ORIGINAL

TRANSCRIPT OF PROCEEDINGS

NATIONAL COMMISSION ON

ACQUIRED IMMUNE DEFICIENCY SYNDROME

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SEX, SOCIETY AND THE HIV EPIDEMIC

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NATIONAL COMMISSION ON AIDS

SEX, SOCIETY AND THE HIV EPIDEMIC

Ballroom
Le Meridien Hotel
614 Canal Street
New Orleans, Louisiana

Monday,
May 18, 1992

The above-entitled matter came on for hearing, pursuant to notice, at 9:00 a.m.

PRESENT:

JUNE E. OSBORN, M.D.
MICHAEL R. PETERSON, M.P.H., DR. P.H.
JAMES R. ALLEN, M.D., M.P.H.
DONALD S. GOLDMAN
EUNICE DIAZ, M.S., M.P.H.
SCOTT ALLEN
ROY WIDDUS, PH.D.
DAVID E. ROGERS, M.D.
HARLON L. DALTON
DIANE AHRENS
DON C. DESJARLAIS, PH.D.
LARRY KESSLER
SHEILA WEBB
THOMAS J. COATES, PH.D.
JOHN H. GAGNON, PH. D.
VICKIE MAYS, PH.D.
VINCENT BRYSON
TOM BRANDT
FRANCES PAGE
IRWIN PERNICK
JOHN MONEY, PH.D.
CAROLE VANCE, PH.D., M.P.H.
JOSE PARES-AVILA, M.A.
RICHARD GREEN, M.D., J.D.
PRISCILLA ALEXANDER
WALTER SHERVINGTON, M.D.
ROBERT SELVERSTONE, PH.D.
PEDRO P. ZAMORA
TIM H.
DR. HYSLOP
FRANK AQUENO
MARK DURHAM
DR. SUSAN ABDALIAN
CORNELIUS KING
PATRICK LEBLANC
NORMA PORTER

I N D E X

PROCEEDINGS

DR. OSBORN: Sorry. We are a few minutes late, but we wanted to make sure everybody was collected, and New Orleans is very tempting with that sunshine out there. I have never seen New Orleans in the sunshine before, so this is wonderful.

I have for starters just a very few opening remarks. The staff has put together a very rich set of presentations for today and tomorrow, which mark the beginning of three hearings in different parts of the country, each dealing with aspects of prevention issues that we feel are very urgent.

Just the very fact that prevention takes so long to pay off makes it all that much more urgent to start with, and so we want to focus now very tightly on that in our meetings here today and tomorrow. A variety of issues dealing with sexuality will be the first phase of that focus, and in subsequent meetings in Kansas City and in Austin later in the summer, we will be talking about behavioral and social research issues, and we will be talking about communications and trying to get an overview of some of the really quite diverse elements that weave into a mode of prevention.

Before we get started, I want to see if Sheila Webb would like to make a few welcoming remarks. She is

deputy director of the New Orleans Department of Public Health, and we have already had the very delightful experience of meeting with her this morning at the high school.

Thank you for being with us to make some initial comments.

MS. WEBB: It is my pleasure to be here with you once again as we did spend some good time together this morning. I am here at this particular time representing the mayor, who sends his -- I guess it is just his real sad feelings of not being able to be here himself, because he is in Baton Rouge.

We were not sure that he was absolutely going to miss this opportunity, but as I got back to city hall, I got the telephone call that he was still in Baton Rouge and asked me if I would come on his behalf.

So with that, I do bring greetings to you from the mayor and city council of the great city of New Orleans. The mayor again sends his apologies for not being with you today.

I did have the opportunity of meeting with him on Friday, and we talked about your being here. He was familiar with some of the work that the Commission has done. One of the questions that he asked rather early on in our conversations is, was Magic going to be here with

you all, and I told him that I was not aware that Magic was going to make this trip.

He asked, however, that I convey to you his strong commitment to the eradication -- and these are his words -- the eradication of the HIV epidemic. The mayor commends the Commission for the outstanding work it has accomplished since its inception in 1988, and also he was aware of some of the previous work that the President's Commission has done.

He asked that I would say to you that as you proceed over the next two days, focusing on knowledge and attitudes, sexuality and their relatedness to the HIV epidemic, and that as you hear from people that are going to come before you to testify, such as the children that you heard from this morning, the professionals and so on, that we are very cognizant of the fact that you will use this information as you go back to help to compile recommendations that essentially will help to influence and to make policy in some circumstances, and that certainly we hope to see a greater emphasis on prevention as an outcome of all of this.

If there is anything else that we can do to facilitate your accomplishing your goals while you are here with us in the city of New Orleans, please do not hesitate to call. Thank you so much for coming.

DR. OSBORN: Thank you very much. Let me comment that Mr. Vince Bryson is here representing Irvin Johnson, Commissioner Johnson, and we are very pleased that he is with us to carry back to Commissioner Johnson the important things that we will be hearing in the next couple of days.

So, Vince, glad to have you with us, and thank you for a very rich morning. Among the many things the Commission does, most of us, I think, go out and talk around the country and talk to people, and while talking is by no means doing, it does help to motivate people at the community level.

And when we have experiences as exciting and informing and inspiring as we did this morning, I for one am very much better off than I was before we started already, and that is even before the testimony starts.

So thanks to everyone for putting together the very special opportunity we had to visit with the School Based Clinic this morning, which was really quite special, I think, for all of us.

With that introduction, let me ask Dr. Tom Coates to join us, and welcome.

Dr. Coates is director of the Center for AIDS Prevention Studies in San Francisco, and we will be talking about the overall thrust of a national prevention

strategy, and giving us an overview that really will serve for this series of hearings here and then the subsequent two, as I mentioned before.

Tom, welcome. Thanks for being with us.

DR. COATES: Thank you. It is a pleasure to be here and to talk to you about something that is near and dear to my heart, and that is the issue of prevention.

And what I hope to do -- I think you have heard a lot about everything that is wrong with the way that we are doing prevention and everything that is wrong with the way that we are doing prevention research, and I don't want to repeat all of that; you have heard it enough. I don't want to bash the CDC, and I don't want to bash the federal government.

What I would like to ask you to consider today is a plan of action that I have put in front of you in my testimony, and a plan of action that I would like to ask you to consider recommending.

The Ryan White Care Act and the issues of care really have dominated the AIDS agenda for the last couple of years, and that has been an extremely beneficial and good process, and I think there are lessons that we can learn from that process to figure out how to do prevention better.

Last Thursday night we had the San Francisco

AIDS Foundation leadership dinner in San Francisco, and it is always a very nice event. A large segment of the community turns out. They honor distinguished people in the community and so on and so forth.

And I brought the booklet along, because it was really poignant in terms of what the AIDS Foundation is saying now, and their campaign for 1992 is, Be Here for the Cure, and what they are trying to promote is early treatment for HIV.

Now, this is the first time that I have heard anyone talk about a cure for HIV. We are certainly a long way off from a vaccine, and people talk about HIV as a chronic manageable disease. Well, in my experience, chronicity is rather short; I think of it more as an acute management disease. It still progresses fairly rapidly, certainly in this country and certainly in other countries.

And it just brought home to me one more time that we don't have a cure now, and it is going to be a long time before we do have a cure, and prevention is really, really, really important, for this country as well as for the rest of the world, so I am not sure if I agree with the AIDS Foundation campaign.

I would like all of us to be here for the cure, but I don't think they have found the answer to the aging

process at this point.

