
Commentary

Deadly AIDS policy failure by the highest levels of the US government: A personal look back 30 years later for lessons to respond better to future epidemics

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Abstract Successful control of any dangerous epidemic requires: (i) early understanding of the epidemiology of the disease and (ii) rapid applications of preventive interventions. Through the lack of both policy and financial support, the United States Centers for Disease Control (CDC) was severely handicapped during the early years of the AIDS epidemic. Senior staff of the Reagan Administration did not understand the essential role of Government in disease prevention. Although CDC clearly documented the dangers of HIV and AIDS early in the epidemic, refusal by the White House to deliver prevention programs then certainly allowed HIV to become more widely seeded. As much of the international health community relies on CDC for up-to-date prevention advice, these actions by the White House surely increased the spread of HIV around the world. To respond better to future epidemics, we need to understand the deadly forces that inhibited CDC at that time.

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The First Reports of AIDS Cases and a Dreadful Start to Prevention

As we pass the 30-year anniversary of what has become known as HIV/AIDS, some have paused to look back and evaluate what was done and what was not. In one very clear review, De Cock, Jaffe, and Curran, take a three decade perspective.¹ In it, they summarize ‘Although the end of the epidemic is not yet in sight and many challenges remain, the

response has been remarkable and global health has changed for the better'. No doubt, that is true. But, as I look back, there is one period when the response was dreadful. Unfortunately, it was the time when the epidemic was most vulnerable to intervention – the moment it was first reported. The United States Centers for Disease Control (CDC) was very capable of responding, as it has done with innumerable disease outbreaks before and since. But with AIDS, the Reagan administration prevented it from responding appropriately to what very early on was known to be an extremely dangerous transmissible disease. Without clearly understanding the deadly forces that inhibited CDC at that time, we may well face them again when trying to deal with future outbreaks.

It all started relatively routinely: a new disease outbreak reported to the CDC, a call to appoint the initial in-house team of experts, and the Director's request for suggestions about what to do next. The call to join the team came to me in June 1981, when I was the Assistant Director of CDC's Hepatitis Division. By that time, I had been with CDC for over a decade during which time I had worked on many outbreaks in many parts of the world. A new outbreak was not surprising. But this one caught our attention. Although only a few cases had been reported from both coasts, two factors raised our eyebrows. First, the disease appeared extremely serious with most cases expected to be fatal. Second, all cases occurred in gay men.

From the onset, CDC staff worked from the assumption that this serious disease was likely caused by an unknown, transmittable infectious agent. Although, within the medical community, this was clearly a minority view at the time, we at CDC, who had spent years studying sexually transmitted diseases in gay men, spoke from experience. We also knew what to do with a new serious disease. Again, it was a bit routine – determine the 'who, what, where and why' of a new disease and, with that information, figure out how to stop it.

As it turns out, the early 1980s was a bad time to have a new epidemic. Before that, whenever there was a new serious problem, wherever in the world, CDC was more often than not able to put together the forces to understand the disease, its transmission, and the targets for control. With that information, it would then design logical control programs and follow with evaluation measures of success (or failure). What was different this time was the new Reagan White House and how their agenda conflicted with good public health practices.

President Reagan settled into the White House in January 1981. Six months later came the first reports of AIDS cases. By the time the epidemic was in full swing, the Administration appointed Dr James Mason as Director of CDC. Although a public health physician by profession, Mason had solid ties with powerful members of the Administration who sat above him in Washington. It soon became clear that those in the upper levels of government had little or no understanding of what government's role was in disease control.

Sometimes in government work, such inhibition may have little impact. But doctors confronting a new epidemic caused by a highly fatal infectious agent are much like fire fighters confronting a fire. Early aggressive action pays off, whereas slow passive action leads to massive destruction. President Reagan and his team were unable to understand this logic and their obligation to follow it. As a matter of fact, President Reagan himself didn't seem to understand the seriousness of AIDS until his friend Rock Hudson announced he had it in July 1985 – 4 years into the AIDS epidemic. By that time over 15 000 cases of AIDS had been reported in the United States and half of these had already died (Table 1). But I am getting ahead of the story.

Every day in the early 1980s brought reports of new cases from new areas of the United States and elsewhere around the world. By early 1982, just a few months after the first reported cases in Los Angeles, we had discovered over 200 cases in the United States. Nearly one half had already died and the remainder appeared to be on a downhill course. Even for those of us accustomed to dangerous infections, such a highly fatal transmissible disease gave us great pause. Soon after the initial cases in gay men, cases were reported in intravenous drug users, female sexual contacts of drug users, and recipients of blood and blood products. By January 1983, the full picture had emerged. AIDS was a deadly infectious disease transmitted by sexual activity and by the sharing of blood and blood products. By that time, the United States was passing the 1000 case mark. A thousand cases of a highly fatal disease caused by a transmissible infectious agent required immediate public health action.

