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A MORTAL PANDEMIC

AIDS is about death. It involves sex and drugs. It is a global pandemic. The generation which faces the challenge of AIDS has not previously known an incurable viral disease which is invariably fatal. This explains why AIDS is, at once, the subject of great alarm and intense fascination.

Inevitably AIDS is beginning to produce a rash of literature and a gaggle of international conferences. At the time of writing, the virus has been banished from the front pages of newspapers by a new crisis - this time in the stock market. Thousands ruined, international despair, doubts about the future. Yet there are some who blame the prolongation, if not the origin, of the economic crisis on the same lack of leadership in the United States of America as is taken to task in this book on the ground of its response to AIDS.

Who would want to be President of the United States? Who would accept the superhuman task of wrenching that vast collection of humanity - a confederation of nations, violent yet pious, religious yet sometimes cruelly indifferent - into a concerted attack on what Dr H Mahler, Director General of the World Health Organization calls "a pandemic as mortal as any pandemic there has ever been"? The lack of the bold leadership necessary to confront AIDS in the United States is the constant theme of this new book on the public policy dimensions of AIDS.

The book comprises the proceedings of a conference held in January 1986 co-sponsored by the United Hospital Fund of New York and the Institute for Health Policy Studies at the School of Medicine of the University of California at San Francisco. Fortunately, most conferences are not preserved in this way. But equally fortunately, this one was. In years to come, when we have conquered AIDS, this and like books will join Daniel Defoe's "A Journal of the Plague Year" as a record of a society's indecision and anxiety as it faced a puzzling, urgent challenge.

Two limitations of the book must be stated at the outset. In AIDS policy, it is hard to publish any material which is not soon out of date. Quite apart from the developments of medical science and treatment strategies, the political, economic and legal responses to AIDS are constantly changing. They mutate, just as the virus does. Their study requires constant updating, even when the focus of it is but one country.

is now nearly two years old. But as a late 1985 record of what was happening in the country in 1986, where AIDS was presenting its most visible challenge, it would be hard to improve on this publication.

The book is magnificently produced. In the best manner of United States publishers, it is splendidly laid out and printed. The titles are plain and elegant. The graphs and charts are stark and well done. The several appendices are comprehensive. The first of them proffers revised case definitions of AIDS, to distinguish AIDS from the related complex (ARC) and HIV infections. Another appendix sets out the addresses of AIDS related organisations in the United States. The index is quite detailed. I found no misprints. To produce such a book within 18 months of a conference is a daunting task. In a fast moving field, authors are notoriously jealous of their reputations. The database keeps changing - suggesting revision of their papers. New problems present which authors seek to show to have been within their wise prescience. The result is usually delay.

The limitations of a book on AIDS policy in the United States - and its utility elsewhere - is obvious. Although that country has, by far, the highest number of reported cases of AIDS in any developed country, it has a number of peculiar features which make its experience of AIDS special:-

- \* The lack of, and divisions in, national leadership - lately made clearer by the courageous stand of Surgeon General Koop, with his views contrary to those of the Administration;

- \* The absence of a universal national health insurance system;
- \* The strong resistance of religious and other groups to candid discussion of the vital strategies necessary to prevent the spread of AIDS, particularly amongst the young;
- \* The punitive attitude of some religious and other minority groups;
- \* The comparative indifference to events occurring outside the United States, particularly in the developing world.

Yet it is the very self centered introspection of the United States society that produces so efficiently an instructive book like this - helpful to others. So we must be grateful for small American mercies.

"DISTRACTING IRRELEVANT MORALIZING"

The design of the book is simple. It starts with an excellent introduction by Mathilde Krim, Co-Chair of the American Foundation for AIDS Research. She surveys the brief history of the virus, its aetiology and the testing procedures which are fortunately now available to identify it. Then there is a review of the prospects for a cure and for a vaccine. As to cure, Krim is cautious. The pace of advances will depend "very much" on Congressional support for large scale clinical research. Only pure research can provide a sure pathway to highly specific and non toxic therapies.

