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FOUNDATION MARCEL MÉRIEUX

INSTITUT DES SCIENCES DU VIVANT

COLLOQUIUM AIDS, HEALTH AND HUMAN RIGHTS

18-20 JUNE 1993

LES PENSIERES, VEYRIER DU LAC, FRANCE

ANNECY REVISITED

Michael Kirby

Australia

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ACROSS THE WORLD OF AIDS

I returned to Annecy by a journey which took me past some of the mile posts of AIDS and human rights. My plane took me over the many lands which lie between Australia and France. For more than a day the cylinder of steel with its human cargo surged over the countries which have seen so many changes in the few years since this series of meetings began. Over my own continental land, which has scored some successes in the struggle against AIDS. Past Thailand with its many new challenges. Down there was Burma, with the ceaseless stream of young women and men escaping poverty and military oppression only to face a more cruel viral oppressor. Over India, which Daniel Tarantola now assigns to a high risk category country. Up the spine of the former Soviet Union. Who would have predicted

* President of the Court of Appeal, Sydney, Australia. Chairman, Executive Committee, International Commission of Jurists. One-time member of the World Health Organisation Global Commission on AIDS.

that its mighty empire would collapse in the time between our last two meetings? What lies in store for us before the next encounter? Past the warring factions of Yugoslavia, locked in mortal struggle into the heartland of Europe. To get here I had to cover half the earth.

For a day, I interrupted my journey to attend the World Human Rights conference in Vienna. It provided a useful perspective by which to confront the issues which we have been addressing. Upstairs, in an empty hall, the representatives of nation states delivered their speeches full of platitudes. But downstairs, the surging, passionate, often angry representatives of the objects of oppression lifted their multitudinous voices in protest. It is an important image to hold in our minds. The issues of human rights, as presented by the epidemic of HIV/AIDS, must be seen in the wider context - of a world still suffering many human rights abuses against vulnerable, alienated, stigmatised groups of peoples. AIDS is but a serious new example.

I flew from Vienna over the mountain tops of central Europe. The late afternoon sun lit the snow with hues of gold and pink. To Annecy the car sped from Geneva Airport. Everywhere there were the signs of happy human life. The young people, of great beauty, throwing beach balls or exercising or diving into the clear lake. The fragrant roses bloomed and lined the way. Amidst so many signs of the blessings of nature and of human existence to return to the sombre story of the AIDS epidemic seemed a suitably Calvinistic occupation for a weekend in these parts. And yet, again, it has been an uplifting experience. Amongst the daunting problems, and seemingly insoluble challenges, our collective minds - samples of humanity - at least struggled to see the way ahead. When will AIDS be a footnote to human history? When will Roy Anderson, or his

successor, show the pattern of this epidemic along with the great plague? When will we be able to pinpoint the turning point of this disaster? May it not be far away.

THE COLLOQUIUM IN OUTLINE

The pattern for our reflections has been logical enough. We started, appropriately, with the raw data on the state of the epidemic, led in this regard by Peter Piot and Roy Anderson. We then moved through a session with colleagues specially well qualified to help us see HIV/AIDS in the context of the global institutions and world-wide aspirations for human health. Jonathan Mann and Mohamed Abdelmoumene, released from mere institutional loyalty, gave us clear and balanced insights from above. We were led again into the special issues of particularly vulnerable groups so far as HIV is concerned:

- * Homosexual and bisexual men;
- * Disempowered women;
- * Intravenous drug users; and
- * Children.

And then we turned to the future programme of action.

On the third day, we examined the vital issue of equity - just access to diagnostic, therapeutic and (when it comes) the vaccine response to AIDS. Finally, with a suitable sense of idealism we closed this colloquium with a session on health, world development and humanitarian assistance. Here we were confronted by Sir Donald Acheson's brave story and by the special, urgent challenge to human rights presented by the crisis in the Balkans.

We will all depart from Les Pensières with a deeper insight into the human rights aspects of public health in general and HIV/AIDS in particular. Each will take away his or her own perspectives. These few words of mine are merely my images. Each

one of us could recount a tale partly similar, and partly different.

