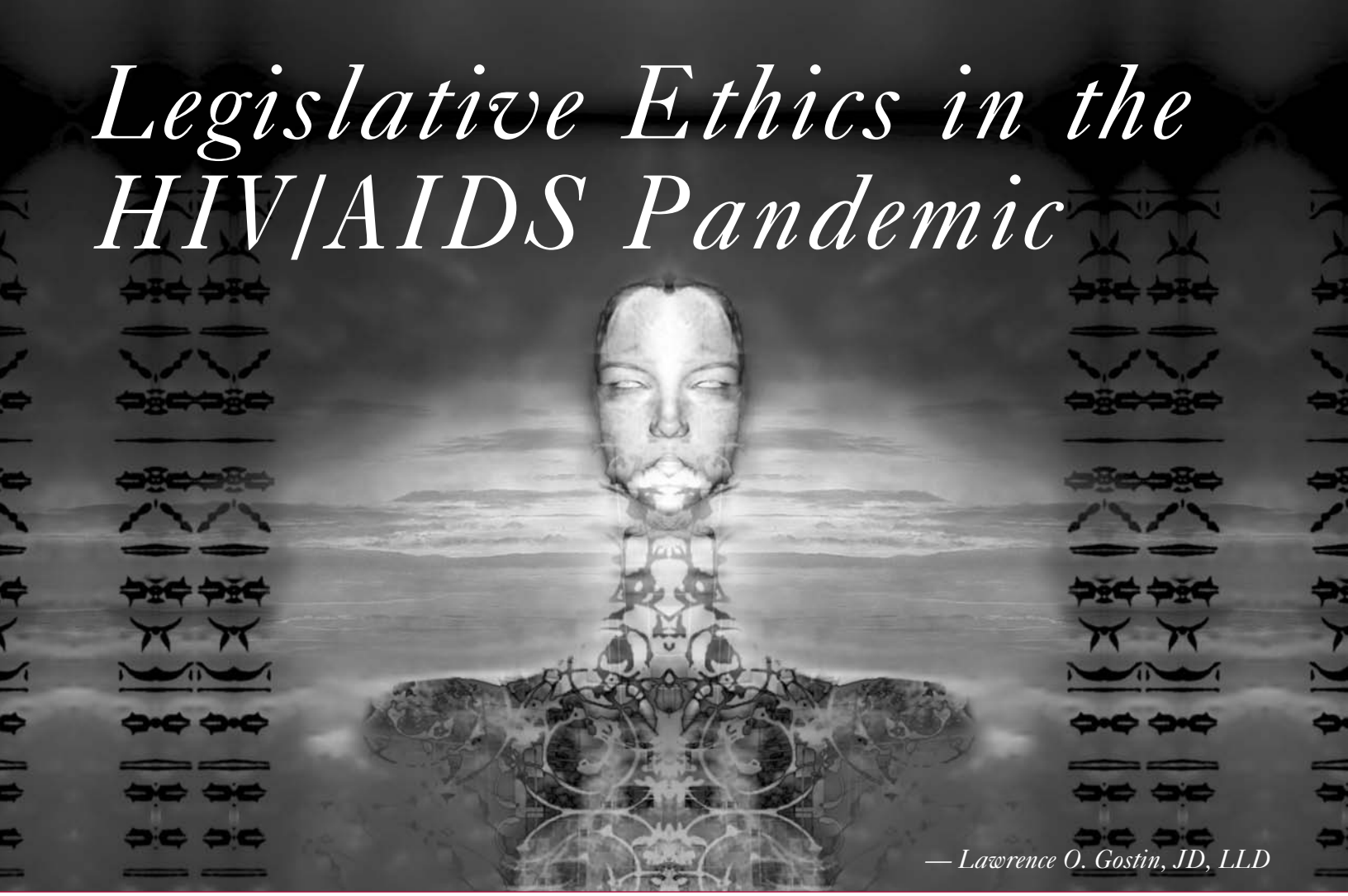
Legislative Ethics in the HIV/AIDS Pandemic



— Lawrence O. Gostin, JD, LLD

Legislators are called on to make a variety of difficult decisions regarding the funding of HIV/AIDS surveillance, prevention, treatment, and research programs. These decisions can involve domestic activities or international financial aid. To legislators, voting on these issues requires making tough choices regarding allocation of scarce resources. To persons living with HIV/AIDS however, these legislative choices are deeply important to the quality of their lives—or even to life itself.[1]

Traditionally, legislators make decisions on political grounds and, of course, they are accountable to the electorate in a democracy. Consequently, legislators pay attention to local constituents (who elect the representatives) and sometimes to special interest groups (who offer financial support). These legislators, of course, understand that they must make difficult judgments with an open mind and without the involvement of conflicts of interest, but are there deeper moral and ethical considerations that ought to influence their decisions? Although there exists no "code of ethics" for legislators to take moral considerations into account, legislators should be motivated by ethical principles. Ethical considerations, moreover, are most important when decisions have powerful effects on the health and lives of people. Voting on HIV/AIDS funding provides a classic illustration of the importance of ethical values in the legislative process. In this article, the major AIDS funding decisions that legislators face, both domestically and globally, are explained; the effects that these legislative choices have on persons living with HIV/AIDS, their families, and their communities are described; and a set of ethical guidelines that can help legislators in making the hard choices they face are proposed.

