AIDS and Public Policy: Old and New Issues

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Introduction

You are all "front-line" people — so I hope you don't mind that The theme of my talk today is "AIDS and Public Policy: Old and New Issues". It was some time ago that I suggested that title, thinking it would be an up-beat way to start your Seventh Annual Conference. I guess I was still basking in the warm glow of awareness that we had a new and more sympathetic federal Administration. At last we had a President who knew how to say "AIDS" in public without accompanying it with either of the words "innocent" or "victim". He had, in fact, invoked the recommendations of the National Commission on AIDS as a plank in his campaign platform [needless to say, I found that heartening]; and even after he won, he again referred to the epidemic and to the Commission's work, especially in the days that immediately followed his victory.

Actually, he gave a fine AIDS speech in New Jersey four days before the election -- one that was to have been carried by C-SPAN. But, as happened quite often in that campaign, the caravan was more than an hour late getting to the ~~place~~ site where the speech was to take place, so the cameras had been and gone before Mr. Clinton got there. Thus his words excited only those few denizens of Hudson, New Jersey, who had outlasted the snafu; the rest of the country remained unperturbed, ~~not to mention uninspired.~~

Perhaps you missed it too, so I thought you might enjoy hearing a couple of excerpts. For instance, he said "For all the quiet courage of [the many heroes who worked so hard...to help people with AIDS, even in the early days when it was dark and lonely, who created service organizations and education programs to help people with care and compassion,] we have still not done enough as a nation to stop the spread of AIDS or to help those who are living with it. Most of us have preferred to believe AIDS is not our problem, that it's a problem for a few particular or isolated groups in our society....But the truth is it is everybody's problem....We don't have a person to waste in our country and viruses do not discriminate."

Candidate Clinton went on to indicate that he knew from direct experience about the grim visage of AIDS, saying "The face of AIDS for me is no longer a stranger's. It is the face of the mother who must leave children before they grow up, the husband who must say goodbye to a wife before they grow old together. The artist who will leave the world a little less beautiful, the athlete who will leave the world a little less graceful. The child who will leave the world a little less hopeful.

"It costs every one of us in ways that are financial and human and moral. We can't afford the cost in dollars or in death....[T]his nation must rally its will and strength to fight this killer. We can do it. We can win the battle but we have to get to work, and we must deal with it all day, every day, with political leadership and community leadership and not just at

election time and not just at heartbreak time."

There! Doesn't it feel good to know we have a leader who ~~will~~ can say such things in public? I'm not trying to be sardonic -- the change in tone of the Clinton Administration has surely heartened almost everyone grappling with the monstrous portfolio of problems around HIV and AIDS that were so far out of control when the new crew took over. That the problems haven't been solved, or even convincingly addressed, is frustrating for those who have been trying so hard for so long; but I do believe the good intentions are there.

Of course, Mr. Clinton inherited vast areas of deferred maintenance across the whole landscape of domestic social policy, and therein lies a lot of the problem. As I used to say in the early days of the new regime, it took a long time to sink so far into this morass created by the virus but deepened by neglect, so it will surely take a long time just to get to the surface-- before we can start to build a sounder foundation. And if the pace of the Administration seems tedious, surely the old adage applies: if you are up to your arse in alligators, it is difficult to remember that your initial objective was to drain the swamp!

As I sat down to prepare this talk, I decided that ~~that~~ even hint of disappointment may be unfair, for some things have **clearly** changed. It may seem glacial, ~~but in order to accomplish my goal of being cheerful~~ but good things have begun, let me take the first few minutes to review some of the progress made. For instance, Ryan White funds and the

programs they kept alive had become an endangered species -- but refreshed funding has revitalized at least some of them. Biomedical Research funding has been supported more generously, and more lip service is being paid to behavioral research. The Office of AIDS Research at NIH has been revised and strengthened, and NIH Director Harold Varmus has made what I think is a wise and distinguished choice in naming Dr. William Paul as its Director. Dr. Anthony Fauci had done a prodigious job of maintaining three different, contributory roles in the epidemic, of which running the Office of AIDS Research was only one; ~~and~~ his accomplishments will make him an enduring hero of these difficult years. But without doubt Tony will continue to be a bright light in his ~~continued~~ insightful leadership of his lab group and as Director of the National Institute of Allergy and Infectious Diseases; and it is good to have someone full-time in the OAR role: I think Bill Paul brings fresh and highly intelligent insights to it.

For those of us who tend to focus with special acuity on prevention, things have looked up as well. The bad old days saw a great deal of censorship, either absolute or so leveling in the requirement to comply with "community standards" of the majority that essentially no one understood the resultant messages, once they had been cleansed. The classic -- and likely to remain so -- was the public service ad that not only didn't mention sex or condoms but restricted its visual image to a guy putting on a sock! leaving **everyone** the task of figuring out what that was all about.