THE EPIDEMIC: DATA & PATTERNS

What should we take from the raw data? From Peter Piot the message is clear. There is a rapid increase in the spread of HIV infections amongst heterosexual people and IV drug users in countries like Brazil. These figures stand as a warning of worse to come. But not only in such areas of the third world - also amongst their brothers and sisters in "the fourth world", to use Dr Drucker's vivid phrase - the impoverished run-down fringes of rich cities in the developed countries. The migratory, poor people, displaced by current social and economic adjustments, are the first and largest of the vulnerable groups we have identified. From these first contributions we were brought to the simple truth: that health improvement and the status of women are intimately related. So many speakers made the point: whilst women are disempowered in terms of basic rights they are vulnerable to many ills - of which HIV/AIDS is but the latest.

Roy Anderson, by his brilliant synthesis of mathematics, informatics and public health data, presented the bodily shape of the epidemic. His immediate quest was: to what intensity does HIV have to rise to cancel out the 2 to 3% growth rates typical of the countries most affected? It was a question which laid the ground for Richard Feachem's invocation to better public health expenditures based on the sheer economic costs of the epidemic - taking as it does its heaviest toll on the countries which can afford it least and on the generations which are the most productive.

One of Roy Anderson's most worrying statistics was that which showed the greater risk of infection in women having unprotected sex with an infected male. He gave a figure of 22% cross-infection. The rate of cross-infection for a male who is uninfected having sex with

an infected female presents a much lower figure of 9%. Although these figures are particular to the subjects studied, they show what the homosexual communities of the West learnt a decade ago: receptors are most at risk. On a global scale this demonstrates if we had not earlier noticed: AIDS is another issue in the contemporary struggle concerning women's rights.

THE GLOBAL STRATEGY QUESTIONED & DEFENDED

Joseph Decosas struck a provocative note when he questioned the efficacy of global strategies in relation to AIDS. Stimulated by his very useful and timely questioning, this became one of the major themes of the colloquium. Decosas's thesis was simple enough: to try to extrapolate from the responses of homosexual groups in metropolitan North America a strategy for AIDS throughout the world was a "scandalous" error. What were needed were tailor-made local responses, in harmony with the special mores and different attitudes of each distinct society. Decosas opposed the calls for much more global spending. AIDS is not like smallpox. It will not respond to a simplistic military-type global campaign.

Needless to say this intervention produced many defenders of the past global strategy and its successes. Think globally, act locally became the rallying cry. The utility of a stimulus for indifferent, unresponsive and uninterested régimes by a clear global voice was explained by many speakers from Sir Donald Acheson to Dr Sittitrai of Thailand. Perhaps the outcome of this debate was a new realization of the obligation constantly to scrutinize and re-examine the mix of global, national and local responses for their true effectiveness in the face of AIDS.

One of the chief defences of the global approach was provided by the very theme which brought us together - the universality of basic human rights in all of humanity. The debates in Vienna about

cultural differences in human rights has had its reflection in the AIDS debates. But if WHO and the Global Coalition do not speak up for women's rights in Morocco and the Mahgreb, for the rights of gay men in Iran to public health messages which may save their lives, and for new approaches to the burdens of IV drug users in North America, Europe and Australia - who will do so? Just as in human rights generally - we need global sentinels to remind the world of the common challenge AIDS poses to our species. The Dalai Lama was excluded from the official meeting in Vienna. But in the movement for human rights and health there should be no exclusions. Civilized, educated people should ceaselessly say so.

Our perspectives of this global approach were enlightened by Dr Lang who explained the impact on notions of public health of the Holocaust in Europe and the Atomic Bomb over Hiroshima. They provided the catalysts for a new world order in which health would be something positive - not just the absence of disease. Anne-Marie Moulin chartered the growing involvement of governments in health care over the course of this century. Dr Moulin traced the growing acceptance of a human right to health in the constitutions of the world. She and other participants emphasised the grim ironical inconsistencies of societies which deny proper support to persons until they are terribly sick but must then, by law, accept them at greater expense into intensive care hospitals when they are dying.

Professor Margaret Somerville was as provocative as usual. Her cartoon of the blank wall with the rolled down paper poster door marked "human rights" brought us down to earth. That is what many governments think about our deliberations of this weekend and of those in Vienna. For them we are gadflies to be placated, controlled and deceived. Dr Somerville suggested that health care was for some Western societies replacing religion as a powerful motive force. As

belief in after life declined, the necessity to prolong the life we have becomes the prime target of humanity. To this "religion" AIDS presents a special challenge. Jim Curran questioned this analogy. He saw religions all too often as a source of discrimination and derogation from other basic human rights.

