Have We Learned Anything After 20 Years of AIDS? Call for a National Health Board

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Jonas Salk wrote before his passing that the evolution of "modern man" would be conditioned more by "survival of the wisest" than the more traditional Darwinian predictions of fitness.[1] In turn, it has been said that wisdom accrues from repeated errors and the acquisition of understanding from those errors. If such is true, then an examination of public health's (and, indeed, society's) response to the AIDS pandemic over the past 20 years would give us some insight into our errors and, in the end, add to our wisdom.

Over the last 20 years, as our scientific understanding of AIDS epidemiology has accumulated, the picture of the evolution of the epidemic has become quite clear. Human immunodeficiency virus type 1 (HIV-1), it appears, is an ancient virus of chimpanzees[2] that is likely to have infected humans repeatedly for centuries as these animals have been hunted and butchered in central Africa. Those who inadvertently became inoculated through the butchering no doubt died of their disease, as may have their sexual partners. In pre-industrial Africa, the epidemiologic conditions were not aligned for expanded spread, and these deaths were likely attributed to tuberculosis or other wasting syndromes.

It was not until the early 1970s that the conditions became ripe for worldwide spread of this dangerous virus. At that time, large numbers of male workers migrated to African urban centers, and female sex workers followed them. In this new setting, the sexual activity of a chimp-infected worker would have dramatic consequences. No longer would a small outbreak in distant communities remain isolated. The world was a different place. Airplanes allowed infected people to arrive in other world centers in a matter of hours. And in these distant centers, new social environments had developed that were perfectly designed to rapidly expand a sexually and blood-borne infectious agent. Gay men were frequenting commercial sex establishments, or "bath houses," and intravenous drug users clustered around commercial needle-sharing establishments, or "shooting galleries." All of these changes in patterns of intimate contact in Africa and elsewhere in the world added immense

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amplification potential to an infectious agent transmitted by sex and blood sharing.

The rest, as they say, is history. From the mid-1970s to 2001, an estimated 53 million people have been infected with a virus having essentially a 100% case fatality rate. Fifty-three million—that's more than the population of three New York Cities! Of course, there are other health-consuming diseases around the world. But HIV/AIDS is different. It is communicable, it is highly fatal, and infectious people are infectious over a long period of time without symptoms or signs. Not since the Black Death of the Middle Ages has a disease of this proportion emerged.

In 1981, the Centers for Disease Control (now the Centers for Disease Control and Prevention [CDC]), through close relationships with local public health authorities, picked up the first signs of the epidemic relatively quickly[3] and began appropriate investigatory and educational activities. But because of a variety of intersecting political and social realities of the time, the CDC was unable to take the next essential step—the delivery of prevention programs equal to the risk posed by HIV.

Indeed, the political environment existing at the time of HIV's introduction into the United States, together with the disease amplification networks, were ideally designed to maximize HIV's transmission rather than reduce it. Politically, upper-level elected officials were incapable of allowing, not to mention guiding, an appropriate public health response to a disease transmitted by homosexual sex and intravenous drug use. There was active obstruction of the essential public health interventions required to decrease HIV's transmission. With the election of Ronald Reagan as President of the United States, a coalition with anti-government spending, anti-gay attitudes, and "them vs us" politics existed that aligned with HIV in a way that clearly allowed this vicious virus to expand its foothold in the United States. Public health workers from around the world had often turned to the US for guidance regarding new epidemics; sadly, in this case the American weakness had a broad effect on HIV's spread around the world.

But I don't believe the blame for the relative paralysis of public health in those years, and even today, in the United States can be solely placed on the shoulders of one administration. There are at least two additional factors.

The first factor: American people don't care much about disease prevention. We value disease treatment far higher than disease prevention. Indeed, it may be true that the American public doesn't care about the health of the poor, the junkie, or the queer. Without value given by the body politic, even the best leadership of a country will be challenged to mount a public health response against a highly fatal virus like HIV that is spread by sex and sharing of blood.