But that has begun to change. New ads are a bit ~~bolder~~ more forthright,

although they still pale beside what goes on in daytime soaps or evening prime time...but I suppose we should celebrate progress. Efforts are sometimes successful now to articulate the known strategies of prevention to many audiences and in the language of their intended listeners. CDC has tried to become much bolder -- and of course no one can fault Surgeon General Joycelyn Elders for her candor! There have even been faint-hearted tries at reaching people with a same-sex orientation, although -- while Mr. Dannemeyer moved on to private life -- we still have Jesse Helms and he continues to sap the resolve of (or even frighten) his legislative colleagues with his homophobic posturing.

I would be remiss not to note, with considerable pleasure, that Dr. David Kessler was spared the partisan axe as the federal leadership changed hands; with new drug development so central to the needs of persons living with HIV; the Food and Drug Administration has a key role to play in modulating the urgency of epidemic need balanced against the mandate to minimize harm, and we are well blessed to have such a thoughtful and committed person as David Kessler serving as Commissioner of FDA at this juncture.

And, very importantly, there are heartening changes in the office of the so-called "drug czar." New money is being directed toward the treatment of drug addicted people at great risk of AIDS -- not yet enough to make treatment available "on demand", as has been recommended by every national group that ever studied the epidemic, but at last beginning the move away from a pristine, failed policy of border interdiction, ~~as~~ which had been almost the sole strategic tactical

maneuver in the war on drugs. What is more, twenty American cities now have needle exchange programs; like almost all public health strategies, those are local options, of course; but leadership clearly matters. The active opposition that killed such fragile new initiatives in the past has been muted, replaced by supportive attitudes and, better yet, by **data** showing that drug use is not increased and HIV transmission is decreased by needle exchange and other "harm reduction" measures. It has helped to have thoughtful Administration backing in achieving those changes in urban America; and much credit goes to another hero of the epidemic, Dr. Don DesJarlais, who persevered remarkably in the teeth of committed opposition to help achieve these changes. (He was, of course, a valued colleague on the National Commission on AIDS and I am pleased to see that he will be speaking to you later).

And of course, health care reform is on the way -- right? President and Mrs. Clinton say, and I agree, that health care reform is fundamental to genuine progress in the fight against AIDS -- but the legislative reform season is young, and right now it seems to be more like a hunting season, with congressional entrepreneurs taking pot shots at every aspect of proposed change. Universal access, to which even the Bush Administration used to be happy to pay lip service as the sine qua non of rational health care policy, now seems to be very much in danger....oh dear! (For now the Clintons seem to be "hanging tough," thank goodness...But that is a topic for a different day -- I won't get started on it here).

Finally, there is now an AIDS "czarina" -- Kristine Gebbie, who brings to her position extensive experience in nursing, health care and public health. She is articulate and committed; but her job description is problematic, for the ready access to the Cabinet-level officials and/or President (for which the National Commission on AIDS called, in advocacy of the position) is not there. In fact, rumors of turf wars with HHS are troubling; for the whole idea was to ease the communication between those with AIDS expertise in HHS and cabinet-level leadership throughout the Administration, so that wheels would not have to be reinvented constantly when issues impacting on the epidemic arose in other branches of govt. If, instead, one gets territorial troubles, the central mission of such a post is blighted at its inception. I certainly wish her well...it's a tough role in the best of circumstances, and the jury is still out.

Finally, people often ~~sometimes still~~ ask me about the National Commission on AIDS: are we done? did we quit? what happened? The questions are flattering and the concern is much appreciated, so perhaps a brief explanation is due. The National Commission on AIDS was not, as is often assumed, a Presidential Commission, but rather had been created by Congress as part of a Public Law passed in late 1988 and appointed during 1989. The legislative language was intended to create a politically balanced group of people from across a whole range of experience and expertise pertinent to the epidemic -- five to be appointed by the House, five by the Senate and two by the President (if you think about it, in 1989 that gave either party six appointments) & ~~additionally, three Cabinet Secretaries were members ex officio~~. That group, once appointed, was to elect its

own Chairman, which is how I -- as a Senate Democratic appointee -- ended up in charge of what many people referred to as "President Bush's AIDS Commission." Parenthetically, 3 Cabinet Secretaries were ex officio member representing the depts of HHS, VA + Defense - the original appointment + Chairmanship mechanisms

One consequence of ~~that~~ was, indeed, an unusual degree of independence (it had been included) -- the bipartisan appointments made by Congress and the President in fact yielded a group of people with whom it was a privilege to work and who were able to function by consensus throughout the life of the National Commission on AIDS, since their common denominator was a deeply felt concern that things go well. The staff of the Commission was extraordinary and shared the same intense commitment. And of course I will always be in debt to Dr. David Rogers, the Vice-Chairman, who brought an extraordinary breadth and depth of experience to our tasks. With him I shared a camaraderie and convergence of goals that added greatly to our esprit as well as to our accomplishments, for which he deserves great credit.