Jonathan Mann urged a new insight into public health - one stimulated by the perspectives of human rights concerns with the oppressed and the vulnerable. It is this insight which is voiced in the Global AIDS Policy Coalition statement *Towards a New Health Strategy for AIDS*. It provided another of the binding themes of the colloquium. The central insight is worth repeating:

The critical relationship between societal discrimination and vulnerability to HIV is the central insight gained from over a decade of global work."

The insight extends beyond HIV/AIDS. But it has a particular urgency in confronting this epidemic.

Dr Abdelmoumene endorsed this approach from the viewpoint of his high responsibility over many years in WHO. But he added a note of anxiety: we are in crisis, he declared. The health crisis is but a reflection of the wider crisis in economic distribution of wealth in the world. Far from getting better this problem is actually getting worse. Will global health expenditures go the same way?

Daniel Tarantola explained the way in which vulnerability could be turned into survival strategies. Basically, there is a need to tackle discrimination just as we must tackle environmental degradation. We must empower the vulnerable and perceive the problem in a global way - yet acting locally to get real results quickly.

NEEDS OF THE SPECIALLY VULNERABLE

One of the most worry sessions this time at Annecy was that which turned this insight of vulnerability into practical

illustration. Hakima Himmich detailed the special plight of women in the Maghreb. Yet they could be the prototype of women in many societies of female disempowerment. "If I am here", she said, "it's because my husband gave me permission to leave Morocco". How is such a deep-seated attitude to women's fundamental human rights to be reversed at a time of fundamentalist religious revival? Yet is it not vital that women be empowered if the spread of HIV amongst the children of Islam is to be contained? Other speakers elaborated this particular vulnerability of women - including Christopher Elias in the last day's session on access by the population to effective means of protection.

Dr Ernest Drucker told his sober story of the fourth world of the decaying Bronx in New York. As I fly back to Australia the image of the decaying apartment block shown by Dr Drucker's photographs over time - deteriorating and then finally levelled - will be burnt into my mind: a symbol of similar action of the law and of society on many humans in the fourth world. If this contribution does not urge us to a new response to the crisis of IV drug use nothing will. Dr Drucker's talk was complemented by brilliant papers by Dr Catherine Hankins of Canada and William Lowenstein of France. Dr Marty-Lavauzelle painted the rather better known story of the impact of discrimination on homosexual and bisexual men and women. The issues of HIV/AIDS and gay men must, he urged, be seen for what they are - a species of irrational discrimination against a disempowered minority. But whereas the gay minority has now begun in many lands to speak up and demand justice - who gives voice to the special needs of women in the Mahgreb? Or IV drug users in the unsterile shooting galleries of New York? Unless people like us do so - unless WHO and the Global Coalition do so - there will be a silence that is *literally* deadly.

AIDS & POLITICS

Professor M Grmek, an historian of the AIDS epidemic - urged the need to study AIDS in the context of men's games - war; a theme also taken up by Daniel Tarantola. Bernard Kouchner, former Minister of the French Republic, sought to explain the limits in a democracy, imposed upon elected Ministers, who have their insights but cannot always carry with them their more cautious colleagues. You will recall that the tale of recalcitrant French officials led one very rude participant to ask the question: "Who rules France?" The answer was said to be "the majority", ie of the French people. But one wonders. It is a duty, in the face of the AIDS epidemic, of elected leaders and informed scientists to educate that majority. And the time is short. The urgency is great. Dr Daniel Défert brought us back to the problem of IV drug use - a major vector for the spread of AIDS in many societies - with special perils for women and children who acquire the virus this way. You will recall Daniel Défert's study in contrasts:

In the Netherlands: no drug user leaves a police station without a sterile needle - even if he only asks for directions;

In France: if a drug user leaves a pharmacy with a sterile needle he or she is taken to the police station - and the direction is a crowded prison: an incubator for AIDS and TB.

Hans Moerkerk explained the distance between global rhetoric, priority needs and the empty coffers of the global health budget. In hard economic times, the funds available for fighting AIDS and for reversing or answering vulnerability are actually shrinking. And who cares?

Dr June Osborn's calm, measured voice explained the work of the United States Commission on AIDS which she has led and which

concludes its work this week. She declared that human dignity is the essential fulcrum of human rights - and a life without health can only be dignified with a mighty struggle. Another image from the Bronx was offered by Dr Osborn: the woman with drug addiction, HIV and separated from her children who turned up to give evidence to the Commission with her only dress - spotlessly clean: and a hat to show the quest for human dignity that underlies the basic demand for human rights.