So far as a vaccine is concerned, Krim considers "cautious optimism is permissible". Animals can be

successfully vaccinated against some of their own retroviruses and protected from the diseases caused by them. But there will be problems in testing, in human testing, vaccines derived from such a lethal virus. Large as that challenge is, even larger, declares Krim, is the problem of "distracting, futile and irrelevant moralizing". For her, AIDS is a public health problem first and last.

#### THE POLITICS OF AIDS

After this thoughtful and typically American "can do" essay, the mood of the book changes, as its substantive chapters open. The first of these is an overview by Philip Lee and Peter Anno concerning the features and treatment of AIDS, so far. They sketch the history of the epidemic against a brief background of United States social policy. They outline various Federal, State and local initiatives - the last especially in New York City and San Francisco where AIDS has struck hardest. Their recurring theme is that the Federal government in particular has failed to "meet its responsibilities". That condemnation seems still largely true - made the more acute in a country with private health insurance only and a strong tradition of individual responsibility.

It is this contrast between wealth and indifference that leads Dennis Altman, the Australian political scientist and chronicler of homosexual politics, to provide his essay on the politics of AIDS. It is written in a sombre mood of restrained anger. The failings of the United States political process, according to Altman, show up in three areas particularly:

public health insurance; the growing and indiscriminate use of the antibody test for AIDS and the failures in the field of preventive education.

Altman includes a splendid story recounted by Mayor Edward Koch of New York City. Mother Teresa went there in 1986 to establish a hospice for people dying of AIDS. She met Koch and told him and his astonished officials "If we open the hospice, I want to see every one of you washing and brushing the floors." Despite assurances of the unlikelihood of contracting this particular virus, Koch and his cohorts were, to say the least, reluctant. "We are not saints", he joked.

But the question posed by Altman (and most of the other contributors to this book) is not whether United States politicians and bureaucrats are saints. It is whether they come somewhat lower in the pantheon of heaven. Altman's conclusion is sober. He describes the "anger and bitterness and fear and alienation" that leads sick people to demonstrate in the winter cold "because they feel their government has failed them". These are apt descriptions that recur in the writings of other authors throughout this book. But there is much close analysis and positive thinking, as one expects from Americans, as well.

Ronald Bayer of the prestigious Hastings Center in Briarcliff Manor, New York, contributes a typically thoughtful chapter on the political aspects of equity, of democratic agitation and of the culture of science in the United States. This courageous ethicist calls for an attitude of strict integrity, including by social scientists. We must beware, he

he warns, against "softening" the data in order to reach palatable conclusions. He cites the "hoped-for" conclusion that heterosexual intercourse may, as apparently it does in Africa, prove as efficient in the transmission of AIDS as homosexual sex. That would certainly make effective public responses to AIDS easier in a country such as the United States. But Bayer is right. There must be no distortion of science, however laudable the motives may be. In the end, all good ethics are based on honest data and good scientific analysis of it.

Emily Friedman, a writer on health policies, calls attention to the need to see AIDS against the background of a "narcissistic culture". Because the AIDS high risk groups are "marginal", their plight points up particular injustices in United States society. This seems all very well. But are the African villages and the Brazilian fringe dwellers with AIDS equally "victims" of their societies? A safer course may be Krim's injunction to remember that this is a health problem. Moralizing may be a barrier to effective action.

Timothy Westmoreland, Counsel for the Subcommittee on Health and the Environment of the House Committee on Energy and Commerce of the United States Congress, examines the politics of sexuality in the United States. He has a few choice shafts for the media. That much vaunted investigative organ of freedom which shelters under the First Amendment of the Constitution does not impress him when it comes to AIDS. President Reagan was not asked a single question on AIDS by the United States media until 1985. Why the silence?



Nor is the health care community exempt from Westmoreland's tongue lashing. His prognosis is gloomy. Far from becoming better, the politics of AIDS will become steadily worse in the United States. "Medical McCarthyites" are already "gearing up" to take over the political campaigns, to base them on fear and moralizing.

