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Remarks
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It had been four days since I spoke on AIDS to a public audience.

This was the first time I had spoken outside the United States, except on the occasions of the meeting of the World Health Assembly in Geneva. This London meeting was of four day's duration with innumerable speakers, who spoke about the effect of AIDS and its ramifications on the health of individuals and societies. I had been asked to address one of the non-medical issues namely, "How does the AIDS epidemic affect the balance between individual freedom and the public interest?

This is something we had thought a lot about in this country, because it had to do with the debate upon testing for the presence of the virus and brought up the old saw about confidentiality vs. the safety of the community.

So, I started out by saying that one of the extraordinary aspects of the epidemic was the very fact that such an issue could be raised at all and it did not seem out of place. When you think of it, individual freedom, professional responsibility, civil rights and wrongs, and many other issues, which seem to be appropriate in the context of AIDS, would be of marginal interest or no interest at all in the context of almost any other infectious disease. The only exception I can think of is leprosy.

I started by talking about an abstract philosophical theory: people in our society once given the facts are able to make a free choice on the basis of those facts and they individually and collectively will benefit. However, conversely, the person in our society who does not know the facts of life and health – facts that known by most of his or her neighbors – is not a free individual able to make a choice – that's not a theory, it is a reality.

In the real world of our inner cities many lack information about nutrition, personal and environmental safety, and we feel a compelling need to relay information about AIDS to hundreds of thousands of such individuals at the risk of infection. So, we have to face the possibility that our messages about AIDS may be as unsuccessful as our messages were

yesterday about diet and family planning and smoking and fire prevention and syphilis and alcohol abuse.

My concern is that we have tried to deliver the facts about many public health matters, and help citizens freely make their own choices, but when they have not been able to use the information I believe they are not free. Having said that, I suggested that this audience might prefer that I speak to the specific issue of how we serve the public interest and permit individual freedom, which is the hallmark of our society in the global sense.

As background, I reminded the audience, as I always do, that AIDS is still somewhat of a mystery, it is virtually one hundred per cent fatal, and is spread by people doing things most people do not do and of which most people do not approve. All this means is that the diagnosis of AIDS will bear a stigma and in the United States, that has been known to deprive one of housing, going to the barber, shopping at the supermarket, attending school or church. This is ostracism and has led to a heightened suicide rate among persons with AIDS. In one horrible instance in Florida it led to the arson of the home of three HIV positive children whose sin was having been born with hemophilia.

Contemplation of such unjust and unfair treatment points up the widely held position of the need for confidentiality in reference to HIV test results and diagnosis. In the long term, confidentiality is not in conflict with the pursuit of the public's interest. Indeed, it augments the public's interest by not driving the AIDS patient underground and permitting that person to enjoy the benefits of what we do know about AIDS.

Contrary to normal health procedure, I had argued at that time in the United States, against any kind of universal compulsory testing. We thought we had about 1.5 million people walking around with the virus. Although we knew that about 90 per cent of all persons with AIDS had been either I.V. Drug abusers or homosexuals or bisexual men, we also knew that these groups were not large and in addition, the overwhelming majority of homosexuals and bisexuals had been untouched by the epidemic. We also knew that this community of men had undergone a very serious and positive change in behavior. (We kept track of the situation not by tracking AIDS, but by tracking rectal gonorrhea and found that it did indeed diminish dramatically and precipitously – only to rise again when the educational campaign aimed at homosexuals by homosexuals was discontinued.)

The future of I.V. drug abusers with AIDS was not nearly as promising. We have always had very poor success in penetrating the drug-addicted culture with every other public health message, including simply saying, "Stop!" Part of this problem is really the addiction itself, because we had about 5,000 deaths from drug overdoses or drug induced violence that had nothing to do with AIDS. So, testing for HIV antibodies will not of itself contain the epidemic nor will any of the other measures some advocates of mandatory testing supported, such as quarantine, identity cards, compulsory contact tracing, public recording of the identity of HIV positives. I supported none of these.

Mandatory testing has a place with some groups, but not for the majority. The U.S. Armed Forces mandate testing of all recruits and active duty personnel for two reasons:

First, they are immunized against every disease for which there is a disease and a live virus vaccination in such a population could be lethal to any HIV positive personnel. Secondly, the Armed Forces are their own walking blood banks, a major reason why our Foreign Service personnel are tested.

On the other hand, pre-marital testing is expensive and would not contain the epidemic. It has nothing to do with the days when a negative pre-marital test for syphilis was required for a marriage license. There was a cure for syphilis, but also in the days this was popular, living outside the bonds of marriage was frowned upon. Such today is not the case, not only is there no cure for AIDS, but the majority of those getting married in America have already been living together. It is also notable that those practice high-risk behavior, in general, are not applying for marriage licenses. Then there is also the combination of the possibility of false positives and the stigma accompanying HIV positivity, which is a risk many young folks do not wish to take.

Finally, the cost benefit ratio is very high, because only a very small number of those tested would be true positives in most communities. At that time it was estimated that it would take approximately $100,000 to find a single case.

Speaking of freedom, we should not forget the physician, nurse, dentist, or other health care worker who refuses to treat patients with AIDS or those they think might be HIV positive. This type of freedom is certainly not in the public interest. It is something entirely new in the United States, it never happened before for leprosy, yellow fever, small-pox, influenza, or polio. And we must not let it happen for AIDS.

It was notable that out of seven million health care workers in America, fewer than a dozen had sero-converted because of job related activity. Eight or nine of them would not have done so if they had followed the simply guidelines set established by the Centers for Disease Control.

At home, testing patients in hospitals for HIV was being managed on a voluntary basis, which threatened no one's individual freedom, yet did seem in the public interest. Voluntary testing with confidentiality was being urged in many circumstances, one major target group being couples who contemplated a pregnancy.

One could only hope that as one becomes more familiar with the disease of AIDS, and as we dropped the myths and misinformation that the stigma associated with the diagnosis would diminish and that education would/will ultimately change behavior to contain the epidemic.

The economic, legal, and ethical implications of AIDS are enormous and threaten the social cohesion of whole societies. The challenge to maintain the balance between individual freedom and the public interest was and is enormous. If we can manage it with fairness and understanding, it may be more important than a scientific breakthrough.

Abstract theory vs. reality
AIDS related arson
Are individuals without information free to act?
Arguments for & against testing
Arguments for confidentiality

Civil rights & wrongs
Compulsory contact tracing
Contraindication for pre-marital testing
Contrast of homosexual & I.V. drug abusing populations
Cost-benefit ratio of testing
Economic, legal, & ethical implication of AIDS
Experience with leprosy, yellow fever, smallpox, influenza, & polio
Failure of previous public health education efforts
Freedom of health care workers to refuse to treat AIDS patients
Individual freedom
Low-risk of sero-conversion in health care workers
Mandatory testing in the Army
Need for confidentiality
Non-AIDS related deaths among I.V. drug abusers
Ostracism & suicide
Professional responsibility
Public interest
Public recording of identity of HIV positives
Quarantine
Rejection of individuals with AIDS
Social similarities of AIDS & leprosy
Stigma of AIDS
Testing of patients in hospitals
Use of identity cards
Voluntary testing before pregnancy