One of June Osborn's important messages concerned the vital rôle of the modern media in promoting the public education which will support the politicians of courage who will lead us from this maze of death, suffering and despair to local and global policies which reduce vulnerability and respond effectively to this epidemic.

In one country, with many problems, a combination of honesty and courage with occasional rare political leadership, has shown what can be done even in desperate circumstances. Yet the problems of Thailand recounted by Dr Sittitrai still seem as daunting, in some ways, as those of the Maghreb. We should not forget his explanation of the stimulus which global leadership gave, at a critical moment, to the Thai responses. Sir Donald Acheson, indeed, saw this as yet another illustration of the beginning of the slow journey towards some form of global government. Angelica Salomao reminded us of the need for a like analysis of the African scene - where sadly there has not been a common response of similar leadership. What can we do in the face of such riveting indifference? Peter Piot, like Richard Feachem, helped to place HIV/AIDS in the context of economic and social development which is an important companion to respect for individual human rights.

VACCINES - SCIENCE & ETHICS

On the last day we opened the debate about the scientific,

ethical and legal issues presented by the prospects of HIV vaccines. We began with an overview of the state of the vaccine art.

Our considerations were enlarged by historical perspectives concerning earlier vaccinologists, including the great Pasteur. These were laid before us by Charles Mérieux and June Osborn. Professor Grmek also added the lesson of history, from his unparalleled experience.

Christopher Elias did not speak only of vaccines - for the session was devoted to diagnostics and therapeutics as well. But from the large experience of the Population Council in the United States. There were lessons to be learnt here. The rôle of the public sector as a stimulus to the private (and as a guardian of equity) was asserted and explained.

Marc Girard was cautiously optimistic about the various vaccine developments which he described. However he emphasised, as a scientist, the importance of first conducting thorough laboratory and animal trials. The particular problems of viral variety were explained, as was the limited effectiveness of all vaccines and the probable need, in any future AIDS vaccines, of constant repeat boosters. The costs of vaccine development and the enormous challenge to the present capacities of the health industry were outlined. But Dr Girard ended on a note of hope. So did the participants actually involved in vaccine developments - Martin Rose and Frank Volvovitz. Mr Rose saw the savings in the arms budget as a possible source of funds for AIDS vaccine development. Mr Volvovitz expressed concern about the inhibitions of vaccine manufacturers' legal liability. Mention was made by him and by June Osborn about the new proposed legislation in the United States to protect those engaged in vaccine development from the horrendous costs of liability suits in that country. This Bill has not yet been enacted by the

United States Congress. Margaret Somerville doubted the priority need for such liability protection. But June Osborn, whilst confirming that no successful litigation had yet arisen out of vaccine use in the United States, confirmed that the prospect of actions arising out of an HIV vaccine, alleged to be ineffective, was all too real. Hence the Bill and the need for its passage to encourage and facilitate vaccine development.

Michael Sela added a note of urgency about vaccine development. With thousands being infected and dying we cannot afford to wait for the perfect vaccine against HIV/AIDS. Discussion turned in this session to the battle strategy and whether battle was an apt analogy for AIDS vaccines. Then to the ethical and human rights dimensions. Several in the audience warned against the new form of medical imperialism which was threatened - testing vaccines in mass trials in developing countries which could not expect to have the benefits of vaccines - at least in the foreseeable future.

Dr Drucker proposed the use of the fourth world prison population in New York as prospective vaccine trial participants. They were at risk. They would benefit. But this would have to be done outside the constraints of prisons and under conditions of fully informed consent by each of the persons tested.

Jonathan Mann as usual asked the searching questions. Particularly: how do we go ahead to prepare the answers to the ethical and human rights problems presented by the prospects of vaccines. Margaret Somerville suggested a first framework of responses. But the one clear message of our deliberations was the need for much further work on this topic - bringing together, as this colloquium did, scientists, ethicists and lawyers. An institution is needed. If WHO does not take the lead in this regard, the Global AIDS Coalition should do so. The lesson of AIDS, so far, suggests

that vaccines will present sharp conflicts and widely differing viewpoints. We should be ready for them, with well considered solutions.