EDUCATION - SCHOOLS AND COMMUNITY

There then follows a series of chapters on AIDS and education. One of these recounts the typically American resolution of a community problem concerning AIDS. As with so many other problems in the United States, it ended up in a courtroom. The case (District 27 Community School v Board of Education) concerned whether a child with AIDS could be lawfully excluded from a school. The education authority said no. The local community went to court. Judge Harold Hyam upheld the authority. In his judgment he wrote wisely: cautioning against an "unsubstantiated fear of catastrophe". Judgment on issues such as this must expose ethical values. Hyam did well to base his views on good scientific data. But the authors caution that the story is far from over.

Several chapters deal with public education and what is described as "otherness". With AIDS, it is always "other" people who are at risk: gays, bisexuals, intravenous drug abusers, other ethnic groups. Fundamentalist religious leaders fuel this alienation by thundering "God is punishing us". But would God "punish" children - newborn and in school? Or haemophiliacs? Ralph Johnson, coordinator of the Age Education Project in New York appeals for AIDS education to

reach out to a wider community and to stress things which all people have in common. Not only would this be the compassionate thing to do. It is also more likely to prove effective in preventing the spread of the virus.

BLOOD BANKS - A SUCCESS STORY?

The book then turns to a series of chapters on AIDS and the blood supply. About three million patients annually depend on the blood service in the United States. These chapters trace the well known legal and administrative steps which were promptly put in place in that, as in other countries, to meet the specific problems presented by the spread of the virus through the anonymous blood products. The issues are familiar. Informed consent, confidentiality of donors, donor responsibility, notification of infected persons, false positives, liability. There is little discussion (as there has been in the United Kingdom and other countries) of the idea of a national fund to compensate haemophiliacs and others who acquired the virus from blood transfusion. Perhaps this is because in the United States it goes without saying that they will sue in the courts. But if they do so, will their verdicts destroy the blood banks? One paper by Nancy Holland, Executive Director of the American Blood Commission warns that AIDS is not the only contaminant. Hepatitis B and chronic liver disease, with the risk of cancer must also be tackled.

The record of the blood banks on AIDS is described as a "success story" by Professor Harvey Sapolsky of the Massachusetts Institute of Technology. But there are problems. The antibody test is not perfect. It may or may not

reveal the presence of the virus in a particular sample. Is the half truth of public assurance the right policy in these circumstances? Sapolsky leaves this nagging question with the reader.

#### HEALTH CARE SERVICES - COST AND COMPASSION

There then follows a collection of essays on "acute medical services" for patients with AIDS. There are four case studies of the ways in which major community health facilities have responded to the crisis. These trace the utilisation and reallocation of resources and the way in which AIDS has forced a new emphasis on outpatient care. The mind speculates. Is this really because it is good for the patient or because it is all that can be afforded? Or, for once, is there a lucky break? Is what can be afforded what happens to be best?

Dr Peter Mansell, of the University of Texas calls attention to a growing problem. This is "care-giver burnout". How can the carers tolerate - however hardy - coping with the constant burden of death amongst young people - some of the best and most talented and creative of the nation? With no cure, despair in an impatient world can take hold - and not only of the infected.

A series of activities organised for the AIDS population in San Francisco is described by oncology Professor Paul Volberding. He also stresses the need to link clinical research with the health care facilities treating AIDS patients. They should be part of the team, working towards the cure.

Various community care services are then reviewed, particularly in New York City and San Francisco. Peter Arno, in a separate chapter, stresses the values, but also the limits, of voluntarism. All of the contributors stress the impediment of hysteria about AIDS. A particularly sad comment on one part of the modern Christian is contained in a contribution by Richard Dunne of the Gay Men's Health Crisis. (GMHC) of New York City:-

"...during 1985, the Catholic Archdiocese of New York announced and then, because of the irrational fears and protests of practitioners and neighbors, immediately cancelled, plans to open a hospice for AIDS patients in Manhattan's Upper West Side... [The] GMHC's attempts to assist the Archdiocese in setting up appropriate and sensitive programs have been rebuffed, and we have not been allowed to see clients who have been placed - and subsequently died - in Mother Teresa's facility."