Another consequence of ~~the~~ being created by legislative mandate, however, was that we had a finite lifespan written into law. The Commission was ~~created~~ authorized initially for a two-year term, renewable once by request of the President (which he did); thus, at the end of four years, on September 1, 1993, we ceased to exist. Given the way acts of Congress work, <u>that</u> Commission could not, under any circumstances, have continued; if one wanted a similar thing, another law would have to be written or a Presidential or Executive initiative would be needed -- and from what I read in the papers, the latter seems to be what is happening.

There has been appointed, already, a Task Force created within Health and Human Services, chaired by Assistant Secretary ~~of~~ for Health Phil Lee, to focus specifically on acceleration of drug and vaccine development and research initiatives. The membership of that group has been named and includes key figures such as Drs. Varmus and Kessler, as well as researchers, community and industry representatives. There has also been announced, in anticipation, the creation of a broader advisory group under the aegis, I believe, of Kristine Gebbie, whose purview would more closely resemble that of the National Commission on AIDS. I hope that works out, for I strongly believe that the scope and range of impact of the HIV/AIDS epidemic is such that all kinds of input will be necessary: biomedical research alone can make great contributions -- and has -- but ~~as I will get to,~~ it cannot solve the problems of HIV and AIDS in isolation, for it grows ever more apparent that AIDS ~~can~~ serves as a remarkable paradigm for a broad array of problems in our society ranging from adolescent sexuality, drug use and STDs on one side to gaping holes in our health care strategies ~~to care~~ of care for chronic illness, on the other.

That is a brief reprise on what I think has been happening in recent months. As I noted at the outset, ~~my choice of topic reflected initially~~ I started out in a mood of high optimism -- and I think that brief review shows that my hopefulness was not entirely foolish. A number of **structures** and arrangements have positioned us (at least at the federal level) to improve on past performance. The hints are there that strong, articulate Presidential leadership may yet be forthcoming — surely this President knows the face of AIDS, and that's a strong start.

But today I also want to take a fresh look at where we are in terms of issues: have we truly made definitive progress, won some battles, thus relegating old problems to the dustheap of epidemic history? or are we still wrestling with tired shibboleths and intransigent obstacles to progress? And are there new problems emerging as the epidemic "matures"? If so, where do we stand with them and what should be done?

As I make my way through that assignment, I will touch quickly on some features of biomedical progress worthy of note, but I won't spend much time pointing out the biologic difficulties posed by the virus of AIDS. Suffice to say they are fearsome and almost surely will not yield quickly to flashes of insight yet to be had; for the so-called "hard scientists" there is going to be hard work for some time to come.

The phenomenon of "breakthroughs" is, in fact, a creation of the press, to a large extent -- true leaps forward in scientific knowledge tend to be recognized as such belatedly, while the frequently-proclaimed "breakthroughs" tend to fizzle or even be retracted once they have been ~~tested in~~ exposed to the light of day. And only high-tech stuff seems even to be considered a candidate for breakthrough status: a drug or vaccine that reduced HIV disease by ninety per cent would be greeted as a wonder! and yet whoever would think of celebrating as a breakthrough the well-documented finding that latex condoms reduce AIDS transmission by over 10-fold, when properly and always used? (When I practiced that line on my adult son, he shot back with "Who even wants a breakthrough with a latex condom?)

So lab progress will be slow, behavioral interventions will continue to emerge as crucial to control of HIV; and yet, the products of those efforts will not, by themselves, be helpful when they emerge. Even now, I think it is fair to say that society has outdone even the retrovirus in setting up roadblocks to progress, for there are many, many things we already know to do that we are not doing. In fact the most refractory problems -- the truly daunting stalemates -- reflect not laboratory sluggishness but dogged ignorance, bias and sometimes out-and-out bigotry. That is useful to keep in mind as an antidote to discouragement, for the most precious resources we have in the fight against AIDS are human understanding, energy and commitment. We AIDS folks were not wrong or narrow-visioned to get into our line of work, for this is the public health crisis of the century. If you sometimes feel like you have strayed into a narrow tributary of concern, off the main stream of life -- as I do in the midwest when someone says "So how is that epidemic of yours going, June?" -- keep in mind that all this is about what the world will look like to our children's children. Much as we would wish otherwise, the ~~change~~ ground rules for ~~in~~ the human life ~~of~~ on our planet ~~was~~ were perturbed just as profoundly by the advent of a subterranean, lethal sexually transmitted disease as ~~it was~~ they were by the invention of nuclear arms. Just like the day after Hiroshima, the world will never be the same again, now that HIV is here and we must do our best to cope and learn to live with it and teach our kids -- or we will have been negligent. I'm eager to hear Dr Easley - for he has been a major source of my knowledge & reality testing over the years. The point I want to make is that, to whatever extent we have progressed thus far, we have done so against a fateful gradient of denial and prejudice. Just think how much more effective we

could be were we not constantly fighting rear-guard actions against stigma and discrimination and the dogged ignorance that breeds unreasoning fear. When someone says "Nothing works!" I say "Oh yes — lots of things work. There is much that we could do right now if we collected & critically sorted the demonstrations & small-scale efforts of the past decade & organized a national plan, backed by a firm national will. We just haven't begun to try on a scale appropriate to this massive national problem!