With time, the frustration grew for all of us who were accustomed to doing our best to protect the public for whom we were responsible: this Administration allowed only partial measures and inadequate funding even as we understood how potentially dangerous was this outbreak.

Table 1: AIDS cases and deaths, by year and age group, through December 2000, United States^a

Year	Adults/adolescents		Children < 13 years old	
	Cases diagnosed during interval	Deaths occurring during interval	Cases diagnosed during interval	Deaths occurring during interval
Before 1981	92	29	8	1
1981	321	122	16	8
1982	1168	452	31	13
1983	3075	1430	77	30
1984	6243	3470	121	52
1985	11 783	6872	250	119
1986	19 040	11 988	339	167
1987	28 586	16 167	506	294
1988	35 481	20 883	618	321
1989	42 744	27 639	730	372
1990	48 697	31 382	814	400
1991	59 706	36 635	813	398
1992	78 646	41 197	949	426
1993	78 948	44 914	923	542
1994	72 174	49 548	814	586
1995	69 098	50 260	676	538
1996	60 216	37 049	500	426
1997	48 467	21 188	300	211
1998	40 567	17 186	217	116
1999	36 575	15 147	150	107
2000	23 932	8867	56	44
Total ^b	765 559	442 882	8908	5178

^aPersons whose vital status is unknown are included in counts of diagnosed cases, but excluded from counts of deaths. Reported deaths are not necessarily caused by HIV-related disease.

^bDeath totals include 407 adults/adolescents and five children known to have died, but whose dates of death are unknown.

My memos at the time revealed our frustration. Here is one to Dr Walter Dowdle, Assistant Director of CDC:

Dear Walt:

The outbreak of AIDS is a huge public health problem which requires a massive infusion of resources. The number of people already killed is large and all indications are that this disease will not stop until thousands of Americans have died.

Our government's response to this disaster has been far too little. Much of this is because the slope of the epidemic curve has been

gradual, lasting years instead of days. We are not accustomed to dealing with outbreaks having long latent periods. But these situations require even greater speed because even after discovery of the cause, we will be so far behind and control will be even more difficult.

The inadequate funding to date has seriously restricted our work and has presumably deepened the invasion of this disease into the American population. In addition, the time wasted pursuing money from Washington has cast an air of despair over AIDS workers throughout the country.

For the good of the people of this country and the world, we should no longer accept the claims of inadequate funding and we should no longer be content with the trivial resources offered. Our past and present efforts have been and are far too small and we can't be proud. It is time to do more. It is time to do what is right.

Searching for the AIDS Bug

In May of 1983, I was appointed 'Coordinator, AIDS Laboratory Activities'. By that time, over 2500 cases had been reported in the United States.

I took on my search-for-the-AIDS-bug job with all of the zeal and enthusiasm that I had had for other CDC assignments. I had all the confidence that we could put together a great laboratory team at CDC. After all, CDC had done this before, most recently with Legionnaire's disease, where Dr Joe McDade and his team found the cause in fewer than 6 months. In retrospect, I was remarkably naïve. Even in situations where support in Washington is solid, as with Legionnaires, it is not easy to find a new disease-causing bug – especially if that bug is a new virus – especially a retrovirus, our prime candidate.

At that time, retroviruses were almost unknown as a cause of human disease. Indeed, CDC did not even have a laboratory dedicated to retroviruses. So we had to build one – even without a dedicated budget from Washington. Unfortunately, our small group, applying the standard techniques used to isolate animal retroviruses, was unable to identify the AIDS virus.

Fortunately, our French colleagues had more success. In late 1983, Drs Jean-Claude Chermann and Françoise Barre'-Sinoussi at the Institut

Pasteur in Paris contacted me to report what they were finding. They needed the important CDC specimens from our AIDS studies to confirm that the virus they had isolated was, indeed, the cause of AIDS. We arranged to rapidly dispatch key specimens to Paris.

By the end of 1983, the US had over 4700 reported cases of AIDS with over 2000 deaths. In February 1984, Dr Chermann came and presented their most recent data to CDC. With the expansion of their work using CDC-provided specimens, it was becoming very clear that the virus they had discovered was, indeed, the cause of AIDS. He also brought a tube of their virus to us and instructed us about how to grow it. Following this guidance, we quickly grew the virus and soon developed our own blood test to detect antibodies. With these tools in place, it did not take long to fully understand the virus, its spread, and its great potential danger. At CDC, we had freezers full of extremely valuable blood specimens – some following gay men for years. These specimens would prove invaluable for determining the natural history of a virus that had a 10-year incubation period. Moreover, since the start of the epidemic, Dr Harold Jaffe and his team, had assembled large collections of blood from AIDS patients and those at risk of AIDS. Dr Joe McCormick had taken a CDC team to Zaire to collect blood specimens from suspected AIDS patients in Africa, and Dr Bruce Evatt and his team had collected specimens from donors and recipients of blood and blood products. Our labs worked day and night testing these specimens to fully understand this virus and to predict the havoc it would cause.