Drawing towards the close, the next part of the book contains a sober assessment of the financial implications of AIDS. Who will foot the bill? Australia, and most other equivalent countries, have national health care insurance and governments (supported by political oppositions) who have, so far, recognized the need for major resource allocation for a public health support of AIDS patients. The United States has no such national health system. Commenting on this important contrast with the United Kingdom, Canada, Australia and New Zealand, an Australian participant at the III International Conference on AIDS in Washington in June 1987 made the "quote of the week" when he declared that the basic mistake of the Republic was in leaving the British Empire too soon!

The chapters on costs examine the direct and indirect costs. They are staggering. One early estimate of the medical

and hospital costs was \$1,047 for each patient, just for treatment. This says nothing about opportunity costs - the lost contribution to the economy, social service payments, the burdens on carers and the family. AIDS is inescapably a costly disease. But so are other end-stage diseases in the United States, where health care is monumentally expensive. The graphs of the projections of costs surge suddenly upwards - like the Rockies. A few plaintive proposals are made concerning medicare eligibility and changes to supplementary security income. No one could dispute pediatrician Joe Boufford's conclusion that "AIDS is a catastrophic problem and a national one". Indeed, that does not go far enough. It is a global problem. It is a pity that AIDS isolationism mars this otherwise excellent collection.

The perspective of the private health insurer is offered by Leslie Strassberg of the Blue Cross. Should pre-screening tests be permissible? This is a question of special importance in a country without a national health scheme.

Finally, in the epilogue, a long term view of the AIDS crisis is offered by Bruce Vladeck, President of the United Hospital Fund. First the good news. The AIDS crisis has certainly brought forward in the United States a remarkable community response - particularly in New York and San Francisco. The response has not been limited to the gay and drug subcultures. It is the more remarkable because it runs counter to the "self interested individualism" which is foundation stone of life in the United States. Volunteers have streamed forward. Yet the fear is that their limits are being

reached. Vladeck hopes that AIDS will be a stimulus to a better health care system in the United States, especially for healing with chronic diseases. But this will only happen "if we are wise, energetic and lucky" and produce a cure and a vaccine "before too long". But what if we do not? And if we do what will the world be like after AIDS?

CHILL WIND IN THE AVENUE KLEBER

I was given this book for review at a recent international symposium on AIDS in Paris. Nearly two years after the conference recorded in these pages, the collected scientists, ethicists and bureaucrats of a hundred lands sat thoughtfully together to hear reviews of where we stood. But the mood of the Paris conference was fixed from the very start upon a global perspective. The Health Minister of the Cote d'Ivoire rose in the first session. In elegant French he posed questions for the audience which I do not see raised by the American contributors to the conference in January 1986. "We stand shoulder to shoulder now. This is a great universal brotherhood we have in the fight against AIDS", the Minister declared. "But where were you when we in Africa stood alone in the battle against measles - which mankind can prevent? Where were you in our fight against malaria, whose ravages we could halt?" A embarrassed silence filled the great hall of the Paris Conference Centre. "And will you still be with us, shoulder to shoulder, when we have the cure for AIDS - but it costs so much? Or when we have a vaccine but its price is out of our league?"

The session in Paris broke for coffee. The delegates walked out into the chill November wind blowing up the Avenue Kleber. Not a bad question, I thought. AIDS is not a problem of others. It is not even a problem for our own countries. It is a problem for the world.

Although presented in microcosm and in the context of the very special society of the United States, the lessons of this latest book on AIDS are relevant for many countries, particularly in the developed world. The rapid spread of AIDS is promoted by the modern technology of travel. Our understanding of the profile of the virus is only possible because of recent developments in virology. Yet the basic issues which challenge our societies and present most sharply are ethical. They concern public health strategies and a response to a disease which kills mostly young people. Suddenly, the World Health Organization has a new and vital mission. Only mankind, joined in rare unity, can defeat this volatile pandemic.

Can you remember the days before the gnawing pain of AIDS? What far off happy days they were - before the anxiety, and the death of friends or family, and the wasting of the promising young challenged human wisdom in the six continents.

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