But the "not valuing prevention" premise may be overly simplistic, for some prevention activities are highly valued, especially those that involved fast-moving threats. Take, for example, fires and airplane crashes—here, the American society is willing to spend considerable resources to prevent injury and death. Indeed, the same can be said for some dangerous infectious diseases. When I was sent by the CDC to investigate and control the first outbreak of Ebola virus in 1976, there was immense interest in preventing its further spread—including putting me and my colleagues in quarantine for two weeks before allowing us to return to our homes. Perhaps the explanation here is that these threats are seen as threats to "us." Other threats, such as AIDS, have been (and still are) seen as threats to "them."

Eager, proactive preventive actions were not launched against HIV. Why? No doubt this is largely accounted for by our lack of commitment to prevention, the anti-gay politics of the extremists on the right, and the general anti-government philosophy of the country at the time. But there are specific qualities of HIV itself that have added to the difficulties of the American public and its political leaders in responding appropriately to this deadly infection. Here is the second factor: the long incubation period of HIV. A long incubation period causes a delay in diagnosing the disease, giving the appearance of a rather slow-moving epidemic—far different from a fire, an airplane crash, or an Ebola outbreak. Health threats that enter slowly are far more difficult for our society to rally against than those that enter quickly and dramatically. Just as in the physiologist's experiment with the frog placed in cold water on the burner, we will stew in a slowly consuming epidemic until, when it boils, it is too late. With a mortality rate higher than Ebola, yet with an incubation period years longer, AIDS was the equivalent of the eventually boiling water. World societies, led by the Americans, were lulled into inaction by this slow-moving, yet remarkably deadly, pandemic.

But I must return to the lack of social value given to preventive medicine, as I believe it is the common thread that helps explain how our society has not progressed (gotten wiser) on many fronts. Preventive medicine has seldom been given its appropriate value. Our society is far more interested in investing in radical lung surgery or liver transplants for the likes of smoking-related cancer or infectious disease–related

liver failure than it is in preventing the root cause. We have been eager to established massive compensation systems to pay for complex, low-return, high-cost therapeutic interventions, but have been far more reluctant to fund simple high-return, low-cost prevention programs such as childhood vaccine programs. We have subsidized tobacco growers and allowed advertising of cigarettes while, at the same time, paying the immense costs of caring for the diseases caused by them.

The lack of social value given to prevention sets up a vicious cycle. If society doesn't value prevention, why should politicians spend political capital to support it? Moreover, why should able leaders, doctors, or administrators pursue careers in preventive medicine? Fortunately, a few organizations, most notably the CDC, have been able to kindle a spirit of excitement over preventive medicine, despite the country's apathy. But that is hardly reassuring. And let's be honest, much of the CDC's early and more recent financial support has come from political leaders' attempts to counteract the threat of biological warfare/terrorism rather than from dealing with the threat of more common infectious diseases. Thus, the great contributions the CDC has made to the world's health have been, at least partially, a secondary benefit different from the initial political intent.

Without the overall social value and resulting political force, how can organizations like the CDC thrive? Without these forces, the can-do recruits interested in improving the public's health get discouraged and find other professional avenues. Worse, the lack of social value leads elected and appointed high-level leaders away from supporting the strong public health interventions that are required to combat new, serious epidemics like the AIDS epidemic.

In the early days of AIDS we saw example after example where the weakness of high-level leaders left a vacuum into which extremes entered and, in the end, aided the spread of HIV. The result was not only discouragement of the public health workers who were engineering appropriate programs, but a further excursion of HIV into the healthy members of society. And then, after the disease had done more and more damage, the same executive leaders (or their replacements) turned to the public health institutions such as the CDC and asked, "Why did you not do more?"