There were other important things that were highlighted in this brochure. They gave a historical account of some of their campaigns. Their 1991 campaign was, Sex is Good, and their 1990 campaign was focused on young gay men, and it was Life, Liberty and the Pursuit of Happiness.

I am sure you have all seen this poster with these two young men sort of one in front of the other draped in the flag and holding up a condom, making condom use part of the American way, and certainly part of the way of protecting young gay men.

Now, of course an important issue in the development of these campaigns has been the fact that the AIDS Foundation has not used federal funding in their development, because they didn't want to be under the strictures of federal funding. They wanted to develop the kinds of campaigns aimed at the populations they needed to aim them to, and to be explicit and to have them important.

There are a couple of other important parts of -- at least important memories from the AIDS Foundation dinner. One is, of course, that we at UCSF and at the Center for AIDS Prevention Studies have had a very close relationship with the AIDS Foundation.

They have used our research in the development of their activities, and we have evaluated what they have been doing, but the other thing that I liked was the worldwide theme, and we usually think of the U.S. as a technology exporting country, but I think we have got a lot to learn.

I am sure you have heard of the condom social marketing programs that have been -- had remarkable and tremendous impacts in increasing the sales of condoms in Africa when they said that African men will never use condoms on a regular basis or on a consistent basis.

And the peer education programs probably have talked to more prostitutes in the world than any other group of people, the establishment of condom-only brothels in Thailand, for example. There have been some very important changes worldwide that I think we can take heed.

So the question is then what do we do here? We are in the second generation of AIDS. We have had a lot of discussion over the last ten years about what we are doing and about what we are not doing, and what I would like to ask you to think about is supporting an initiative for a national AIDS prevention strategy.

I would like to walk through my testimony just briefly. If you have it in front of you, I would invite you to walk through with me.

First of all, starting on page 3 of the testimony, I wouldn't want to give the impression that we in California have our act together; far from it. We recently did an evaluation of the California AIDS prevention program, and it says a lot about what is wrong and about what can be improved, and I would like to just make two points about that.

And the first was when we started to do this evaluation, the state office of AIDS couldn't even enumerate what programs they were funding. It was all sort of in files someplace, and nobody had a computerized listing; and the second, of course, in this call for evaluation, the kind of evaluation that is done is head-counting: how many people have you served?

Well, anybody who is getting money from any agency will do what they need to do to please that agency, so if you are going to count heads, then we will reach as many people as possible, which means we will do it by the most ineffective means possible. We can distribute a thousand brochures in a half an hour. We can have one-hour workshops. And that is exactly what is going on in California.

So how do we reform this whole process? Well, the idea is to take what we have learned from care and perhaps apply it to prevention, and on page 4, I lay out

four steps that hopefully will help us with that process.

The first step is developing a vision. This Commission, in its report on America Living with AIDS, called for just a vision, and now I think it is time to take the next step. Somebody needs to create that vision, whether it be this Commission or a panel empaneled by this Commission or the National Academy of Sciences or the Institute of Medicine. Somebody needs to create that; it is time, and it needs to be done quickly, because more and more people are becoming infected.

Step 2 on page 5: we need to use what is effective in HIV prevention. In the area of care for people who have HIV disease, there is a standard of care. AZT, antiretroviral, starts at a certain level; prophylaxis for various opportunistic infections starts at a certain level; there is a standard of care.

We have reached the point where we know enough about AIDS prevention that we can develop standards of care. These are the kinds of things that work. These are the minimal levels of interventions that we know will be effective, and we can develop those standards.

And again, an expert body needs to do that, and we need to bring more and more and more people into a consensus-building process so that that happens.

I might mention that of course the kind of plan

that I am proposing here is also being used and borrowed by other people. Senator Kennedy's office, as you know, is about ready to introduce legislation on the Comprehensive Adolescent Services Act of 1992, very germane to the school clinic that you visited this morning and the kinds of issues that are present in that clinic.

And I think one of the really genius parts of that legislation will be targeting the interventions for adolescents who have multiple problems; violence and drugs and unprotected intercourse, unprotected sex, STDs, early pregnancy, so on and so forth, with a good evaluation component, so we are not alone in thinking about this.

Step three on page 7 is to develop mechanisms to support innovation. And I realize that a key piece of the Ryan White Care Act are the local planning councils, and that many people have asked the question, Are the local planning councils worth the effort? You get the groups together, and that takes time, and they have got a process, and they don't always understand the planning process.

But what they do understand are two things: number one, what the local needs are and how best to meet those needs in that community with an understanding of the standard of care for prevention.

It probably goes a step further. I guess there

were two points to be made, and one is, of course, that no group, and least of all the health departments, have any divine insight into what is going to work best in a community. Most often the process works by a very different mechanism; that is, somebody makes a plan.

In the case of California, the plan comes down from the state office of AIDS. Somebody makes a plan; then RFPs are issued, and then people respond to those RFPs, and they sort of go after the money.

Well, rather than doing it by that process, let the local communities decide. It doesn't work equally well everywhere, and we can learn from the Ryan White Act why it has worked and where it has worked and how it can work.

But the most essential part of this is community involvement, and if there is any key to behavior change, it is community involvement, and particularly if that community can be gotten together and helped to think about its underlying problems.

It is not just how can we promote safer sex but how can we solve some of the underlying problems of that community, and I can give you some examples of that, of how we are attempting to do that in some of our research on community mobilization.

I think a key issue, of course, is where a

program like this would be located, and of course the logical agency is the Center for Disease Control, and that may be okay but only under one circumstance, and that is only if the CDC is protected from political interference.

If that can't be guaranteed, there is no sense in putting that program there. We don't need to continue beating our head against the wall. All of us have a threshold; we have reached that threshold. It is time to move on and either protect the CDC or cut bait and go someplace else.

Step four has to do with research and evaluation, and there are really two key ideas here on page 10. One of course is that ADMHA has been reorganized, NIMH, NIDA and NIAAA are moving into the NIH. They are moving into the place where "real science" is done.

Now, this is unfortunate, because what it does is separate behavioral research from service, and I think it is a very unfortunate move; I have been opposed to it all along, but it is a done deal.

So the question is how can we make the best out of this situation? Well, I think two things have to happen. The Congress, year after year, has said to the NIH, You need to spend 10 percent of your budget on behavioral research, and we want a report to Congress.

Well, a recent report of the Institute of Medicine indicated that in the fiscal year 1990-1991, the NIH devoted 3.1 percent of its funding to behavioral research, so that worries me a lot, as the two agencies that are doing the bulk of AIDS behavioral research, the NIMH and NIDA, move into the NIH. That needs to be protected.

Now, it partially has, because the legislation calls for an office of AIDS in each agency; however, I think another mechanism needs to be set up, and that is an AIDS behavioral oversight committee reporting directly to the director of the NIH, because otherwise it is going to get smothered in the other priorities of the AIDS program.

The only thing that needs to happen, of course -- and I think the other speakers in this series will be talking to you more about this -- is AIDS behavioral research also needs to be protected from political pressures, and we need data and research on the negative side effects of our interventions.

If it is true that if we do a national survey of sexual behavior of adolescents and that the major concern is that the libidos of all the adolescents in the country are going to be released and so that we are going to have incredible increases in -- or an incredible downward spiral on the age of first intercourse, at least

we ought to find out. I doubt it, but we need to find out.

This is a burning question; it affects policy in this country; it affects policy all over the world. People are afraid to promote condoms, because they are afraid that it is going to promote promiscuity.