Old problems -- solved?

But so much for sermonizing: let me get down to work. First, let's look at some old problems, solved and otherwise. (I should comment here that my choice of issues is rather arbitrary and decidedly incomplete -- when I began to try to sort out issues with an eye to what was and wasn't new, it was a fascinating exercise but quickly the lists became much too extensive for one talk; I commend ~~it~~ the ~~thought~~ to you as one way to take stock of where we are).

Anyway, one should take heart in how much progress there has been over the decade since the virus of AIDS was revealed and the extent of its silent dissemination was first appreciated. I think it helps to recognize how much of a handicap we were up against. It took a while to realize that the human immunodeficiency virus had already had a ten year head start by the time it was recognized; and I think that awful fact has still not penetrated ~~the~~ public awareness. People continue to take false comfort in the distributive statistics of AIDS cases, and yet even with the new AIDS definition which has helped some those are still misleading demographic clues, in that to a large extent they ~~still~~ reflect the era before we knew there was a virus. The trends are what we should care about, and they show us that the U. S. epidemic is becoming more and more like the epidemic in the rest of the world: more

women, more children, more heterosexual transmission -- does it really make sense to cling to a ten-year-out-of-date road map when we are trying to cope with a changing terrain? Yet people still cling to stereotypes, and fight against the truism of transmission by **all kinds** of sex. There has never been an STD that confined itself to one sex, and from the outset it was evident that heterosexual as well as homosexual intercourse could transmit HIV, but the homophobic dismissal of AIDS as "just a gay disease" can be heard to this day.

But as that identity of ~~HIV/AIDS~~ HIV as a **sexually transmitted ~~disease~~** pathogen has been reluctantly acknowledged, a new line of argument has arisen: if ~~it~~ AIDS is an STD, why not treat it like all other STDs? In fact, why are we making an "exception" of AIDS? Shouldn't we do all the good old fashioned public health things we always did? I always wonder, when I hear that, whether I am on the same page with such advocates; for by my reading, we had done miserably with STDs before AIDS came along. - and with due respect to many exceptions in general

Indeed, in a ~~certain sense~~ that context some of us, including me, were inadvertently watching as the HIV epidemic began -- for in 1975 NIAID, under the leadership of Dr. Dorland Davis, led declared STDs to be at a national crisis level and therefore worthy of "special emphasis" by the Institute. NIAID put out a call for program project proposals to establish centers where multi-pronged approaches to the microbiology of STDs could be launched. I was one of a small team of microbiologists used to review the resultant proposed projects, and thus during the years from 1976 to 1980 traveled at intervals the virologists making up part of

to many of the cities where, in retrospect, HIV was spreading silently. As we learned, on such site visits, of the increasing range and complexity of STDs and sexual behaviors, we even mused among ourselves that, from a microbiological point of view, the very intensity of the STD epidemic was ~~worrisome~~ almost qualitatively different from earlier times. We certainly didn't have the perspicacity to say "What if there were a new, lethal, sexually transmitted retrovirus?" but we did recognize that there was fertile soil for new and dangerous microbial things to happen.

So when someone harkens back to the "good ol' days" and suggests using the ~~old~~ good ol' STD model as a preferred approach to dealing with HIV, it leaves me ~~quite~~ cold. Quite to the contrary: I think that many of the innovative approaches taken to HIV, were they amplified and well-deployed, would stand to make a considerable dent in our abysmal record at dealing with STDs, not to mention adolescent pregnancy, unwanted pregnancy, abortion and all the related problems stemming from our national failure to approach sexuality rationally.

Dr. Ronald Bayer has claimed authorship of the phrase "AIDS exceptionalism" as an implicitly pejorative way to characterize our current, non-classical approach to HIV -- in contrast to other STDs. I will surely agree with the idea that our efforts to deal with AIDS have not been classical; and thank goodness for that! We have tried to deploy every new insight we can, to bring to bear behavioral as well as biomedical science on strategies of prevention, and to take a fresh approach that incorporates all the

new knowledge that can be gleaned. If that is AIDS "exceptionalism" I'm all for it -- furthermore, I recommend it to the traditional STD folks! The dramatic drop in AIDS diagnoses in San Francisco announced last week -- if it holds up -- validates that stance as have many prior studies and demonstrations of innovative interventions in which the subjects are dealt with in their own language and as equal partners in the prevention enterprise. That was <u>not</u> a prominent feature of the "good ol' days."