Before suggesting some potential solutions for this problem, allow me to give a few historical cases in point from the AIDS epidemic that will illustrate this cycle:

Transfusion-associated AIDS, 1983–1985. There are few clearer examples of where the CDC sounded an alarm but did not have the resources or the backing from high-level administrative leadership to prevent tens of thousands of deaths. In January 1983, the CDC called a meeting with the blood industry to explain its immense concern for the recipients of blood and blood products. With AIDS cases mounting among intravenous drug users, hemophiliacs, and recipients of blood transfusions, the risk of blood-borne transmission appeared clear to those of us working at the CDC. But those responsible in the blood industry did not have a preventive medicine mentality. Their role was to collect blood and have enough on hand for transfusions, and they resisted any addition of AIDS-prevention modalities that would eliminate gay men from blood donation. They exerted their considerable muscle through the administrative channels open to them and resisted the CDC's recommendations. The CDC had neither the support from above nor the staff below to counteract the power of the blood industry. As a result, tens of thousands of preventable deaths occurred in the United States from transfusion-associated AIDS, and thousands more occurred elsewhere as the weak American preventive response was emulated in other countries.

Safe sex education for youth, 1986 to present. The public health community has been all but paralyzed in delivering preventive programs to slow the spread of AIDS among the country's youth. When delivering any public health program, one must find access points to contact targeted groups economically and effectively. Schools are ideal sites to deliver behavior change programs to those beginning sexual activity. The need for accurate information on the transmission of AIDS is obvious. Young people, both heterosexual and homosexual, are, or soon will be, at risk for HIV infection. Not having insertive sexual activity or protecting such activity with latex condoms are obvious solutions to encourage through behavioral-change programs. Public health institutions need to organize well-designed prevention programs that deliver information, motivation, skills, and peer support to change the sexual behavior of our youth. But consider the times when such programs should have been launched—the upper levels of the national leadership were hardly interested in delivering sex behavior modification programs. They were more concerned with the likes of removing the teaching of evolution from the school curriculum so that biblical creationism could replace it.

Public health officials were prevented from delivering the necessary programs. In their structure then (and now), public health agencies were not free to act outside of the political realities of upper political management. Without a mandate from the executive

branches of federal, state, and local governments setting the policy necessary to allow programs such as youth education and providing the resources required to deliver them, AIDS prevention was not going to be delivered. It was abundantly clear at the federal level that neither policy nor resources were going to come for such programs. In this vacuum of federal leadership, it was left to the states to protect their constituents. In the absence of strong support from federal organizations such as the CDC to which states had traditionally turned for guidance and resources, local public health leaders had to venture out on their own. But such new roads were difficult to construct. One could wonder, looking back, whether governments were aligned on the side of the virus or on the side of the people.

Take an example from California. By the mid-1980s, California had begun to see the ugly face of AIDS. A small group of respected leaders from public health, academia, and the gay community approached state politicians to draft legislation mandating school AIDS education programs. The need for action was clear, and legislation was designed that would require schools to add AIDS education to their curricula. Despite active objections of the highly influential "family values" groups, AIDS school education legislation was passed through both state legislative houses and went to the governor for his signature. At the same time, the conservative factions that opposed the AIDS education bill passed parallel bills. Those bills required any education that involved sexual activity to stress abstinence. The AIDS educators actually had little objection to abstinence as a prevention modality as it was an acceptable alternative to prevent HIV transmission. The key word here is "alternative." Choice is known to be an essential principle of successful behavior change programs. In the end, Governor Deukmejian vetoed the AIDS education bill and signed the abstinence bill. This same cycle occurred for each remaining year of Deukmejian's term.

When the need to protect the public's health conflicts with the will of political leaders, public health workers cannot protect the public's health. Sadly, in the arena of youth education and behavioral modification, the abstinence-only debate continues 20 years later.[4]

Intravenous drug addiction, 1985 to present. Few members of society are disliked more than junkies. Early in the AIDS epidemic, as women and their babies were infected, it became clear that injection drug users (IDUs) were the major avenue for HIV to enter the heterosexual community in many parts of the world. As epidemiologists examined HIV transmission in this group, it also became clear that it was not drug addiction that was the cause of HIV transmission; rather, it was the sharing of injection equipment. Thus, the logic of the simple-minded disease interventionists suggested the obvious—give addicts their own injection equipment and instruct them not to share. The logic here extended far beyond the mere supply of equipment. In the process of exchanging injection equipment, addicted people, traditionally very hard to reach for any prevention or treatment program, came out of hiding. But, like the proposal to provide condoms to youth in school, the proposal to provide sterile needles to IDUs hit head-on with many political leaders. Here the logic of public health collided with the anti-crime, send-them-to-jail campaign promises of most conservative politicians.