Let's collect some data. In fact, some good data are beginning to accumulate that well-done AIDS prevention programs actually delay onset of first intercourse, not bring it downward.

And the last thing that we need to do, I think, is to have strong mechanisms for linking services in research. People who get NIH grants to do AIDS behavioral research need -- just as we now need to include an IRV approval, and we now need to include how we are working with women and minorities, I think there should also be a dissemination plan.

Some of the investigators I work with come to me and say, So-and-so has asked for my questionnaire; So-and-so has asked for my treatment manual; should I send it to them? And I say, Nobody has ever won a Nobel prize for a questionnaire or a treatment manual. Get it out there. We are not talking about careers; we are talking about lives.

So I think that should be part of the NIH

application package, and I think we need to set up programs to offer incentives to researchers to work collaboratively with CBOs in the development of programs and the evaluation of those programs. We are doing it in San Francisco, and it is working remarkably well.

The last thing that I would say to you and again ask you to do is to consider these recommendations, to indicate that we have a wonderful opportunity here, and hopefully we can prevent a few more people from getting HIV until in fact we do find a cure. Thank you.

DR. OSBORN: Tom, thank you very much. That is wonderful to walk us through this, and we will be reading it and rereading it with great care, but it is very nice to have you do that, particularly because it gives us a chance to interact with you a little bit, which we much appreciate.

Commissioners? Mr. Goldman.

MR. GOLDMAN: I have three separate questions, and if you would take them in order, I would appreciate it.

Could you provide some concrete examples of exactly what you are talking about that might be included within the kind of vision or prevention plan that you are referring to?

And my second question is, you were saying

something about community involvement issues, and I was wondering if you might expand on some of your research and findings in that area, and the third is, I guess, a rhetorical question, and that is, at least in my experience, in terms of federal government agencies, I suppose the CDC certainly doesn't suffer from greater political involvement than other government agencies within HHS, and if you want to get out of CDC, I am not sure whether you are going from a frying pan to a fire, and I am not what agency has less politics or more.

If you can find an agency of government that is politics-free, I would love to find it; I haven't yet.

DR. COATES: Let me take those -- do you mind the order?

MR. GOLDMAN: No. I have no objection.

DR. COATES: Can I take them in reverse order?

MR. GOLDMAN: Sure. That is fine.

DR. COATES: Okay. There was an ad recently produced for a national campaign. Whoopi Goldberg said, There ain't no making whoopee without a condom. Okay? Explicit, direct, beautiful. Whoopi Goldberg; what a wonderful person to be making this plea.

It was pulled. Now, I don't know if that is for fear of political repercussion or what, but that is a tragedy. That is a real tragedy, and as long as we

tolerate that, this country is going to go into a downward spiral, and more and more people are going to be getting HIV.

I am getting emotional; I am angry about it, and I don't want to bash the political interference and the programs that have been carried on by the CDC. Either the leadership has to get stronger or there have to be protections. We can't put up with this.

MR. GOLDMAN: The only point I --

DR. COATES: We are over it. People are getting infected.

MR. GOLDMAN: I don't disagree with you. My only point that I was making, I am not sure that the same thing wouldn't have happened in any other agency, and I agree with you that that is wrong, and that that should stop, but it is not -- we ought not deceive ourselves into thinking that merely changing the place of the agency is going to solve the problem, because changing the place of the agency is not going to solve the problem.

The problem is going to exist wherever it lies, and the underlying problem of political interference has to be dealt with, not merely the house in which the program resides.

DR. COATES: Then let's solve the problem.

There are two other issues, and I will continue

in my reverse order. The community involvement issue: we are moving into the second decade of the AIDS epidemic. The question becomes now, in this decade of the AIDS epidemic, how can we mobilize communities to deal with AIDS in the context of everything else that they have to deal with?

Let me give you two examples. One is from a study that we are engaged in with gay and bisexual men in several cities in the Northwest. It is part of a community demonstration program, a controlled evaluation study. The issue is no longer one of doing clever things to encourage safer sex. In fact, this program has two pulls to it. There are two objectives: one is to increase safer sex but also to maintain it over time, and the second is to encourage and motivate early intervention, for people to get tested and to know whether or not they are HIV and to seek out care, because that is also a point at which people can be motivated to practice safer sex.

We have been reading and working very much with the work of Powell Frery [phonetic], one of the important community organizers, and the issue is to get people together and not only have them think about how to solve the surface problems but also how to solve the underlying problems, and this works in any community, any group of

individuals.

Now, the underlying problems for that community are loss, bereavement, loss of sexual freedom, loss of friends, loss of function, stigma, double stigma and discrimination.

So our objective will be to engage in a dialogue with that community about how to solve those problems. In the process of solving those problems, the issues of early intervention and safer sex get placed into a context and can be solved within the context of all of the problems that the community is solving.

Let me give you a second example. I had the privilege last year of visiting some of the AIDS prevention programs in Zimbabwe, and that of all countries -- in that country they have done a marvelous job of organizing and developing peer outreach and peer education programs. David Wilson in that country is one of the people who has been very involved in this, and went out with a group of peer educators -- these were mostly commercial sex workers -- and first went into one of the townships and went into a small house and spent about an hour and a half listening to this great peer education program.

It was all in a language I couldn't understand, but it was very interesting, nonetheless.

And then we went to a beer garden, and these beer gardens in Zimbabwe are huge. They are these big open spaces where people sit around and drink vile millet beer and get stoned out of their minds.

And the prostitute peer educators go into this environment, and they do these great peer educations; singing songs in the African rhythms. I mean it was really marvelous to see.

Now, there were two things that were striking about that. One was that one of the commercial sex workers was wearing this T-shirt that said, Use condoms every time, and then the message on her back was, Stick to one partner, and I saw her back as she was negotiating her business for the night, so it was kind of interesting to sort of see that message in the light of what she was doing.

But that gets at my point, and that is the issue there is not necessarily safer sex but economic survival, and in fact that is what David is moving to do with this commercial sex workers, is to try to organize economic collectives that will take these women out of the commercial sex trade so that they can earn their keep some other way.

Now, that still doesn't mean that they are going to be perfectly protected, but they have some

alternatives and perhaps can reduce the number of partners.

Back to number one, a concrete example of a vision, a concrete example of a prevention plan. The prevention plan needs to contain several steps, and the vision needs to contain several steps. The first is a refocusing on where the epidemic is now, who needs the intervention the most and how to prevent it from spreading.

The second has to do with this establishment of the standards of care. What do we know is effective and what kinds of programs should be stimulated so that in fact we can prevent further infections with HIV among those groups in the population who need the prevention the most.

The third step then has to do with getting various groups to buy in. We need consensus that this is the right way to go. Now, this needs to happen rapidly.

So that is the framework of the vision. It is not complicated, but we don't have it, and we don't have the leadership that says, This is our vision. We don't have the war on cancer leadership; we don't have the anti-smoking leadership that we have had.

The first surgeon-general's report on smoking came out in 1964. Surgeon-General Koop issued one every

year. It was certainly part of the mixture that went into the passage of Product 99 in California that has brought a lot of money into the anti-smoking campaign, that is driving the rates of smoking down in California. That kind of thing needs to happen.

DR. OSBORN: Thank you.

Commissioner Ahrens.

MS. AHRENS: I was very interested in what you said about the need for local planning councils. I think a lot of us have felt that this is the building block to addressing the issue locally.