If you haven't seen it, by the way, Dr Bayer takes another turn at this topic of AIDS exceptionalism in what I think is the most recent issue of AIDS & Public Policy and there is a wonderful rebuttal by Mike Isbell of GMHC that is well worth the effort to find + read.

I can't resist a brief diversion at this stage, for the fact that we are meeting in Orange County reminds me of the several interesting times in 1987 and 1988 when Congressman Dannemeyer and I jousted in Congressional hearings about such matters. It happened often enough that in a certain way we became acquaintances; and in any hearing at which I appeared, he invariably accused me of selling out public health in the name of civil liberties; and I always parried by asserting that attention to efficacy and to human rights and dignity was at the very heart of effective public health.

There was a day in 1987 when I and Dr. Sam Thier -- then President of the Institute of Medicine -- were trying to talk about the crucial role that forthright AIDS education played in prevention of HIV spread, while Mr. Dannemeyer intermittently accused me of liberalism and on several occasions cited a poll in which 80% of people supported some draconian intervention. (It was at a time, of course, when virtually nothing had been done to

present the American people with systematic AIDS information (which they would have needed to develop intelligent opinions). Anyway, at the end of the interchange, Mr. Dannemeyer waggled a finger at me saying "..and Dr. Osborn, I want to tell you that even Thomas Jefferson himself said that government should be by the will of the people!" to which I replied, "Oh no, Congressman Dannemeyer, as I read it he said by the will of the **educated** people!"

The banter was fun -- I won that round, anyway -- but the message was deadly serious. Through a mix of failure to communicate what we know, inadequate critiques of past failures, and cliche-ed invocation of "good old fashioned public health", we are still foundering when it comes to clear communication about HIV and AIDS. There are far too many people who excuse their inattention by saying AIDS is a problem for "others". That was never true, but as the death toll in just thirteen years approaches one quarter of a million Americans and the projected losses of the next couple of years will push that number beyond the total mortality of all American armed conflicts since the Civil War -- as those dreadful, inexorable numbers climb, it is time to rethink that business of "others." There are no others!. And that is an old lesson that ~~still~~ seems to needs re-learning.

I will return repeatedly to the refrain that self-perpetuating ignorance is a problem. But during the past decade, achievements in the "hard science" of the epidemic give much cause for pride, and I want to be sure I pay due credit to those as well. First and foremost, from the outset epidemiologists painted

a clear picture of risk and non-risk, and their conclusions have been strengthened and refined with essentially no surprises.

when I talk about science

Parenthetically, I always like to start with epidemiology, since I fear many people think it doesn't belong in the category of "hard science" whereas it is in fact at the absolute center of it -- the proof of the pudding with which all other findings finally have to conform or be clearly off the mark. I have already nodded to a couple of heroes of the epidemic years, but I would remiss not to note the remarkably sustained, rational, productive role played by Dr. James Curran of CDC. He and his team did a job of initial shoe-leather epidemiology that will be esteemed decades hence when many other scientific contributions have been overturned half a dozen times. What an accomplishment that was: imagine how much worse things would have been if HIV had been transmitted like flu or measles or, worse yet, if we didn't suspect - and then know - from earliest days that it was hard to transmit by means other than sex or blood!

If I sound a little defensive about epidemiology let me

~~I must~~ digress ~~here~~ again to tell ~~a~~ another favorite story: there was a time in about 1988 when a visiting young NIH biochemical virologist and I were sharing a platform at a local physicians' symposium in Michigan. I had been introduced as a Professor of Epidemiology, and neither the audience -- nor, as it turned out, the emcee -- knew I was a virologist. Anyway, during the Q+A period ~~at one point~~, a person in the audience brought up ~~cited~~ a recent study in which HIV had been successfully recovered from a lab bench an hour after being smeared on it ~~placed there~~ and then grown in tissue culture; didn't that mean there was

environmental danger lurking? I pointed out in response that the real-life risk of HIV had been put to an incredibly rigorous test within the families of people dying of AIDS, where the sharing of toothbrushes and razors, kisses and utensils (and in fact everything but sex) had failed to result in even a single instance of non-sexual transmission. Thus the demonstration that HIV could be rescued from surfaces and coaxed back to life in tissue culture did not "connect" with real world experience. When I had finished my homily, the physician chairing the meeting said "Thank you, Dr. Osborn. Now let's hear what the **scientist** has to say." So much for epidemiology as a hard science!]

But getting back to progress: the virologists and immunologists have made extraordinary progress in their understanding including, of course, lucid and useful insights into the pathogenesis of AIDS. Remember how it seemed so mysterious at first? and yet the diligence of research has pressed understanding to the point where prognoses can be proffered and treatment strategies devised in ways that were unthinkable only a few years ago. It is hard to remember a world without HIV, much less to bring back to mind that brief interval in the early '80's when we knew we were in trouble but didn't understand why. As always, familiarity breeds contempt, so it is worth noting how much that new knowledge has meant to us all as the past decade evolved.

