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## Some Lessons Learned from the AIDS Pandemic

Mark E. Wojcik\*



When the *Annals of Health Law* was first published twenty-five years ago, the United States and many other countries were in the grips of AIDS hysteria. The then always fatal disease had been discovered only a few years earlier, in 1981. By 1985, it had spread around the country and around the globe. Fear and denial of AIDS, and misunderstandings about how HIV was transmitted produced reactions that many people today simply cannot believe.

AIDS was seen as a disease of outsiders, whose moral practices put the general public at risk. It was a mysterious and fatal disease that conjured up many irrational reactions and fears. There are many examples to cite. Public health officials and emergency personnel often would don full body suits to visit someone who had the disease, even in a hospital setting. A judge in Maryland ruled that defendants who tested positive did not have the right to trial in a public courtroom, and would have to be tried in special rooms at the county prison. Television studio technicians walked off the job to avoid taping an interview with a man who had AIDS. A woman phoned a hospital emergency room to ask whether her son should wear rubber gloves when using a public telephone. Churchgoers in Peoria, Illinois became concerned that they could contract AIDS during communion.

After an antibody test was developed to screen donated blood, some people advocated using the test widely. Some argued that everyone in the country should be forced to undergo regular, mandatory HIV testing. Some wanted to identify and test only those who were in "high-risk groups," such as commercial sex workers, Haitians and other non-citizens, intravenous

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drug users, hemophiliacs and other persons who received any donated blood or organs, and men who had sex with men. Some thought that all homosexuals should be tested if they were applying for work as a food handler, waiter, health care worker, or day care nurse. Others advocated testing every foreign visitor coming to the United States, as if the disease were not present in this country and as if excluding infected foreigners would somehow protect us. One state (Illinois) enacted short-lived legislation that required testing of those seeking marriage licenses.

What might happen to persons who tested positive under these various proposals for mandatory testing? In 1985, a newspaper poll showed that forty-eight percent of those surveyed approved of issuing identity cards to persons who tested positive for HIV (then called HTLV-III) and that fifteen percent favored tattooing those who tested positive. Author and editor William F. Buckley, Jr. proposed that “[e]veryone detected with AIDS should be tattooed in the upper forearm, to protect common needle users, and on the buttocks, to prevent the victimization of other homosexuals.”<sup>1</sup> Officials at the Pentagon considered forced tattoos of military service members who tested positive, and officials in the Reagan administration considered quarantine measures for anyone who tested positive. At least one state introduced legislation to identify and quarantine all persons who tested positive in that state.

The calls for forced testing, tattooing, and isolation recalled practices used in the concentration camps of Nazi Germany. The calls for quarantine and isolation stirred up memories of sending loyal Japanese-Americans to internment camps at the start of World War II or banishing lepers to Kaluapapa on the island of Moloka’i in Hawai’i. Although these testing and quarantine proposals never materialized in the United States, national mandatory testing was instituted in the island nation of Cuba, where those who tested positive were sent to live out the rest of their lives in special *sidatorios*.

Simply taking an HIV antibody test could subject someone to acts of discrimination, even if the results were negative, because these individuals had reason to take the test, and because test results might not always be accurate. When test results were positive, people were thrown out of their jobs, schools, and homes. One man came home to find that his landlord had emptied the entire contents of his apartment into a dumpster, including his clothing, photos, documents, and all of his personal possessions—his entire life was lost. Some who tested positive could find themselves deprived of child custody and even visitation. They could find that their health and life

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1. Michael L. Closen, Susan Marie Connor, Howard L. Kaufman, & Mark E. Wojcik, *AIDS: Testing Democracy—Irrational Responses to the Public Health Crisis and the Need for Privacy in Serologic Testing*, 19 J. MARSHALL L. REV. 835, 838 (1986).

insurance policies had suddenly been revoked, that there were new limits on the amount of money available for medical care, or that medical claims simply could not be covered. Those who tested positive might be denied even the most basic care in a medical facility, nursing home, or dentist's office. One person who had tested positive was told by his dentist that he could not come in for treatment because the dentist had just gotten new carpeting. Medical charts were labeled in ways that never even considered patient privacy. And even those who died of causes related to HIV/AIDS were discriminated against in death when funeral homes denied them basic funeral and burial services. These and other acts of discrimination were by no means limited to persons living in the United States.

Acts of discrimination were rampant against anyone who tested positive and sometimes even against those who simply took the test, regardless of the results. Fear and stigma were associated with the test itself, which pushed the disease further underground when those at risk avoided getting tested. Furthermore, legal protections were non-existent or not enforced in the early days of the disease. Antidiscrimination laws had not yet been extended to persons with AIDS or HIV, medical privacy rights were often simply ignored, and the only laws that seemed applicable were laws to criminalize the transmission of HIV, even by ways that would not transmit the disease.

Thankfully, the situation today is much different. We now understand that HIV is not spread by mosquitoes. We understand that HIV does not discriminate based on morals, or race, or sexual orientation. We appreciate the importance of legal protections for persons affected by the disease, including laws such as the Americans with Disabilities Act and state laws against discrimination. We recognize the importance of respect for medical privacy. We recognize that those who have HIV do not have to be thrown out of their school, home, church, or place of employment. Acts of discrimination may still arise from time to time, but there are now legal protections and remedies. We recognize that AIDS is no longer an invariably fatal disease, but rather one that people can live with for decades with appropriate treatment and care. Despite tremendous progress, we have not learned all of the lessons that the disease should have taught us, and we have failed to provide treatment and care to all of those who need it.

The path to where we are today was one forged by both legal protections and advances in medicine and science. But looking back from where we are now, we recognize that public health measures were effective only within a human rights framework that respected individual dignity and fundamental human rights. We also recognize the critical importance of international cooperation in combating disease and promoting health. Careful study of the responses to HIV/AIDS can inform our approaches to other public health issues, such as SARS or H1N1. The public health battle

is one that requires continued international cooperation. Successful responses require a free exchange of information on medical and scientific developments, informed and effective public health strategies, and respect for fundamental human rights.