But one of the questions I guess I would have is you have looked at these local planning councils around the country where they have been effective. What would you say to who appoints -- it seems to me who appoints is rather critical -- and how can we go about trying to motivate local elected officials to address this issue, because it seems to me that they can either move it ahead or stand in its way?

And how can we enable particularly people at the federal level to understand that the local elected officials need to be motivated just as much as many of those that we are concentrating on so adamantly?

DR. COATES: It is interesting -- this last weekend, of course, was the mayors' march on Washington.

One would have hoped that it would have been similar to the march on Washington in which Martin Luther King spoke so eloquently.

I wish somebody would have dreamed a dream about the problems that we are having in our cities, and I think local elected officials are facing many, many serious problems, and I think the answer to mobilizing them is the same answer that one would use in mobilizing any community, and that is understanding their problems and understanding how a program like this can help them to solve some of their problems.

Their problems are drugs, violence, crime, poverty, health, how to take care of people who are getting sicker and sicker.

And I think if a program like this can be pitched as one solution to some of those problems, some of them will buy in; others won't, but that is okay. I think we need -- as in any social movement, what one does is set up stellar examples, and if those examples can be held up to the light so other people see them, some others will follow.

It is a little bit like the diffusion of any innovation. It happens. There are early adopters, middle adopters and late adopters and never adopters. That is okay. We just need to get some model programs going to

say we can do this and it can work.

DR. OSBORN: Commissioner Diaz.

MS. DIAZ: You called for a standardization of prevention in HIV and I wonder if you have any quarrel with the amount of work that has already been documented by CDC about prevention in HIV guidelines on which they based results of the many programs which they funded throughout the epidemic.

And I was quite impressed with the amount of work in what is suggested there in some of the essential elements and components of prevention programs. Do you have any quarrel with those as such? That is my first question.

DR. COATES: First of all, let me just make a -- sort of -- it is a nuance. It is not a standardization of prevention but an establishment of sort of a minimum standard. Prevention is inherently frustrating because it is not like developing a vaccine.

What you learn in one place needs to be looked at to see how it applies to another place and it may or may not apply because there are so many things that need to be adapted to any particular group of people so it is not saying here is the code book, here is how to do it, but saying these are some minimal standards.

MS. DIAZ: And that is exactly what they did.

They looked at the programs that they had funded under the prevention initiatives and looked at the valuation or composite of those and have called for or have issued guidelines for prevention programs in HIV.

So I just wondered if, you know, you had difficulty of how that is put forth.

DR. COATES: I think that the major difficulty I have with the CDC program is that over half of its prevention monies are spent on surveillance and counseling and testing and one of the references that I have in my testimony is to a paper that was actually published by scientists at the CDC that questioned the efficacy of counseling and testing as a primary intervention strategy.

So the major objection I have is that emphasis and I think that we have learned a lot about mobilizing communities and it is really more in a process rather than in certain codified ways of doing things that changes behavior and maintains behavior change.

MS. DIAZ: My second question: I find it interesting that you don't recommend that prevention be tied directly to service or access to care and that you did recommend that it be tied to research. There are a number of models now and where CDC is funding primary prevention programs together with the service model with ERISA.

There are yielding some pretty good and dramatic results that need to be documented for other populations. Did you strictly mean research or would you, again, look at the possibility that, in time, particularly with the populations we are talking about, minorities, disenfranchised populations where you are tying the service or access to care component to active prevention strategies. Would you amplify that a little bit so --

DR. COATES: Yes. No, actually I think that is a very good point and that is an oversight in this document. I think that is a very good model because, I mean, clearly in any kind of prevention program, if you have access to people who are infected, they are the ones who are going to be spreading the infection to other people so that is actually an excellent model and it is an oversight in this testimony. I would be a strong advocate of that.

MS. DIAZ: Thank you.

DR. OSBORN: Other questions from commissioners? Thank you very much. We appreciate --

DR. COATES: Thank you very much.

DR. OSBORN: -- the work that has gone into your written testimony as well as your willingness to join us and --

DR. COATES: Carry on with your good work.

Thank you.

DR. OSBORN: -- it was very helpful overview to start with. I now have the pleasure of asking John Gagnon and Vickie Mays both to come up. One at a time. Okay. John, it is nice to see you and Dr. Gagnon is at the State University of New York at Stony Brook and will be talking with us on "Research on Sexual Behavior: Implications for the HIV epidemic." Welcome.

DR. GAGNON: Thank you. Thank you very much for inviting me to speak with you. My testimony will be somewhat different than Tom's. I don't have a list of recommendations but what I would like to talk about is the way in which the HIV epidemic has interacted with the field of research, in which I have been involved for a long time, and try to sort of talk in some historical way about what has happened and how the epidemic has affected it.

DR. WIDDUS: Can you pull the mike a little closer to you or --

DR. GAGNON: What do I need to do to make this more sensible? Okay. Fine. I just heard more voices than my own.

When the HIV epidemic came on line in 1982, and it was -- became publicly recognized, I think that -- the first thing that happened was the people who were directly

involved with looking at the sources of the disease recognized very quickly that there was a sexual component in transmission.

And what they did at that moment was they came to the sex research community and they said, What do you know about -- can we ask you some questions about the things that we need to know? And we went to the cupboard and it wasn't exactly bare but it was fairly -- it was in a fairly parlous state.

And the consequence of that rather empty cupboard in terms of the sex research community was that it was perfectly possible at the beginning of the epidemic to use Kinsey's 1948 data on the numbers of men who had sex with men in order to estimate models of how many men were infected in the United States.

We were asked additionally how many people -- how many partners people had on the average and the number of times they might on the average have sex. And it turned out there wasn't very much data about that either. And then when they asked questions women in the sex industry, it turned out that they had been off the research agenda for at least the last 20 years.

So that basically when people who were interested in HIV came to sex research, they came to a place which was in fact in fairly bad shape as a research

community. Now, sex research in the sense that we mean it, really began with Kinsey in 1948. This is a study which I tend to view as a national aberration as I cannot understand how it is that Kinsey got away with it in southern Indiana during the second world war in a society which in fact did not really have a sense of the kind of miraculous event which occurred here because there isn't any good social explanation for how he managed to do his research.

Now, the response to Kinsey is a very important one because it tells us something about our society. The Kinsey study, which everybody recognized at the time had deep flaws even recognized by its own authors, became the national sex report. And like I suspect many parents do when their children ask them about sex, once they have told them the answers, they go, That is over.

And they feel that they have engaged in some sort of an inoculation of their children and they will never have to do this one again. And I think when Kinsey did his report, everybody said, My god, that is over. We don't have to hear about that one more time.

And I think part of that has to do with a kind of societal response to sex which is really quite odd. American society seems to deal with sex in one of two ways. One way is to treat sex as if it were sensational

in the form of sexual excitement.

And then we have another response which is merely only censorship or guilt about our excitement. It is very difficult with these two kinds of things being caught between basic instinct as one possibility in American society and Just Say No as the other alternative to engage in rational and reasoned descriptions of what happens to the society sexually.

We vacillate, therefore, between these two and these I think is the context in which most sex research gets done. What would an HIV researcher wanted to have found if he had come to a well-stocked cupboard? A researcher would have wanted to have found some theories and explanations about why people engage in sexual behavior.

They would have wanted to use those explanations in some kinds of ways to think about how to engage in behavior change. They did not find that. They would want to find some methods and techniques for doing research, that is, tried and true scales.

Do we know about how to interview? Do we know whether you should use same-gender and same-ethnicity interviewers -- all those kinds of nuts and bolts questions of technique which are involved in doing research. And there -- and how would you put these new --

these techniques to some useful new purposes?