HIV/AIDS Funding and Policy: What Are the Effects on the AIDS Community?

Legislators certainly can take credit for substantial funding for AIDS programs in the United States. The government spends almost $15 billion annually to combat AIDS domestically, including $2.6 billion for research on vaccines and pharmaceuticals.[2] Of note, Medicaid, the largest single payer of direct medical services for HIV/AIDS, covers 55% of persons living

with AIDS and 90% of children living with AIDS.[3] Federal and state Medicaid expenditures for people living with HIV disease were estimated to be $7.7 billion in fiscal year 2002.[2]

The federal Ryan White CARE Act (RWCA), including the AIDS Drug Assistance Program (ADAP), grants money to the states to provide HIV/AIDS drugs to the uninsured. The RWCA was enacted in 1990 to improve the quality and availability of care for people living with HIV/AIDS and was subsequently renewed by large majorities in both houses of Congress in 1996 and 2000. Estimated to reach over 500,000 Americans each year, RWCA funds totaled $1.9 billion in fiscal year 2002, including $639 million for ADAP.[2]

Unfortunately, ADAP funds have not been sufficient to meet demands in recent years, forcing states to cap enrollment and place some persons on waiting lists. As of September 2003, nearly a third of all states (15 states) have capped ADAP enrollment, imposed cost sharing, or reduced the formulary. Of these, 10 states already have waiting lists, and 4 anticipate new or additional restrictions in the coming fiscal year (2 of these 4 already have some restrictions).[4] Waiting lists and cost-sharing measures can have dire consequences for those in need of drugs to remain healthy: 5 people in Kentucky and 3 in West Virginia died in 2003 while on waiting lists for life-saving AIDS drugs.[5,6] Recognizing the need for additional funding, Sen Charles E. Schumer (D-NY) and 7 cosponsors tried to add over $400 million in RWCA funding, including $214 for ADAP, to the fiscal year 2004 appropriations bill for the Department of Health and Human Services. This proposal was defeated, leaving funding for ADAP flat relative to the previous fiscal year. Given the current situation and the lives being lost, ADAP needs either more money or a way to prioritize the administration of drugs to avoid losing lives.[7]

Substance abuse—particularly injection drug use—plays a primary role in the transmission of HIV infection. In 2002, the Centers for Disease Control and Prevention (CDC) estimated that 28% of new US cases, and 36% of US cases since the beginning of the HIV/AIDS epidemic, could be traced to injection drug use.[8] However, federal law prevents anyone from using federal funds for needle exchange programs.[9]* This ban may result in a significant number of new infections each year; studies have demonstrated that needle exchange programs result in a reduction in HIV transmission and no increase in drug use.[9]

Globally, the Joint United Nations Programme on HIV/AIDS, the World Health Organization (WHO), and the World Bank, among others, have sought funds to meet worldwide needs.[10] The WHO estimates that it will need $9 billion to meet its goal of providing antiretroviral drugs to 3 million people by 2005 (the "3 by 5" program).[11] In Africa, just 1% of HIV-infected people—50,000 out of 4.1 million who need it—have access to treatment.[12] The global lack of funding results in countless lives lost in resource-poor countries. Even if the WHO is successful in gathering the funds necessary for its "3 by 5" program, millions of people worldwide will remain without treatment.

In an attempt to reduce the global burden of AIDS, President George W. Bush in his January 2003 State of the Union speech promised that the United States would provide $15 billion over 5 years to help people with HIV/AIDS.[13] This funding was designated for 14 countries in Africa and the Caribbean and included over $10 billion in new funds. Given the WHO's estimates that $9 billion could provide antiretroviral drugs to 3 million people, $10 billion could have an enormous impact on the pandemic.

Although the Bush Administration promised $15 billion over 5 years, only $2 billion has been appropriated for the first year. Senators Mike DeWine and Richard Durbin in October 2003 sponsored an amendment to a foreign aid bill to bring this year's amount up to $2.4 billion, instead of $2 billion. Although the measure passed the Senate, it contains a provision overturning the Bush Administration's policy of barring money to international organizations that perform or support abortion.

President Bush has threatened to veto the bill, which would mean canceling the original $2 billion promised.[14] Even if the bill is enacted and signed by the President, the Administration's decision to administer the funds separately from the Global Fund is likely to make those funds less efficient.