In some areas such as San Francisco, where public health, law enforcement, and political leaders spoke with a common voice and community activists had already begun needle exchange on their own, approval was achievable. But in the vast majority of areas, needle exchange was obstructed and is still not practiced decades after the epidemic started. Moreover, society's overall approach to IDUs is misdirected, but I will address that issue below.

Vaccines, 1985 to present. Despite the fact that many of our epidemic diseases have been eliminated or controlled with vaccines, vaccines are undervalued by our society. Indeed, the lack of social interest in vaccines is, in some respects, a direct result of their past successes. Vaccines are now viewed as those injections that caused each of us, or our children, to wince in pain. Never mind that horrendous diseases including smallpox, polio, diphtheria, whooping cough, tetanus, yellow fever, and the like no longer extract the huge toll they once did.

Again, we see disease treatment given higher value than disease prevention. Look at AIDS, where the priority (i.e., money) of both the public and private sectors has been given to treatment. Organizations of community activists, government researchers, and private pharmaceutical firms organize to spur development of drugs to *treat* HIV disease. As a result, the advances have been considerable. This is good. But the same interest and the resulting advances have not been seen for vaccines. Without social value given to vaccines, the investment necessary to develop this essential disease control tool will not be found. This is bad. Everyone knows that, in the long run, vaccines are the only tool that will stop the HIV pandemic, but this is intellectual understanding without translation to action. Sixteen years after the discovery of HIV, books equivalent to *And the Band Played On*,[5] chronicling the weakness of

our nation's inadequate early response to AIDS, now are chronicling the weakness of the AIDS vaccine effort.[6,7] And, finally, a few non-government organizations are springing up in partial efforts to highlight and correct this important disparity (e.g., the International AIDS Vaccine Initiative, headquartered in New York City, and the AIDS Vaccine Advocacy Coalition in Washington, DC).

Past successes and future directions. But not all has been bad. Some progress has been made in AIDS prevention over the past 20 years. Despite the weak initial national response in the United States, some corrections have been made. Local government and non-government organizations have risen to the occasion and have had some dramatic effects. Declines in transmission rates in gay men[8,9] and intravenous drug users[10] have, in some areas, been impressive. Some countries, most notably Switzerland, Thailand, and Uganda have been courageous in dealing frankly with their epidemics. Leaders in these countries stepped forward. In the United States, large sums of money are now dedicated to both the treatment and prevention of AIDS. Much of the credit for the change in the United States is due to the joining of forces of concerned citizens, community groups, and government officials. Together they provided a force that the highest levels of government could not resist.

Looking ahead, how should we address AIDS? Using what we have learned, where do we go from here? There are many things that need radical change, but I will highlight only five.

1. A National Health Board. If we have learned anything, it is that public health activities need to be protected from political interference. Training gay men how to have safe anal intercourse, training intravenous drug users how to inject their drugs safely, and training young people and female sex workers how to use condoms are programs that are essential for protecting the public's health. But they are hardly programs that attract even well-intentioned public figures. Worse, they are lightening rods for ill-willed politicians who use divisiveness to gain public attention. If we examine the history of AIDS, we find that in all but a few areas of the world the obstruction of ill-informed power brokers has usually overwhelmed the influence of the well-intentioned. The status quo, or worse, has prevailed. The status quo in the midst of a deadly epidemic is a prescription for misery and death. It happened for AIDS. It will surely happen again for other diseases unless there are major structural changes.

A structure is needed that will insulate public health authorities from political interference.