And then the situation, what they found, was a very fragmentary body of methods, not well developed, a very uneven quality. Finally, if you came to us and you asked us -- as sex researchers, you would ask them -- their other question: what is in the filing cabinet?

What do you know for sure? How can we use it? And what then happened was perhaps they could have reorganized it if the data had been gathered in different ways, but essentially they found a really relatively empty space with which to work characterized by the examples which I gave you.

Finally, what they really would have wanted that is to have embodied these explanations, these techniques, these data, was a community of researchers who would have been able to turn their attention to these new problems in intelligent and useful ways.

Now, what they found -- I mean, they would have liked to have been -- I know that Dr. Osborne may quarrel with me -- they would have at least wanted a community as well-developed as virology so that virologists could have then turned their attention to a new set of problems and her vision of how well-organized virology was may be different than mine but I am further away from it so I don't know.

But essentially, that is what they would have wanted to have found. They would have wanted to have found a well-developed field of ideas and methods and data that could have then turned their attention to this new set of problems. What did they actually find?

They found a very marginalized community; that is, sex researchers were probably as marginal to the national scientific effort as the subject matter which they studied. They were a small number of researchers. They were not terribly well-organized.

There had not been any consistent record of research. Much of the research they were doing was against the grain. There had been, secondly, a disinvestment in sex research over the prior two decades. That is, not only had there been a disinvestment in research, general social science research beginning in the 1970s, but there had been a disinvestment in sexual research beginning in the early 1970s except for a very narrow number of studies.

In the 25 years between, say, the death of Kinsey and the public phase of the AIDS epidemic, from 1956 to about 1982, what we really have is a relatively mixed bag of research, a whole series of uneven efforts. There was a sudden burst of interest in sex therapy.

There was an interest in pornography. There

was a short burst of interest in homosexuality as it was then named. There was a series of sort of uneven lurching kinds of efforts. Probably the most consistent set of studies that were done during the entire period were concerned largely with the fertility of young women -- the unwanted fertility of young women, at least from the point of view of researchers.

But those studies largely only had two or three questions about sex in them because they were largely fertility studies. Many of these studies were purely problem-driven. And what I mean by that is that there was not a general interest in sexuality but there was an interest in the problem.

I am interested in the problem of fertility and that then defines what questions I ask, what thoughts I think. Finally, many of the studies had a limited sexual content, two or three questions out of a whole interview. Well, what happened when HIV came along?

A series of good things have happened. One good thing that has happened relative to HIV is there has been a remarkable increase in the amount of good, sound methodologically-competent research engaged in from people who have gone in from the HIV perspective about sexuality.

It is methodologically competent. It is work which is involved in surveys and behavior change. I can

think of a fairly large body of work done by -- at Tom Coates' organization, Center for AIDS Prevention Studies, but I can think of other studies as well.

The HIV epidemic has done something which in fact had never been done before. It brought new researchers into the area of sex research; that is, it brought people in who had not done sex research before but under the circumstances, who began to become interested in these kinds of problems.

These were people located in mainline institutions. Now, it may seem mundane, but in fact, to get research done requires that you deal with the concrete institutional problems of getting work done. You need researchers in buildings with laboratories, colleagues, rewards, all of those kinds of things.

And that is exactly what the sex research community did not have. I think there were a large number of what I would call second order gains in knowledge and technique. In the course of doing AIDS surveys, people began to learn how to ask sexual question.

In the course of doing behavior change, they began to understand how to study behavior change and sexuality. Now, that, I think, is all for the good. But there are some things which seem to me more problematic. And one of them is that there is a relatively-narrow focus

which comes from AIDS-driven focus; that is, there is a narrow focus on specific aspects of sexual behavior which are of interest to epidemiologists, physicians, and not so much an interest in the larger framework inside of which the sexual act resides.

AIDS dictates what you are interested in. It chooses the population you do research on. It sets the priorities. And as the epidemic evolves, new agendas are externally set. In the opening phase of the epidemic, people worried a great deal about transmission.

Now people worry about relapse. But it is the evolving demands of the epidemic that sets the agenda for research. Now, one of the negative consequences of that is when it becomes clear, and from limited ways clear, that a form of conduct is unimportant in the transmission of the disease, it is dropped from the agenda.

So the decline of interest in the United States, at least, in the study of sex workers in the last five years, I would think, has really been a function of they don't constitute a vector for transmission; therefore, they are not interesting. Secondly, there are sets of behaviors which are not of interest at all.

For instance, one of the things which is not studied in any of the surveys is masturbation, which I would argue is one of the fundamental safer sex

techniques. But it is off the research agenda, because, in fact, it is not linked directly to transmission, but it represents a piece of the entire economy of people's sexual laws; that is, if you try and see HIV in the larger framework of how people behave sexually, then masturbation clearly becomes a component of it.

A third problem is the public medicalization; that is that given the epidemic, there is a tendency to medicalize sex itself, that the sexuality becomes the object of medical concern and we lose that other part of sexuality which people have a legitimate right to, which is sex as pleasure.

And so the pleasure component of sex disappears as it becomes defined as a problem for people rather than something about which there may be a problem but which is not linked specifically to sexuality. Finally, I think there is a great weakness in many of these surveys about the problem of background areas.

I have a study which I admire a great deal but which I have a -- which I have some reservations about, specifically on that issue. The CDC is engaged now in a national study of risk behaviors among high school students. And I think that is really quite a remarkable high quality piece of work; that is, what they are doing is meeting all of the standards that you would normally

expect of any survey.

They randomly sample high schools. They randomly sample young people or they make sure that they get a high response rate. It really is an admirable piece of work. At the same time, they only ask three or four background variables, so you cannot explain what is going on.

All you can have is relationships between age, ethnicity, gender. But that doesn't explain why young people end up in high-risk categories. It just gives you a surveillance system. So one of the things I would say is that the problem of focusing on surveillance is one which tends to narrow your capacity for explanation.

Let me say -- conclude by making some remarks about why it is we seem to be, as a society, so focused on sexuality in terms of sensation and in terms of censorship. And I think it has something to do -- the way in which research is often constructed around AIDS has something to do with that.

As a society, we tend to see the sexual act naked; that is -- what I mean by that is we tend to see sexuality as sort of two people doing it unclothed. And I think that that is one -- that we tend to strip away from that act all of its social and psychological emotional meaning.

And it leaves the act subject to extraordinary amounts of fantasy. And I would like to propose clothing sexuality in the following way: I think if you are interested in sex, you ought to be interested in gender. And what I mean by gender is not males and females but men and women.

I think you ought to see sexuality occurring between men and men and women and women and women and men but gendered. These are sexual activities not from organs but from people. A second kind of clothing sex ought to have is the clothing of culture, the clothing of the fact that people are -- bring to their sexual experiences different kinds of culture origins and specificities about what it means to them.

So much of our conception of the sexual really is denuded of these kinds of components that make sense to people. I think thirdly we ought to be concerned with issues of social class. Whether you are rich or whether you are poor does have something to do with your sex life.

It shapes what sense it makes to you, what your access is to care about it, all kinds of other things of that kind. I think we ought to be concerned with age. I think whether you are young or whether you are old makes a difference. It makes a difference of what sex means to you, how important it is to you in your life.

That is, we ought to be somehow seeing the sexual things that people do in the clothed form rather than simply in the form that we get it, either in when we are engaged in denial that it exists or in excitement that it does exist. And that is where I think we really have to move.