With the French virus and CDC's skill at applying sensitive blood tests to important specimen collections, we put many of the pieces of the AIDS puzzle together in a remarkably short period of time. By April 1984, it became readily apparent that the French had, indeed, discovered the cause of AIDS. Two decades later, in 2008, the Nobel committee gave their prize to the French team for that pioneering work.

The Reagan Administration's Rejection of an AIDS Prevention Plan for the Nation

Once we had the cause and the huge amount of initial laboratory work had been completed, I switched jobs. In the spring of 1985, Walt Dowdle, the very capable head of the Center for Infectious Diseases at CDC, asked me to help him put together an AIDS prevention plan for the nation. Again, being more than a bit naïve, I accepted the task without

hesitation. My experience with changing people's behaviors in the face of dangerous infectious agents was considerable, as I had worked with people in various parts of the world who were faced with dangerous infectious diseases from Smallpox to Ebola. In those situations, people felt directly threatened by the diseases and responded when we offered them vaccines or other 'tools' to protect themselves. I thought the same would be true for AIDS. After all, our work on the natural history had shown that this nasty bug was more fatal than any of the other dangerous bugs with which I had previously worked. Indeed, our early calculations with the HIV led us to estimate that over 80 per cent of infected people would die of their infection. In the end, the estimate was low and, with time, it looked like essentially everyone infected would succumb. Such danger instilled great concern especially in those of us who had experience with other deadly bugs.

The plan was to give the people the latest information regarding the seriousness of this disease and its means of transmission, so that they could use the information to support changes in their risk-taking behaviors. So with the usual CDC zeal, I met with behavior change experts to come up with a plan and a budget of what it would take to decrease the risk of AIDS in both gay and straight people at risk. In the absence of a vaccine to prevent HIV infection, the approach to prevention was rather straightforward – teach *uninfected* people how to remain uninfected and teach *infected* people how not to infect others.

Frankly, it took me some time and considerable brow beating by behavior-change experts for me to really understand these elements. AIDS involved a whole new field for me – behavior change medicine. In my naïveté, I thought it would be enough to simply give people the facts: that HIV has a 100 per cent mortality and that to get infected will ruin your day – thus, don't risk infection. I thought, if people heard 'this bug would kill you if you do unsafe sex or drugs', they would, for sure, avoid infection.

In my previous work, quick messages like 'Ebola is a horrible disease, keep your distance' or 'smallpox is in your village, get vaccinated', had worked very well. But in these situations, much of the behavior-change work was done for us by the epidemics themselves. These deadly outbreaks were visible, fast moving, 'in-your-face' phenomena. Getting people to join the prevention effort was quite easy, given immense motivation with the very obvious mortality from the outbreak. For

diseases like smallpox, taking a vaccine is a short-term effort requiring a minimum of behavior change for the target population – just give me your arm for a few seconds and it's done.

It was different for AIDS, where a prevention program needed to change people's sexual or drug use behavior. And the changed behavior would have to be maintained forever – not just for a few weeks until the outbreak dies out. Moreover, with a 10-year incubation period, this disease did not get people's attention as the others I had previously confronted.

Our plan focused initially on the urban areas with the highest rates of cases. It was straightforward, frank, and not extremely elaborate. It involved hiring teams of people, educating at risk populations of urban areas, testing them for antibodies, and counseling them on ways to prevent further spread. The cost was substantial for those days, \$37 million, but I felt justified considering the dangers that HIV posed to the population. Senior management of CDC reviewed, finalized, and sent it to Washington.

This, the nation's first AIDS prevention plan, worked its way up the administrative channels to the highest levels of the Department of Health and Human Services. It didn't take long for the answer to come back down. I remember the response so well because it alone predicted the future of AIDS both for the United States and for much of the world.

The day was 4 February 1985.

I was on the 4th floor of CDC's main building. We had just completed one of our many meetings in Dr Dowdle's corner office, and I was chatting after the meeting in the common area. Dr John Bennett was the central coordinator for AIDS at CDC serving as the chairman for our AIDS Task Force. John pulled me aside to tell me what 'our leaders' in Washington had to say about our plan. John is not an overtly emotional man. But when he pulled me over, there was no doubt that what he wanted to talk to me about was serious. In a quiet, but clearly pained voice, he relayed to me what the highest levels of government said about my plan to limit further spread of HIV. 'Don, they rejected the plan. They said, "Look pretty and do as little as you can."'