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* *Title II, Subtitle E of Public Law 100-607 prohibits funds provided under the Public Health Service Act from being used to provide individuals with hypodermic needles or syringes so that they may use illegal drugs, unless the Surgeon General determines that a demonstration needle exchange program would be effective in reducing drug abuse and the risk that the public will become infected with the etiologic agent for AIDS. This prohibition has been renewed and the Surgeon General has declined to lift the ban, even though the conditions had been met.*

These and many other funding decisions by both the Congress and the President take a heavy toll on human lives. The ethics of these policy choices are explored below.

Morality in Voting Choices by Legislators

The most common perception of legislative ethics is basic—legislators should not take any action that would compromise their ability to make an unimpaired decision or would enrich them. Most legislative ethics discourse, then, focuses on impropriety or the appearance of impropriety.[15] However, most discussions of ethics stop short of the next obvious question: On what basis should a legislator make a decision? What is needed is a sense of morality or ethics that informs the legislative voting and decision-making processes.

Many legislative decisions are based on accountability to constituents and attention to special interests. Indeed, these two factors—accountability and special interests—have sometimes benefited the AIDS community. Constituents, or community-based organizations, have lobbied hard to put AIDS funding on the political agenda, despite resistance from government officials. However, there are at least two reasons why this kind of influence has waned in recent years. First, the burden of HIV/AIDS is shifting in the United States from gay men to racial minorities and the poor. These groups often have little political influence and seldom sway the legislative process. Second, the overwhelming global burden of HIV/AIDS is felt in the most resource-poor countries, particularly in sub-Saharan Africa. These countries, too, have very little influence on US funding decisions. Should more robust ethical values then, beyond attention to constituents and special interests, influence voting in a democracy?

There are several important ethical values that should drive the representational process: promoting the public interest, doing justice, behaving responsibly as a global citizen, and respecting human rights. Legislators have a duty to serve the public interest, but what does that mean? First, it means attending to the needs of the entire community, not simply those of a legislator's constituents. Some may feel that since there are relatively few persons living with HIV/AIDS in some jurisdictions, there is no particular political obligation to support expanded funding of AIDS programs. However, members of Congress serve all Americans, including the estimated 1 million people living with HIV/AIDS throughout the country. These people rely on government services and/or funds to meet many of their care and treatment needs. Absent of government intervention, their health and lives are placed at risk.

Legislators understandably may respond that they have to allocate scarce resources and must serve many different interests—national defense, highways, and tax relief, to name just a few. Why should the needs of persons living with HIV/AIDS be a priority? The answer relies on theories of justice. There are many ways of allocating scarce resources, but many ethicists suggest that the fairest criterion for allocation is need. Those who have the greatest need have the strongest claim to services. People form governments to meet their needs, and the first need of citizens is health and life itself. Legislators, if they were to imagine that someone they knew and loved was living with HIV/AIDS or another serious disease, would certainly want to ensure that access to effective treatment was a high priority. Moreover, treatment benefits not only the sick person but also the entire community, because an HIV-infected person receiving treatment is less infectious. Drug treatment programs, like needle exchange programs, therefore, serve both the individual person and the wider community.

Even if legislators agree that Americans living with HIV/AIDS deserve priority in resource allocation, they might argue that no such priority should be afforded to people in other countries and regions of the world. However, those legislators—like all of us—live in a global community, and there are compelling reasons for the United States to support international AIDS programs. Making people healthier and happier anywhere in the world is valuable in itself. As the richest and most powerful country in the world, the United States has a duty to help those living in resource-poor countries.

There are good reasons beyond the purely humanitarian to support global AIDS initiatives. International trade, commerce, and travel are making the world smaller. HIV disease and other contagious diseases can spread from one country to another and one continent to another. Consequently, HIV prevention and treatment programs abroad can benefit the American population. Secretary of State Colin Powell has called international AIDS programs a national security priority.[16] His observations reflect the understanding that all countries, and all regions, are dependent on each other for health, safety, and prosperity.

Human rights obligations provide another important reason for giving

priority to AIDS funding at the national and global levels. The International Bill of Human Rights affords the right to health and to life. Some courts, such as the South Africa Constitutional Court, have already ruled that restricting access to antiretroviral drugs can amount to a deprivation of the right to health.[17] Perhaps there will be no court in the United States that will find a violation of the right to health, but human rights should play a role in the moral obligations of legislators. And one of the first moral obligations is to provide treatment for those in desperate need.

Legislators may think their ethical obligations can be fulfilled simply by avoiding conflicts of interest and attending to the interests of their constituents. But they also have a broader, and richer, ethical obligation to serve the public interest, do justice, behave as good global citizens, and implement human rights norms and standards. The measure of a civilized democracy is how it cares for its least powerful, most vulnerable citizens. AIDS policy and funding decisions test a great democracy like the United States.

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Professor Gostin acknowledges the research and assistance of Sara Hoverter, a JD candidate at Georgetown University Law Center.

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