I think that we have to move to a kind of world where we are concerned not with excitement or denial but a world in which we are concerned with understanding and with knowledge which allows one reflection and time to think about what is going on outside those two orbits. Thank you.

DR. OSBORN: That was terrific, John. Thanks very much. I think that I, at least, will hang onto the transcript of that for some time. And I will see if there are questions from the commissioners.

DR. ROGERS: Your comment psyched onto me the very narrow focus that the whole AIDS dilemma the HIV infection has brought to it, ways that we can get out from under that and yet still bring information to bear on this epidemic. What can we -- you gave us a last cataclysm there in terms of what we should we do but how are we going to get funding for that sort of thing?

DR. GAGNON: How are we going to get funding for it?

DR. ROGERS: Or simply -- I don't mean to put it that narrowly either. Just understanding of it or --

DR. GAGNON: I think --

DR. ROGERS: -- a better American attitude toward studies of sexuality.

DR. GAGNON: I don't know how to -- it is extraordinarily difficult to break out of our -- the fact that sexuality -- that we are so uncalm about it. I know that when we do -- when people do sexual things, they want to be excited but when they think about them, they probably want to be calm.

And I think that it is getting to that point of saying, How do you do research on a subject which is sensitive and relevant? But essentially, unless you ask the questions about going in through a kind of recognition that sexuality, say, occurs between men and women, you are not going to get to any notion about how to reshape behavior.

I mean, if you constantly think these are males and females doing it rather than sort of people who have on them the entire cloak of social life, then it seems to me that you start at the wrong place. I mean, most of our prevention efforts are going to be done with people with all their clothes on because they are going to be very, very far away from the sexual act.

So we have to think about them in that condition and ask ourselves how do they get from being fully clothed people to that place? And that, I think, requires a larger imagination that one would say, Well, we just have to stop anal sex. Well, how do people get to anal sex?

How does it become something which is part of your life? How does it develop social meaning? Why anal sex versus other kinds of activities? I mean, it does seem to be central -- central issues of those understandings will be central to behavior change.

MR. DALTON: Thank you, by the way. It is nice to see. One practicum question: Diane asked me whether your remarks had been written, the last part, because we are both sitting here transfixed, not writing it down and hoping not to lose it forever.

So, like David, I am trying to figure out how -- where to carry this or how to carry this. You spent some time talking about the marginal status of sex researchers within the scientific community. And obviously part of the struggle is claiming a higher seat -- or I am not sure what the image is.

And what you have just described today -- that is, clothing sexuality, gendering it, culturing it, et cetera, et cetera -- it seems to me to be a way of talking

to other scientists, social and otherwise, that helps them understand the importance of sex research.

So obviously, you can do that. That is, if we could just have you run around enough, it seems to me, as the embodiment of sex researchers, I think that the field as a whole might have some of the respect that it deserves. But I guess when I -- like David, I am trying to figure out how outside of the scientific community, when it comes to funding research, how this could be made a reality, how -- let me put it as a question -- let me put it this way: if you talk about national sex survey, to members of Congress, they think of bodies joining. They think of naked bodies.

DR. GAGNON: Unclothed.

MR. DALTON: Unclothed bodies. That is right. They think of anal intercourse. I wonder if there is some way to talk to that kind of audience about sexuality in the way that you have talked to us that makes it clear that what you are talking about is trying to understand human beings and what makes us tick, what makes us thrive, what makes us not thrive.

Undoubtedly, you have tried that and I guess I am wondering whether the very same kind of message that you brought to us can have a political pay-off as well in terms of being able to look forward in conducting the kind

of research that hasn't been done since the [unintelligible] was born and/or was never done.

DR. GAGNON: I think that the unclothed body is very much like the unclothed question in the resistance to doing a national survey. Sexual behavior questions were read out of context from the surveys, making the questions as unclothed as the behaviors.

No one meant to ask those questions of those people in that way but essentially the research itself was somehow denuded in the very process. I don't know. I guess -- it is very hard to argue with people who know the answers to the questions before you have done the research.

It is very difficult that people are persuaded that they know what sex is, they know how it works and they know what the consequences are going to be. It is extremely difficult to get them -- I mean, if they know ahead of time, then why do the research at all.

And I think that -- and there is this kind of -- for lack of a better phrase -- a certain kind of authoritarian quality which characterizes people for whom knowledge -- just knowledge is a threat. I would answer the same way Tom Coates would, that is does seem to me that doing a survey on sexual behavior is very, very unlikely to change the sexual behavior of adolescents,

given all the other things that are happening to them; that is that most of the change in adolescent sexual behavior that occurred, say, since 1965 to 1982 occurred without anybody doing sex research at all.

So clearly there may be something else operative in terms of producing it so that that strikes me as a puzzle. So my sense is I am not sure. I think there is a kind of -- and until -- and I think there are people in the Congress who have been willing to extend themselves to support this kind of research.

But there is a great deal of anxiety about being the Congressman about whom it is said they supported this dirty study in which they asked this question on the television set when you are running for office. And that is -- and I recognize that anxiety and it is not an easy -- in a society in which there are people caught between the sensational and the pure and the denial, it is very hard to stand up and say, I think you ought to know things about this.

MR. DALTON: Just one other different question. Now on the sensational side or the titillation side of our -- the kind of the way we approach sex, is it possible to do research on the sexualization of -- name it -- automobiles. That -- I guess -- I don't know whether sex researchers have -- and maybe it hasn't changed but my

sense is over the last two or three decades that in fact in society have commodified sex, used sex for all sorts of purposes in ways that we haven't in the past.

And it seems that to me that that probably had some impact upon early sexual behavior. It seems to me there is a lot of research to be done on that side of the spectrum and maybe that would be easier to get funded.

DR. GAGNON: One of the problems of doing research on television is it is like fish doing research on water. I mean, it is everywhere and you swim in it and so there is a certain sense in which it is sort of hard to assess what its effect is because its effect is everywhere and people watch it so much that somehow -- what would be the control group who weren't affected by the constant watching of this thing.

It is truly so monstrous that it is everywhere all the time and it supplies us all with knowledge about nearly everything and I am not sure how one does research on that. I think the world -- I am old enough to remember a world in which the Sears Roebuck catalog was the most exciting thing.

I was also a slightly rural child as well. So -- but -- and I do think that the world has gotten visually -- I mean --

MR. DALTON: You didn't have National

Geographic?

DR. GAGNON: Pardon?

MR. DALTON: You didn't have National Geographic in your house?

DR. GAGNON: No, no. We were the truly disadvantaged, I guess would be said. And I am just -- I mean, I haven't done any studies on this but I really don't do a lot of research on things that I sort of know. I think that the world is sexier now than it was when I was growing up.

And I really do believe I know that and I think in a strange and odd way that people in the United States were probably sexier than their environment in the 1930s and '40s and they are less sexy than their environment in the 1980s. And that is a straight speculation but I offer it to you as a -- that we are not nearly as sexy as Basic Instincts or any of those things would make it appear.

DR. OSBORN: You could pick up a lot of support for that theory from the Victorian era, too, I think. I mean, that is an even further extreme of the difference. Scott?

MR. ALLEN: One of the things that we are dealing with CARE is that when we start out looking at we need to care for HIV but we have some other social ills we have to deal with as well and that interconnectedness

there -- and you spoke of that interconnectedness with the totality of one's being and how do you respond sexually in that context.