One of the reasons I revisit those achievements is to remind us how far we have come in a few short years; for it has been fashionable, especially since the Berlin meeting last summer, to

talk as if the Sisyphisean stone had rolled all the way back down the hill. To be sure, there have been disappointments: the hope that zidovudine (or AZT as it is more commonly called) would be a durable intervention ~~was~~ had already been shaken by the frequency with which HIV eventually develops resistance to that drug. ~~Furthermore,~~ But in Berlin AZT's role in early intervention -- that is, initiation of AZT well before symptoms of illness appear -- was challenged significantly by some large-scale European studies that involved longer-term follow-up than had been used in initial validation of the regimen. Clearly it is not as easy as it seemed to decide on an optimal therapeutic strategy for AZT use.

But don't be confused: in taking care of PLW HIV+ AIDS we are far better off than was the case a decade ago: prevention or effective treatment of opportunistic infections, ~~effective treatment of others,~~ increasingly focussed approaches to certain tumors and maintenance of fundamental good health and nutrition are at least as central to "early intervention" as is any available antiviral therapy, and there is no doubt that, overall, the clinical intervention "package" has extended both duration and quality of life for people living with HIV, regardless of how the AZT ~~argument~~ role in early intervention turns out.

And don't over-interpret, either: AZT and its relatives among the reverse transcriptase inhibitors are still very effective therapies for many symptomatic people with ~~HIV disease~~ AIDS. The unsettling findings coming out of the so-called Concorde study, the one that was reported in Berlin last summer, were about the durable efficacy of AZT as part of early intervention; no study disputes the therapeutic usefulness of AZT for symptomatic people with

advancing AIDS.

Some of the most fearsome problems of ten years ago have truly been brought to heel: for instance, in the wake of the frightening uncertainties about transfusion risk before 1985 when screening for HIV antibody was instituted, the blood supply has been brought to a level of safety never before achieved. Tests not only for HIV-1 and -2, but also for hepatitis C, have been added to a rigorous regimen of analysis; and slow but committed progress toward true blood substitutes suggests that a day will come when dependence on blood donation can be greatly eased if not eliminated. There remains a so-called "window period" in early HIV infection in which antibody screening is not useful, but education of donors has resulted in near-elimination of HIV transmission nonetheless, and the efforts to close the window still further are on-going.

However, the health of the public at large is still dependent on blood donation, and that is one of the contexts in which old problems persist; for when blood shortages arise, as they often do, it turns out that nearly one in four Americans still fearful of donation because they perceive, falsely, that the very act of donation poses a risk of AIDS. That seems like an awful number of people ignorant of the realities of risk: and yet it is not very different from the numbers of people who fear close contact with a person with cancer! We have a lot of work to do in the realm of health education in this country, as those depressing data suggest.

That brings up a broader area in which we are constantly having to fight old battles: that is, the issue of whether HIV causes AIDS at all. One would think the degree of proof by now was overwhelming. And yet a very few dissidents, perseverating far beyond reason and denying the validity of evidence that has persuaded virtually all of their colleagues, continue to insist that HIV has nothing to do with AIDS -- + lately that AIDS may not even be a disease. In the U. S. that causes a tiresome and unwelcome hassle to be dealt with when there is so much to do; but in Africa, I fear, it is real trouble! When I was in Marrakech, Morocco for the "AIDS in Africa" meeting in December, I was horrified to learn that mistrust of things western (or Eurocentric, however you like to put it) had provided fertile soil for that iconoclasm. The London Sunday Times, with its historic legitimacy now overtaken by its new owner, Rupert Murdoch, has taken up the cudgel of HIV-doubt with such effect that people in many subSaharan African nations are once again having to persuade their government leaders that there even is such a thing as AIDS! With the number of AIDS orphans in Africa skyrocketing, with the wards of African hospitals overwhelmed by people with HIV disease, imagine having to keep defending the premise that there actually is a disease out there!!

I am reminded of something David Rothman once wrote: that people seemed not to recognize or grapple with a disease until it had a name - this seems to be a troubling illustration of that mechanism in reverse — if something isn't called AIDS, maybe the problem won't exist.

I'm not sure I know where all the credence of such blatant revisionism comes from -- but certainly it reflects in part the same failure of public education about health in the modern world that I noted before. If you don't really believe in viruses to start with, it becomes easier to dis-believe in HIV and its effects. I guess that would be okay - except that it completely

blunts the most effective weapon of control that we have or are likely to get -- that is education for prevention. And surely some of the disbelief comes from profound mistrust of the sources of authority.

