Introduction to Symposium on AIDS

Waxman, Henry A.

http://hdl.handle.net/1811/64439

Downloaded from the Knowledge Bank, The Ohio State University's institutional repository
Introduction to Symposium on AIDS

HENRY A. WAXMAN*

During the AIDS epidemic as in other times of national emergency, American lawyers have special responsibilities, as officers of the court, members of society, and educated professionals with positions of credibility and respect. Specifically, lawyers must educate the public, political representatives, and the courts about the facts of the disease. Lawyers must provide for the care of AIDS patients within the present broken system of health care and social justice. And lawyers must repair this broken system to ensure that those in need are cared for and that the experience of this decade never be repeated.

If lawyers begin to fulfill these responsibilities, AIDS can be dealt with as a medical crisis. If we do not, it will become a legal one as well.

INTRODUCTION

This Symposium deals with what I believe will be the legal legacy of this decade. The Sixties will be remembered for civil rights, the Seventies for the environment, and the Eighties for the epidemic. We will remember and regret saving a few million dollars and losing hundreds of thousands of lives. We will remember and regret shying away from education and instead moving to mandatory testing.

We will remember the hearings, debates, budgets, legislation, lawsuits, and ballot initiatives. We will remember nothing but ominous silence from the White House and the executive branch offices assigned the tasks of dealing with health policy, and we will remember tortured rationalizations from the Department of Justice officials assigned responsibility for nondiscrimination policy.

In counterpoint to these political actions, however, this era will also be remembered as the beginning of an infrastructure of health and legal practitioners who have come to understand illness and dying as part of their professional lives. The first years of the epidemic will also be remembered with respect for the remarkable emergence of the thousands of volunteers who have simply shown up to do the necessary work that no official or institution was willing to do.

* Democratic Congressman from California, 24th District; Chairman of the House Subcommittee on Health and the Environment; principal author of legislation regarding AIDS research, counseling, discrimination, and confidentiality, which subsequently was incorporated in the AIDS Research Act, S. 2889. The subcommittee has held over 20 hearings on AIDS over the past six years.
AIDS AND THE HEALTH CARE SYSTEM

Dr. June Osborn of the University of Michigan has said that the Greek gods could not have created a drama that would be more tragic and more ironic than this disease, at this time, during this Administration. In many ways, such tragedy and irony have made AIDS unique among health policy problems.

At a time of massive reductions in domestic spending, AIDS demands a sudden increase in research and health care funds. Policymakers who find it difficult to tell heterosexuals about contraception must now tell homosexuals about safe sex. A press corps that just five years ago could not use the words “gay” and “lover” must now explain how “bodily fluids” are exchanged. A legal system that does not recognize sexual privacy among adults must now deal with lovers’ powers of attorney. And gay people—who for years wanted only for the government to leave them alone—now have a real need for protection and assistance from governments that they fear more than ever, and with more reason.

But in other fundamental ways, AIDS is not unique and has only shown in harsh light the cracks and flaws in the American health care delivery system. The epidemic has been a crystallization of the worst problems in preventing illness and caring for the sick.

AIDS has shown that the American health insurance system is unreliable and unfair. If you lose your job because of the economy or your own disability, you lose your insurance.

AIDS has shown that Medicaid is shallow and inadequate. Many middle-class Americans are learning the hard way that, in most states, you can qualify only if you are totally disabled and have less than $1,500 to your name.

AIDS has shown that we can produce medical miracles for the rich and plain neglect for the poor. AIDS drugs and treatments are priced for kings, while Medicaid is only for people who have been made paupers.

AIDS has shown that our best private hospitals are basically businesses, ready to dump those patients who have no insurance. It has shown that our public hospitals are crowded, understaffed, underequipped, and bankrupt.

To respond to the epidemic, the Nation must solve both sets of problems, the specific and the fundamental. It will fall to lawyers to work with medical and public health officials to ensure that the society that lives through the epidemic is a society that is livable.

AIDS AND THE LEGAL SYSTEM

The U.S. Public Health Service has estimated that one and a half million Americans are already infected with the virus believed to cause AIDS. They go on to say that more than a quarter million Americans will become ill from this infection within the next three to five years. Very soon, the number of Americans who have died as a result of AIDS will outnumber the American casualties of Viet Nam.

I have used this comparison for years now, and I repeat it here not because I believe that the seriousness of the epidemic is not known, but because I believe these
numbers and the Viet Nam comparison are useful in understanding the political and legal problems to come. We face social dislocation unlike any event other than war.

The losses of the Viet Nam War deeply changed this country and the world. International politics were re-aligned. Domestic policy was re-examined. Patriotism, party loyalty, and civil protest were all radically redefined.

In the next few years, AIDS will deeply change America as well. If AIDS claims as many lives as projected and costs the country the billions it appears it will, there will be serious national stress and division. Fundamental changes will occur in those institutions that middle-class Americans have come to take for granted: medical care, insurance, education, employment, and—most of all—privacy. Lawyers, in cooperation with our colleagues in medicine and public health, must work to prevent these issues from dividing the country and from disabling our response to the disease.

AIDS AND THE RESPONSIBILITY TO EDUCATE

In important ways, this work is assisted by the nature of the epidemic itself. As hard as it is to imagine, AIDS is not as bad as it might have been. It is infectious, but it is not easily caught. It is not the bubonic plague of the Middle Ages. It is not the flu of seventy years ago. AIDS is not the worst case scenario for medicine or public health or good law.

The first agenda must be to convey that simple fact to the public. At a time when public fear of AIDS is pervasive, everyone who understands the basic facts of the disease is obliged to provide public education. Education programs—both in academic and workplace settings—must face the ongoing dilemma of how to lower irrational fears while increasing the legitimate sense of urgency for social response and for personal changes in sexual and drug practices.