Do you have some type of delineation between where that interconnection is, where do you stop? I mean, we could be clothed for winter in the middle of summer in New Orleans here. Where are the lines of what is interconnection. You spoke of it briefly but I am just wondering if you have that type of concept that would be helpful in the research or -- do you see the question I am asking?

I am just wondering when is it enough when you add the totality of one's being? How do you stop them?

DR. GAGNON: I think that the things which I think are essential to understanding sexuality as we do it and as opposed to the kind of very expanded version which is that people who set fires are also acting out of sexual motives and might tend to have the arson vision of it rather than the other one.

But the crucial things I think -- the A, number one, top-of-the-line issue really is the issue of gender. We really do have to set the sexual activities of people into the fact that they are enacting the roles of men and women and how much that really shapes the way in which sexuality is produced.

And the differential empowerment of men and women in sexuality seems to be absolutely essential. Issues around violence, issues around the lack of control that women have over their own sexual activities, the occasions of sexual activity, seem to be absolutely crucial, that if you study sexuality without taking that as one of the kind of framing issues which you walk in with, you are going to miss the point.

MR. ALLEN: Do you take that in the context of the present situation or as the history of one's life from growing up in an abusive family or -- and -- that -- I mean, you just opened up another -- where do you --

DR. GAGNON: It is striking, you know, that sex research -- that if you look back at the history of sex research, that the problem of abuse was really brought to the attention of the community by feminists; that is, it was not something which if you would ask that community of that discipline to ask itself what questions were important.

I am increasingly persuaded that the questions about experience of violence, both as a child and as an adult, are really central to understand sexuality of women and men in this society, that those are, if you ask -- if you are interested in asking questions about sexual life, what we do is we -- for instance, we ask questions about

divorce and marriage and that sort of thing automatically then we assume that somehow -- but I really -- that very often what we think are the independent variables, what we think are the things that shape people's behavior, we often evade when it comes to thinking about sexuality, because if we in fact thought about the situation of women in American society, it would require that we so radically rethink how we dealt with ourselves and other people that it would be a trauma of recognition.

And I think the same issues around race that -- and ethnicity -- if you look and see what is really there, then the shock is so profound that it is very hard to walk away with much dignity.

MR. ALLEN: Well, I am confused. I have just a few more questions. I am kind of confused when you talk about race or about when you are talking about rich, poor, what you -- I am uncomfortable somewhat with that but what happens to, say, a white poor person as -- is this what you are saying: a white poor person as opposed to a black poor person or a black rich person as opposed to a white rich -- what are you talking about here? I mean this is --

DR. GAGNON: Well, I talked about --

MR. ALLEN: And I mean, it is very sensitive and I don't know --

DR. GAGNON: Okay. I will tell you. I think that if you -- I spent the last two years looking at AIDS in New York City and if you look at central Harlem and if you ask yourself how many primary care physicians are there there? What happens in the emergency rooms?

Who treats people? What kind of health care is available? How many infants die in the first year? You begin to accumulate a set of sort of the kinds of terrible circumstances which are more than simply a poverty index or a simple -- it is greater than that when 25 percent of the young men in a community are in prison between 18 and 29.

There is a synergy of disasters which makes that larger than, say, simply a category called race. Then that is sort of a shorthand for that cultural situation, cultural economic and social situation. So that was the point I was -- I was not trying to say that poor white people aren't worse off or --

MR. ALLEN: Well, I am just curious about --

DR. GAGNON: I used to be one.

MR. ALLEN: That could also be a sociological dynamic being put onto an individual as opposed to an individual, the totality of that individual's being. I mean, that is a concern that I have when -- and it is very uncomfortable. And I am still not clear on that.

The last question that I have is: you are talking about men and women. Is there a difference between boys and girls as we are looking at -- we just left a high school where boys and girls are very sexually active and life revolves around sex and so forth. So do you find that that also should be delineated?

You said -- mentioned age but I am just talking about --

DR. GAGNON: Yes. I think that we as a society have been sort of very evasive about adolescence. We have created a circumstance in which I think for historical reasons, a very complicated set of historical reasons, age at first intercourse -- which is not age at first sexual experience but sort of is a proxy that we intend to use -- is -- has declined dramatically over the last 15 years -- probably settled. For the last five years, there haven't been many differences, but roughly it has redeclined into relatively middle and early adolescence.

In the process of doing this, we have not done very much about instructing those young people about what responsible relationships might entail. And I think that what we have done is we have carried -- the adults have carried with them the attitude of, if nothing goes wrong, we don't have to deal with it.

But things may be going wrong for which there

is no signal. There may not be a pregnancy. There may not be an STD. Kind of -- yes, that is a real problem. But there may be problems which are up for the long term in terms of chronic disorder in the relationships which -- what will become men and women, attitudes which will develop of our respect for each other.

And so I think that we have been evasive about the -- I think that -- so that is my sense of that. Yes, I think that their behavior has changed. I have doubts that adults have really come to terms with that change.

MR. ALLEN: Yes. I guess my question is -- I am sorry, but the question is -- like there are times in our prevention early on and probably still now that we have tried to place a prevention message from one culture onto another. I am just wondering, from your point of view, are we trying to put a message, an adult message about sexual behavior and package it in just a smaller package to meet -- and is that -- are we really reaching the adolescents with this kind of mentality or are we -- do we need to really redesign what is going to tick and what are the cultural manifestations of an individual that is in that smaller -- or younger context.

I think that it is sort of inevitable that you will bring an adult message with you. I mean, you can't -- there are a whole bunch of adult messages which

aren't bad ones. But I think at the same time we have to recognize the world in which young people do live everyday.

I think that is what is missing is a failure to understand the satisfactions and the pleasures which they get from living their lives. For us it is a prevention strategy. For them, it is life and so we tend to sort of misfit them all the time and we don't sound very persuasive, I think, sometimes.

I think that we often sound not so much like hypocrites but we sound like -- we tell them things that aren't going to happen to them and kids are very quick to understand that they have been lied to. And if you lie to them a lot, then they really stop listening entirely.

And so one of our problems is to design prevention programs that are true, which is that they have to be more complicated. If you do certain kinds of things, some dangerous things might happen to you but it won't happen all the time, that these are not universals, that there are odds here and that is the kind of thing which I think we have to tell kids is the truth.

DR. OSBORNE: John, thank you very much. You have put me -- part of -- the last part of your testimony puts me in mind of a Jonathan Mann comment that I have always found to be good which is that a truly male-

dominated society is inimical to the public health.

DR. GAGNON: That is probably true. Thank you.

DR. OSBORNE: Thanks very much. It is my pleasure to invite Vickie Mays to come next. Dr. Vickie Mays from UCLA will talk about Culture, Ethnicity and Gender in Sex Research. And welcome, Vickie. Good to see you again.

DR. MAYS: Thank you. Let me just start -- because part of what we have talked about quite a bit -- and I am probably going to change a little bit in view of some of the comments what I was going to say because some of it would just be an elaboration of it.

Let me start by putting things into context because that is part of what we advocate that we do within the context of doing HIV research, particularly in terms of sexual behavior, so that you are very clear that some of the comments I am going to make really come from, I think, a population that may be a little than we have been getting some of the information from in the literature.

In terms of what we have been doing, in terms of our research out at UCLA, is that I have been pea-eying a study on young adults, a multi-ethnic which includes Latino, African Americans, Asians, whites and Middle Easterners. Again, given where we are, we need to pay attention to some different populations out in

southern California.