And that brings me to one ~~last~~ other old problem that I want to highlight: mistrust. It came as a dreadful shock to us on the Commission to hear, from many of the most distinguished people of color in the United States, that mistrust of the establishment was pervasive in many communities of color with respect to HIV, AIDS and treatment or prevention strategies. The shadow of the Tuskegee experiments, in which African American men were allowed to live with their syphilis untreated long after effective ~~treatment~~ therapy was at hand, casts a dismal pall over biomedical science as perceived. Research is suspect, whether it be therapeutic or fundamental. Participation in clinical research is viewed with ~~an~~ a ~~almost schizoid~~ paralyzing ambivalence: participation in trials, on the one hand, needs to be representative to be perceived as having full relevance to a given community. And yet the investigators are not necessarily to be trusted -- a situation which is created or intensified by the fact that far too few people of color hold positions of authority as researchers and professionals involved in the conduct of such trials. That is an area of need to which we tried to call attention years ago - along with many other voices - but renewed efforts must be mounted + sustained for the deficit is huge.

So deep is the anxiety and estrangement, that a startling number of people of color, when asked, confirm that they believe HIV to be an escapee from a government laboratory -- perhaps even a deliberately genocidal tool aimed at them! It is awful even to say these things out loud -- but as I say repeatedly, the first

step to solving a problem is to see it clearly, and <u>that is an important part of our problem!</u> The old, tired racism that ~~has been~~ so dreadful & ~~so dynamic~~ ~~a part of~~ our heritage is there to be dealt with if we really want to get a grip on our HIV problem — this is one of the many things that prompts me to say that, in a very real sense, the only thing new is the virus — that's a large part of what we're struggling with represents old problems never faced, or else patched over & left to fester & break under the pressure of epidemic circumstances. If we "get it right," the impact will reach far beyond AIDS.

"New" issues — or are they?

Let me turn, ~~then~~ (to a few myriad) to some new issues — matters that have taken much of our attention ~~since~~ the second decade of AIDS got underway. Striking among them is the matter of HIV risk in the health care setting. There was a while there in 1991 & '92 when it looked as if a national panic attack would result in the banishment of thousands and thousands of trained health professionals from the venue of their useful work, just because of their HIV status.

I greatly fault the AMA for, ~~that~~ perhaps, for as virtually every other organized professional group weighed in on the matter — saying that a single dentist's practice was unique [in the literal sense] and that universal precautions were the way to go — the AMA came out with the remarkable statement that any risk of HIV greater than zero was unacceptable. Think about that! What ~~a terrible~~ an astonishing stance for biological ~~beings~~ Gentes to take — for the only totally risk-free condition I know of is death! Here ~~I am~~ we are, arguing for better health education & increased participation in health-related choices on the part of the public, and the AMA declared zero risk to be its minimum acceptable standard!

Among the most poignant & powerful hearings held by the National Commission on AIDS were those dealing with these issues early in 1992 — and I'm proud to say a report we issued, along with some very hard work on the part of many people but notably Dave Rogers, saved us from ourselves — SO FAR! That issue has enormous "phoenix-potential", though — I fear it can rise from the ashes at any time, so let me briefly talk you through it.

First of all, the issue was wrongly posed — we should be concerned first and foremost about Safety in the health care setting, for care giver & receiver alike. That was, in fact, the basis for the very rational institution of universal precautions starting in 1987. And, having refocussed on Safety, in the face of this young epidemic & some of the complexities of its study, we should look at known risks, using them as benchmarks against which to compare HIV and as surrogates to assess the efficacy of the universal precautions strategy — and that is part of what was done. Hepatitis B, while not a perfect model, served well — for it represented a very real, documented risk

in the health care setting and is at least 30–100 fold more readily transmitted than is HIV by the same routes. Patients had been infecting HCWs, with Hep B + little outbreaks of Hep B had been traced to individual HC prof'ls, for years. And then, as of 1987, such events virtually ceased in the context of universal precautions. [No, it wasn't the vaccine that did it, for as you know, there is dificulty getting people to use that excellent vaccine even to this day.]

Better yet, other questions pertinent to safety were asked, (this was one problem that was seen clearly, and therefore curiously) some of them for the first time. What amplified needlestick risk? were there ways of avoiding it? How well was Hepatitis B vaccine being used? What was the most effecacious way to deploy it in the context of HCWs?

Those questions have yielded very useful answers — especially the low-tech insights that careless disposal or recapping of "sharps" and failure of Hep B vaccine utilization were big, fixable contributors to the degree of un-safety in health care.

And as to risks posed by HIV-infected HCWs, thorough + exhaustive "look-back" pursuit of literally thousands of people operated on invasively by HIV-infected surgical or dental professionals has failed to reveal even one replica of the Dentist practice that set off the bra-ha-ha — it remains unique!

One cannot prove a negative in the world of Science, but these are notable & reassuring findings. This is a massive worldwide epidemic, with literally millions of health care interactions occurring monthly. Without doubt, at sometime in the future, another outlying event will re-trigger the public panic and political posturing that nearly overwhelmed us this time. I do hope we can think our way through the inherent issues during this relative calm between storms so that we keep on getting it right when the phoenix rises once again!