In past years, such insulation structures were part of public health authorities. In those times, boards of health protected health officers and their political bosses from the adversities associated with such things as quarantine of ships and the isolation of infectious patients. With such a structure, politicians are insulated from the political minefield of socially controversial prevention programs required to control infectious diseases.

In other government departments, insulation structures have been put in place to protect important decision makers from political influence. The most prominent one is the judiciary; a totally separate branch of government was established to insure independence so that one branch of government could not abuse its power and injure the public. Another example is the Federal Reserve Board, which makes decisions that have huge economic impact independent of political influence. Here again the intent is to ensure that decisions are made for the greater public good. A similar structure needs to be established to protect the public's health.

An independent public health board must be carefully designed to allow it to operate independently, yet responsibly. I suggest that the United States establish a National Health Board that would oversee the CDC. This Board would appoint a National Health Officer to direct national public health programs. It would be the responsibility of the National Health Officer to develop multi-year budgets and submit them to the National Health Board. The Board would then have special mechanisms through which the budgets would be granted by the legislature.

2. Addiction policy. If this country is going to make any impact on the negative personal and societal influence of drug use, major policy changes will have to be made. Here the Swiss model should be emulated. Switzerland, faced with a growing HIV epidemic in injection drug users, especially in Zurich, struggled with all of the issues of needle exchange, medically supervised injection sites, and social and medical support to reduce the harm of addiction. The Swiss also faced the reality that one canton like Zurich could not act in isolation from other cantons. In the end, even the most conservative cantons voted for "medicalization" of addiction. The positive effects in both infectious disease and crime have been dramatic.[11,12]

3. High incidence areas in less-developed countries. In some areas of the world, predominantly sub-Saharan Africa, a third of the adult population is dying of HIV-related disease. Such huge social disasters cannot be ignored by the rest of the world. If we have learned nothing else from the AIDS epidemic, not to

mention the events of September 11, we should have learned that the lives and the health of poor people in other parts of the world dramatically affect us here at home. The National Security Council of the United States and the Security Council of the United Nations, among others, have issued strong statements highlighting the security threat AIDS poses to the entire world. Outside support for prevention and care programs will be essential to minimize misery and ensure stability in these areas. For us to say, "We don't care about them," is clearly unwise.

Although the level of infection occurring in the United States is less than that in Southern Africa, Americans have had some experience in dealing with high-incidence AIDS areas. For example, San Francisco lost almost 3% of its adult population in the era before highly effective anti-retroviral therapy became available. Of highest importance was social and medical support for the dying and social support for those left alive. Similar services will have to be provided for Africa. In addition, support will be needed for the care of the 1.4 million children orphaned each year as their parents die from AIDS. Again, it would be very unwise to ignore such a disaster occurring among our neighbors.

4. Vaccines. It will be a vaccine that halts the worldwide onslaught of HIV. The public sector can stimulate basic research, but the skills of the private sector must be harnessed to move basic research ideas forward. For the private sector, pursuing vaccine development depends on economic incentives. The private sector will invest the necessary resources if there is a reasonable chance for a financial return. As long as the social value given to disease therapy exceeds that given to vaccines, therapeutic drug development will take precedence. Stimuli will be required both to "push" development (development grants, support for clinical trials, etc.) and to "pull" development (indication that HIV vaccines will be purchased, protection from non-negligent liability, etc.).

5. Declaration of unacceptable levels of transmission. In the end, it will be the people who decide what level of HIV infection is acceptable. Given the high mortality with HIV, one would think that the level should approach zero, but to attain such a level without a vaccine would require considerable behavioral change that some will feel is too extreme. Thus, it will be up to "the community" to decide what is acceptable behavior for HIV-positive, HIV-negative, or HIV-unknown persons.

In summary, much can be done to interrupt HIV transmission, but little will be accomplished without some major changes in the policy, resources, and structure of public health programs. Such changes will not occur until the society at large declares some increased value to disease prevention in general and HIV prevention in particular. Such social declaration will require a level of social maturity that, to date, we have not attained. Let's hope that the wisdom we have acquired by examining our past mistakes will lead us to that level of social maturity.

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