AIDS & HUMANITARIAN RESPONSES

And so we came to the last session. Richard Feachem gave an insightful and compassionate economist's scrutiny of the costs of HIV - falling as it so often does in those countries which can afford it least. Sir Donald Acheson told of his team's visit to the Balkans with its own sad metaphor for HIV/AIDS:

- * A cruel war;
- * Devoted, nearly burnt-out and exhausted medical staff;
- * Irrational and selfish attitudes by some citizens;
- * Cruelty and suffering amongst those affected; and
- * A watching world unable or unwilling to intervene with sufficient resolution and resources, as Dr Lang pointed out.

Patrick Aeberhard explained the magnificent French initiatives in global humanitarian assistance. Truly we heard from three citizens of a global community who take their anxieties about suffering beyond mere words. The world is one - linked by increasing travel. But the responses to HIV/AIDS are still disparate. That is why France has proposed a *Declaration on the Rights of the Sick and of People Living with AIDS*. Yet paper legal rights and advice to "just say no" will not at all equal strong practical steps to contain this epidemic: such as the supply of condoms and the supply of sterile needles. Needles, it seems, will be crushed by the police in France if found on a suspected drug user. The possessor may even be

prosecuted for having an instrument of drug addiction. Perhaps out of the desperation of the AIDS peril (and the example of countries which have been willing to take bold steps) will come encouragement to France and like countries to introduce the necessary reforms which will help save lives.

THE LINGERING IMAGES OF ANNECY

What, then, are the messages and images we take away from this encounter?

- * Of the boat journey on a clear lake with the vision of mighty mountains and happy people at play?
- * Or of the shooting galleries in the decaying Bronx?
- * Of the sparkling champagne by the lake with its rare happy effects?
- * Or the need for a "cocktail of vaccines" urged by Dr Sela in his urgent intervention on vaccines?
- * Perhaps of the poor woman in Morocco without power to even ask her husband to use a condom and who knows only too well of the dangers of HIV infection which she faces as a consequence?
- * Of the peaceful lawns in front of Les Pensières and the flowers in summer bloom?
- * Or of the homosexual men, exhausted by a decade and more of loss and by collective memories of centuries of deadly discrimination?
- * Of the delightful, elegant dinner speech by our hostess for Tufts University at the Abbaye last night?
- * Or the description of the stream of young girls crossing the Burma border for the brothels of Thailand with resulting HIV infection within weeks or even days?

- * Of the earnest interdisciplinary conversations in this most beautiful part of this most beautiful country: the land of *Liberté, Egalité, Fraternité*?
- * Or of a society which, like others, cannot even put a methadone programme in place to help save some of the addicted and to put them on the path towards respect for their own basic human dignity?

These and many more messages we take away with us. But with important new insights into the link of public health and human rights. And a new perspective of the need to tackle the problems of the specially vulnerable, without which talk of a global struggle against AIDS is empty.

WORDS OF THANKS & OF HOPE

There must be words of thanks:

- * To Dr Charles Mérieux who has been our guide and mentor in the three meetings in this series. With wishes from us all for continued good health. And with a fond message, expressed this morning, to his grand-daughter whose marriage yesterday reminded us of the continuity of human life, of love and of survival;
- * To the Foundation which brought us here, to Dr Caroline Dupuy and her dedicated colleagues and the Foundation officers and employees;
- * To Tufts University at Talloires which offered us an historical environment for our dinner together;
- * To our chefs and waiters at Les Pensières - who reminded us, even in moments of despair, about the enduring glory of French wine and cuisine and the joys of life;
- * To our own intrepid record-keeper Mme Esway who faithfully, and

without break, recorded our sessional words hopefully for a wider audience far from here; and

* To our three interpreters who helped us, by the lake, to bridge the gaps of language and to bring the minds of so many together in a general harmony.

When I was in Vienna on Friday, under the spell of jetlag, I stole away from the sad World Conference of anger and frustration. I walked to the great Opera House on the Ringstrasse. There, Gustav Mahler exactly a century ago was conductor, Keiserliche and Königliche. The great Gustav did not finish his Tenth Symphony. He knew that for Beethoven and Schubert their Ninth was their last. He was fearful as he too reached the Tenth. I touched the doorknob of the conductor's entrance to the Vienna Opera House where Mahler's hand once rested. I saw that the struggle for human rights was like writing the mighty symphony of humanity. We now have some of its movements in place. We must be bold enough to continue with the necessary work - each of us contributing our own little piece. But always keeping an eye and ear on the great harmony with its uplifting theme for a new and better world - a world where AIDS is tamed and the shadow is eventually lifted.