So for now, we can continue to enjoy the benefit of the ongoing health profits we are to have HIV but can continue their good work.

Tuberculosis

One other "new" issue I want to turn to, for a moment, is the resurgence of Tuberculosis. [I almost wince to call it a new issue, for it was always there waiting to happen, and we had at hand all the necessary science to predict and prevent it long ago. In fact, I taught about TB as a brand new assistant professor of infectious diseases in the mid 60s and my lecture notes are still perfectly useful!] There are well known truisms about tuberculosis: it is usually not very contagious — unless you cram a person with cavitary disease into a space crowded with other people under conditions

of poor air exchange. That works well to spread the bacillus; and it works even better if some of the people in the crowd are unduly ~~so~~ susceptible because of weakened immune systems. With our mandatory sentencing laws aimed at drug users who are much more likely to have HIV + who now crowd prisons to two- and three-fold their intended capacity, we tested those tenets in the 1980s and by golly! we had been right — those are the necessary + sufficient ingredients to re-awaken Tb.

But there was one more thing & we taught long ago: that if you let therapy be discontinuous or erratic, you end up with multi drug resistant Tb — and voila! with little or no prison health care and no continuity of care on release/parole, that has "worked" too, and so now we have added multidrug resistant Tb to our worries — and that is really scary.

I don't say it that way to sound smug — I just want to underscore how much we do know that we're not using. Now there are calls for more biomedical research on Tb, for fancier diagnostic tests and

for more and more new drugs to serve as alternatives when resistance occurs. I surely agree that more research is needed, for Tb has been neglected — especially given its importance around the globe. But if all we do is more bench research, while ignoring what we know to do already, then we are being profligate and foolish!

A similar case can be made about vaccines against HIV — another "new" area where things are changing. Vaccine work is going slowly & it's going to be hard — testing on a large scale will present stunning problems to achieve demonstration of efficacy: problems of design + community involvement and sustained participation. It doesn't look likely that those steps will be completed in the next few years — but that has a positive side to it. For there is a lazy streak in the public thinking that says that when the vaccine comes, all this hard health education & behavior change stuff can be put aside, and that's not true. Even if we had the best vaccine in hand, ready to go today, it would only be an adjunct to what we

already know to do about prevention. A vaccine will never be as good as avoidance of HIV in the first place — so we must take very seriously the business of evaluating and using what we know. There will be no escaping the need to start dealing more effectively with the issues of sexuality & drug use for our children's sakes!

I could go on like this, but I want to leave time for questions — the take-home message I intend is that this epidemic isn't going away anytime soon; that we should be quite heartened by what a lot has been learned in the past decade — especially since so much of it in the realms of social & behavioral science, public health and health care (and even in basic research) is applicable far beyond AIDS. But we should also be chastened (or at least sobered) by the terrible discontinuity laid bare between our ability to generate new knowledge and our seeming inability to take advantage of what we know.

When the NCA wrote its final report a few months ago, we devoted much attention to making accessible the 15 previous reports of the Commission — focused recommendations dealing with themes such as substance misuse, housing, adolescents, communities of color

We hoped they would be durably useful if and when the nation began to treat the epidemic with the awe & respect & urgency it warrants. So we catalogued & indexed and made a useful list of all the wonderful people who were witnesses & shared with us the anguish & the expertise of the first decade of AIDS. [Can be gotten there - CDC AIDS Clearinghouse]

But we kept our final comments & recommendations brief (& I will quote them even more briefly). We entitled the report "AIDS: An Expanding Epidemic" & in a preface ~~Dave Rogers & I gave~~ we gave vent to our sense of frustration as follows: (see p. 13 of your handout book) handout 32 & 33

And then we made just two final recommendations: the first sounds painfully similar to some of Candidate Clinton's exhortation that I read to you at the outset: ~~that is~~ our rec. read: "Leaders at all levels must speak out about AIDS to their constituencies." We commented, in that context that "Our Pres. . .

Second, Rec. 2, "We must develop a clear, well-articulated national plan for confronting AIDS." I have touched on that at several stages of this talk — and ~~it~~ nothing brings ~~it~~ the need home more

compellingly than the awful convergence of disturbed drug, prison health and discontinuous care practices that have spawned the new & difficult problem of multidrug resistant Tb. Only through pulling together as health care prof'ls and communities ~~and needing~~ and academics of various stripes and govt leaders across a spectrum of levels — only by getting together will we be able to see our problems clearly and then begin to bring to bear knowledge at hand or new knowledge to begin to solve them. This isn't going to be easy, & it really requires both national planning and a national will.

Hubert Humphrey once said that the true test of a society was how it cared for those at the dawn of life — the children; in the twilight of life — the elderly; and in the shadows of life — the sick and the handicapped. As a generation of Americans we are being put only to the test as we try to meet the challenge of the epidemic of the century! but how well we do will, I believe, provide a true measure of our American society — so the stakes are high!

Thank you!