In providing this education, it is clear, however, that because of the legal and social confusion surrounding sexuality in this country, AIDS may not be the worst case scenario for medicine or law, but it may be for politics. Ideologues who have always hated gay men and lesbians are arming themselves with the new rhetorical weapon of AIDS. Such people will manipulate public fears, regardless of public health.

In service both to their clients and the community, legal professionals must be prepared to rebut these medical McCarthyites. Lawyers should reveal them for the propagandists that they are and should respond with facts. Such education is necessary before any other progress can be made in AIDS law.

AIDS AND THE RESPONSIBILITY TO PROVIDE CARE

But even after these educational and plainly political issues are dealt with, there will be many hard problems, many of them discussed in this Symposium. As Professor Vogel notes (see Vogel, Discrimination on the Basis of HIV Infection: An Economic Analysis, 49 Ohio St. L.J. 965 (1989)), we will have to evaluate what employment rights are in this country of opportunity. We will have to examine the cost accessibility of health care in our high-tech society. We will have to reconsider what we mean by insurance and risk-pooling in a time of uncertainty.
In addition to these specific problems, we will have to provide routine health and legal services to people with AIDS in ever-increasing amounts. As Professor Rivera says (see Rivera, Lawyers, Clients, and AIDS: Some Notes From the Trenches, 49 Ohio St. L.J. 888 (1989)), representing people with AIDS is inevitable, and few legal fields will remain untouched by its particular difficulties.

The first point that must be made loudly and clearly, as Mr. Gostin does (see Gostin, The Politics of AIDS: Compulsory State Powers, Public Health, and Civil Liberties, 49 Ohio St. L.J. 1017 (1989)), is that the law should support defending the public health. The responsible protection of individual rights is not at odds with the protection of public health. Contrary to its portrayal in the popular press, AIDS is not a question of individual rights versus public well-being. No one advocates such an extreme defense of individuals. To do so would be to defend yelling "Fire" in a crowded theatre.

During the AIDS epidemic, public health has not conflicted with civil liberties or civil rights. Quarantine is both useless medicine and legal tyranny. Keeping a job is not inconsistent with good public health.

Rather, the law should be revised to work well with public health and medical strategies for responding to AIDS. What is known and understood about this disease is known because AIDS patients and gay men have cooperated with scientists. When civil liberties for these people are threatened, the only outcome will be that the disease will be driven underground. We will know less, and our chances of stopping the epidemic will grow smaller.

Unfortunately, attempts to provide clear federal protections of the rights of those infected have been thwarted at every turn. Lawyers must work to reverse this stance and to enforce the current law as it was intended. Discrimination is bad private practice and bad public policy. In this case, it is also bad for the health of the Nation.

In addition to these global issues, however, legal professionals must brace themselves for the flood of daily demands for AIDS services. Lawyers must be prepared to resist both the attacks of ignorance and ideology as well as the seductions of con artists and snake oil salesmen. People with AIDS and the people who represent them must become the sophisticated consumers of health and social services that many elderly and disabled people have become. Professor Rivera eloquently catalogues the demands and needs that lawyers must be prepared to address.

This is a saddening realization, not just because of the amount of work that must be done, but because articles like Rivera's are an implicit acknowledgment that AIDS is not just an emergency that will be dealt with and be over. The epidemic is not just a public health drama played on a political stage.

It is also daily life—tedious, mundane, maddeningly slow, and detailed. It is not just getting a drug approved, but also paying for it. It is not just getting insurance, but also understanding deductibles. It is not just signing up for research, but also getting fully informed consent.

Lawyers must equip themselves for these services as conscientiously as they would to provide tax planning or family law. AIDS is not just a catastrophe for the nation, but also daily life.
AIDS AND THE RESPONSIBILITY TO REPAIR

As difficult as these first tasks are, the third is even more so. Legal professionals must look beyond the AIDS epidemic and plan for health and legal systems that will serve Americans better. As AIDS becomes more assimilated into the daily life of the Nation, care must be taken to manage the enormity of the epidemic without neglecting the other sick and disabled of society. Even those doctors and lawyers most concerned for people with AIDS and the special tragedy of this epidemic will have to deal with the routine of keeping the whole system functional.

When the battle to have AIDS recognized as an illness and not a curse and to have people with AIDS recognized as citizens and not victims is won, AIDS professionals and patients must continue to care for others as well as for each other. If there is one clear lesson from the epidemic, it is that the Nation cannot have health or legal systems that are “Every Man for Himself.”

Today AIDS is headline news. Legal AIDS cases will create precedent, generate publicity, and lead to journal articles and celebrity support. But other health care groups have found such attention fleeting. The halls of Congress are filled with disease societies and disability foundations. None of them has made the health care or legal system better for more than a moment for more than a few individuals.

As the costs of the epidemic mount, such a single-issue approach to AIDS law and medicine might lead to impossible forced choices in policy, such as whether to pay for AIDS drugs or for prenatal care, whether to pay for nursing home beds for people with AIDS or for the retarded, or whether to do research on AIDS or on Alzheimer’s.

Such fighting over slices of a small, badly made pie will help no one. If the mean-spiritedness shown to people with AIDS is allowed to divide them from other disabled and sick and disenfranchised people, then the epidemic will have divided and conquered the nation.

Instead, we must use the hard-won wisdom of AIDS providers to remake the health and legal systems into institutions that prevent illness, care for the sick, and protect the disabled. If we do less, then we will have to say that over forty thousand Americans have died in vain.

If we can achieve this, we can know that they did not.