Weak states have sometimes had policies that exacerbated the pandemic (e.g., free-trade patent protections and privatization of health care institutions) imposed upon them. Increasingly they have fought back and asserted their sovereignty, sometimes with beneficial results, as in the case of Brazil. At other times, the very weakness of states has made them reliant on external governmental and nongovernmental actors, which more and more are working with local officials and organizations, with positive outcomes. The case studies show that HIV/AIDS is a profoundly moral issue, bringing into sharp relief the degree to which normative principles are or, too often, are not upheld domestically and internationally. The pandemic is about human security and human rights, suggesting that prerogatives and priorities of governments and businesses do not always comply with the needs of the people they are supposed to benefit. The case studies in Part 2 also point to another conclusion: international ethical norms must be implemented; they are essential to effective practical public health policies and the protection of human, national, and (in the long term, perhaps) even international security. This means that all people and all governments, whether motivated by self-interest or a desire to do good, have the most profound interest in working to stop the spread of HIV/AIDS as soon as possible and to bring comfort to those who already suffer from it. And to be truly effective, these efforts must be animated by the goal of resolving the power inequities—at the individual, societal, and international levels—that have fostered and supported this deadly pandemic since it began.

## Notes

I wish to express my heartfelt gratitude to Patricia D. Siplon for her helpful comments on this chapter, her hard work and diligence as coeditor of this book, and especially her efforts as a researcher, teacher, and sometime activist to limit the spread of HIV and to help those living with AIDS.

1. Nicholas D. Kristof, "At 12, a Mother of Two," *New York Times*, May 28, 2006, Sec. 4, p. 11.

2. Joint United Nations Program on HIV/AIDS [UNAIDS]/World Health Organization [WHO], *AIDS Epidemic Update 2005* (Geneva, Switzerland: UNAIDS, 2005), 1–2. Available at http://www.unaids.org/.

3. UNAIDS, *An Exceptional Response to AIDS* (Geneva, Switzerland: UNAIDS, n.d.), 1. Available at http://www.unaids. org/ (accessed August 18, 2005).

4. UNAIDS/WHO, *AIDS Epidemic Update 2005*, 1.

5. Ibid.

6. UNAIDS/WHO, *AIDS Epidemic Update 2004* (Geneva, Switzerland: UNAIDS, 2004), 5. Available at http://www.unaids.org/.

7. Ibid., 6.

8. UNAIDS/WHO, *AIDS Epidemic Update 2005*, 33.

9. Ministry of Health, People's Republic of China; UNAIDS; and World Health Organization, "2005 Update on the HIV/AIDS Epidemic and Response in China," January 24, 2006. Available at http://www.unchina.org/unaids/2005-China%20HIV-AIDS%20Estimation-English.pdf. See, for example, "China Can Use Lessons from Anti-SARS Battle to Take on AIDS, U.N. Expert Says," *AIDS Weekly* (December 1, 2003), 10; Edmund Settle, "AIDS in China: An Annotated Chronology 1985–2003," *China AIDS Survey*, November 2003, 101. Available at www.casy.org/chron/AIDSchron_111603. pdf.

10. For analysis of HIV/AIDS policy and social activism in the United States, see Patricia D. Siplon, *AIDS and the Policy Struggle in the United States* (Washington, DC: Georgetown University Press, 2002).

# 2

# Power and the Politics of HIV/AIDS

Patricia D. Siplon

Consider three decisions. In the first, a teenage Tanzanian girl succumbs to demands to become the second wife of a much older man whom she barely knows. She does not want to marry, instead wishing to find a way to return to secondary school. But her father is dead, and her mother has no way to support her. The man that the girl has married is seeking a replacement for his second wife, who has recently died of AIDS—though he does not reveal that to his new bride. The young woman gives birth to two babies consecutively, but both die at three months of age. Only after her husband also dies, and she is chased off his property by his family, does she find out that she also has AIDS. She returns to live with her mother until her death after several years of painful, untreated illness.

The second decision is made in France. There the mother of a boy with hemophilia and HIV that he contracted through government-provided HIV-contaminated blood products chooses to join the activist group Act Up Paris.[1] There she finds common cause with other AIDS activists—some drawn from the gay community, others looking for ways to protect the rights of immigrants—in targeting the government, which they all believe is responsible for a host of sins of omission and commission leading to their becoming infected with HIV. Together, they are able to use a variety of tactics—from protests to media campaigns—to put pressure on the government and raise the issue of its accountability. Ultimately, high-level members of the French government are even brought to trial—they are acquitted by the legal system but not by the court of public opinion.[2]

Finally, a third decision is reached by the government of Malawi as to the magnitude of assistance for fighting its HIV/AIDS crisis it should request from a new source of international funding. Burdened with an estimated one million cases of HIV/AIDS—approximately 15 percent of the adult population—the country seeks relief from a new entity, the Global Fund to Fight