Neither one of us had much to say. Looking back, I think we expected a dismal response from this group of 'leaders' who, since the beginning of AIDS, had repeatedly refused to allow CDC to do what any reasonable executive should have required it to do. We came to easily recognize the pattern. The elite of the Reagan administration, and later the Bush

administration, had no idea of their responsibility to protect the health of the people who had elected them.

The Director of CDC during those days, Dr James Mason, was also not willing to fight his bosses to protect the public from AIDS. Mason was a conservative appointee from Utah. Years later, as he looked back at the early AIDS years describing his inability to confront the conservative leadership, he stated ‘there are certain areas which, when the goals of science collide with moral and ethical judgment, science has to take a time out’.² The issue here centers on how a public health leader determines what his/her responsibilities are for protecting the health of all of the public. Mason took the easy way out, choosing not to confront the primitive forces in the Administration. It seems to me that neither a practicing physician nor a public health physician has the option to make such moral judgments about the people for whom they are responsible. Their job is to save lives, to protect the public’s health. Period.

But a proper response to the ever-so-serious AIDS epidemic was just not going to happen. Looking back, we could see the disaster coming. By the mid-1980s, we were becoming fully cognizant of the peril posed by HIV. We had data from many locales in the United States showing that the epidemic, by the time it surfaced with clinical AIDS, was well seeded across the country, and early recognition that the disease was not limited to the United States. Dr Joe McCormick’s data from Zaire showed that the infection was widespread in Central Africa. And other countries, especially Haiti and France, had reported considerable numbers of cases.

By mid 1985, over 10 000 cases of AIDS had been reported in the United States, and many other countries in Europe and Africa were reporting epidemics. In the terminology of public health, this previously localized epidemic was rapidly turning into a *pandemic* involving the whole world.

Traditionally, both national and international public health experts looked to the CDC for guidance on the control of new pandemics. But for AIDS, guidance was not to come. The ‘look pretty and do as little as possible’ *guidance* that CDC got from Washington, was rooted in the simplistic view of President Reagan and his colleagues in the White House. The Reagan crew was determined to cut government spending. Their simple-minded approach had no room for complex concerns like AIDS. If no AIDS resources (money) were going to come from Washington, then there was no room for discussion of good public

health policy, structure and how to apply it. Ignoring AIDS was not a passive endeavor. It was an active policy of the Reagan Administration.

Publicly, the Reagan Administration called AIDS ‘the federal government’s number one health priority’. But within their own halls ‘the Reagan Administration maintained that federal health agencies should be able to meet the growing AIDS threat without extra funds, simply by shifting money from other projects’. The past president of the American Public Health Association put it this way ‘[The Reagan Administration people] tend to see health in the same way that John Calvin saw wealth: it’s your own responsibility, and you should damn well take care of yourself. While the Reagan administration dozes and scientists vie for glory, the deadly AIDS epidemic has put the entire nation at risk’.³

The Surgeon General at that time, Dr C. Everett Koop should have been the one to lead the charge so that CDC could deliver an appropriate prevention program. However, he was forbidden to say anything about the disease for five and half years of Reagan’s term. Koop finally broke ranks with the Administration and issued a Surgeon General’s report in October 1986. For that, Koop was attacked within the Administration by a list of notables: Education Secretary William Bennett, his aid, Gary Bauer (who later became White House domestic policy adviser), and Patrick Buchanan, White House director of communications.⁴

Buchanan had shown his colors well before joining the staff when he wrote about AIDS ‘The poor homosexuals. They have declared war on nature and now nature is exacting an awful retribution’.⁵

So much of our early response to AIDS was mishandled and misdirected in the United States. As much of the world turns to the CDC for leadership in cases of new epidemics, the resulting vacuum had much wider ramifications. But with AIDS, it was not just an absence of leadership. It was often active obstruction of logical responses. These people caused immense preventable suffering and death – and it is likely that no one in the Reagan Administration will ever be held accountable.

About the Author

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References

1. De Cock, K.M., Jaffe, H.W. and Curran, J.W. (2011) Reflections on 30 years of AIDS. *Emerging Infections Diseases* 17(6): 1044–1048.
2. Andriote, J.M. (2011) *Victory deferred: How AIDS changed gay life in America*, 2nd edn. Chicago: University of Chicago Press, p. 137.
3. Talbot, D. and Bush, L. (1985) At risk. *Mother Jones*, pp. 29–37.
4. Koop, C.E. (1991) *The Memoirs of America's Family Doctor*. New York: Random House.
5. Morris, E. (1999) *Dutch – A Memoir of President Reagan*. New York: Random House, p. 816.

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