And in that study, part of what we are trying to do is look at and track over time HIV-related risk behaviors and prevention activities of these young adults. We also have come in from the field with a national study of black men who have sex with men, which has about over 800 respondents and we are just starting to really analyze that data and be able to give some feedback.

And finally, we are in the field right now -- and that is probably one of the most interesting things that I can kind of comment on as I go along. We are in the field right now on a study of black men at risk and this study is of black men whose education is less than high school, who are chronically unemployed.

Many of them are homeless and they don't belong to any set group such as intravenous drug users. They aren't coming through clinics. We usually get them on the street and I think it is a different perspective when people are not part of social networks in terms of what impacts, upon why they do some of the things that they do.

So it is kind of from that perspective that I am going to make some of my comments in terms of research on sexual behavior. Now, one of the hardest things for me in terms of being in any of the roles in the above studies that I talk about is the issue of not really having proper

tools.

I mean, this is a very formidable job to do and to do well. What is missing in terms of -- we talk about the critical pieces here in terms of sexual behavior research. What is missing is that there is not a body of culturally-appropriate empirically-derived research, data from which we can start.

We always are kind of starting with what we think and spending a lot of time having to do pretests and focus groups and things like that. And people always want the answer kind of yesterday. But the other thing that I think really complicates some of the sexual behavior research that we engage in is the fact that we really need to have a great deal of leadership that really will promote social policies that facilitate a greater understanding of sexual behavior in all of its diversity.

I think that a lot of our research has focused on, quote, unquote, different aspects of the mainstream but that -- I think we have overlooked some populations. They are some of the ones that I want to talk about today. In particular, what I want to focus on is the issue of the -- in terms of the limited time that I have is the issue of culture, the issue of ethnicity and to talk a little bit about gender and how these issues are important in terms of prevention of HIV disease.

First of all, when we talk about the notion of culture, whenever that word is used in reference to ethnic groups, there is often an assumption that what one is talking about is purely ethnicity. The two things are not always synonymous and sometimes they are very hard to ferret out but I think it is important to really think about them when we do our research.

In attempting to understand sexual behaviors ultimately for the purposes of modifying those activities that result in exposure to HIV, it is important to understand the cultural context in which the activities may occur. It is not enough.

And I think that is what both Dr. Gagnon and Dr. Coates have talked about. It is not enough, really, to just study sexual behavior in terms of we talk about the number of times a particular behavior occurs or we talk about the type of partners or we talk about some specific acts of sexual activity.

What our goal needs to be in the second decade of this epidemic is not nearly surveillance and surveillance is a documentation of sexual activity, but rather, what we really have to focus on is an elucidation of the how, the when and where sexual activities occur that expose specific sub-groups to HIV when we need to understand sexual activity within the context of

relationships and in terms of interpersonal relationships.

I think Dr. Gagnon was discussing that quite well. We need to understand them within the context -- concept of attractiveness, why people do what they do within the concepts of, you know, what they feel about themselves, what they do in terms of how they feel about their partners.

We need to do it within the context of identify, particularly as we go out to do our prevention. We sometimes don't understand what group a person really identifies with and how it is we are going to change that person's behavior because we are giving a general message and it may be that as they hear these terms, they do not identify with them.

We need to understand in terms of things like social stratification. What does one's social status have to do with HIV prevention research? We need to understand it in terms of things like labor market activities, whether one has a job, how they feel about their job, and how all of that relates all the way back to the issue of sex and sexual behavior within the context of relationships or out of relationships.

We cannot change behavior if we do not know how it is decided that a person is going to do it or not do it. If we have learned nothing else in the first ten

years of the epidemic, the lesson that we have probably learned well is that values are a critical source of variation and behavior and hopefully this has been imprinted on many of us in terms of trying to understand differences.

For instance, the act of anal sex, while seemingly the same behavior has a value, sometimes it may have a very different function for a gay man who is very gay-identified versus a heterosexual woman wanting to protect herself in terms of her virginity.

So we must therefore be sensitive to the need to collect data on sexual behavior in a way that allows for multicultural explanations of the same phenomena across different subgroups. It is in really exposing and recognizing the cultural diversity of various groups whose activity may at times put them at risk for HIV disease that we may find that in many of our studies, we have already done a poor job.

While many individuals have become aware of the movie, Paris is Burning or Tongues Untied as a result of a lot of the political controversies, what I really wonder is how many of us have really taken the time to understand what is portrayed, to understand that it is not mere entertainment, understand that it is not surrealistic, but instead that is an aspect of culture of maybe a not-so-

small subgroup of the African American population.

Now, long before we saw Marla Riggs or we saw Living Color really try and popularize the issue of what we call the snap phenomenon, there were those of us in HIV research who were actually talking about his. I remember being at one of the public health meetings where one of our really premier AIDS educators, Craig Harris, suggested a presentation on scatology as a way to get AIDS educators to better understand the life and the communication patterns of African American gay men.

To try to modify behaviors that we have very little insight into how they are described, when they happen and the way they happen is very wasted effort and right now funds are very precious. In many instances as sex researchers, our ability to conduct meaningful research, though, is complicated by policies that prohibit the use of appropriate language or by cultural value systems that view same-sex activities or masturbation or sex for money as aberrant.

What I want to do is just take a moment to kind of illustrate this point. I mean, part of I think what happens is we usually sit here and we kind of talk about -- let me kind of show you. Can I get the overhead? You may or may not be able to see this very well and actually the point of it is, part of what we did in one of

studies -- in our national study of black men who have sex with men is realizing that we have to deal with a lot of difficulties such as regional issues, age, the whole bit.

We did a series of focus groups and part of what we wanted to know in those focus groups is how do these men think about sex, what is the terminology that is used? And what you see in the first one is usually the terminology that is used when you go in the clinic -- you know, the terminology that is often used by professionals.

The second one may be the terminology kind of on the street. It is much more of a white gay vernacular. And then what we found out was the points at which those things differ for black gay men. Now, as we did our research, part of what we find out is that often people think, well, you send indigenous interviewers out and you can ask them things when the questionnaire does not really reflect the culture of the group they know.

The questions they give -- the answers -- I am sorry -- that they give you then are much more reflective of answers that they think that you want rather than of their own culture. Many of the men would tell us: We can tell when, you know, this is not done by someone in our culture.

And part of it has to do with the terminology that we use. Now, either I have been fortunate -- and

especially listening to the comments of the people prior to me -- or foolish in the sense that we have used this kind of terminology in our questionnaires.

I -- and unfortunately, I stand in great trepidation because this paper will be published in August that people will start coming after me in terms of my funding, that there will be pressure in my Congressional district and what have you. Can I get the next one? Again, this is just an illustration. I am sorry. That is not the next one. They must be out of order. There is another language one. Thank you.

Again, this is really an illustration of how people refer to different types of partners and if you know a little bit about the word of who that partner, you will have a much better sense of the social networks that they are operating and the meaningfulness of that relationship and where it is that you as a person doing prevention may need to go to.

So again, it is like sometimes we just ask them about partners and the types without a clear sense in their environment of what these partners might be like. Again, what clearly emerges here are differences in the conceptualization of sexual behaviors.

Messages used for white gay men for us in terms of our study did not have the same level of association of

sexual practice for some African American gay and bisexual men. For these men, sex was thought about and talked about with a different set of symbols and meanings.

This should not come as a surprise to us since language and metaphors about sexual behavior differs in terms of various groups. They differ between heterosexuals and gays. They differ among ethnic groups and they also differ between men and women; yet, when such groups as African Americans, Latino or women, never see their experiences reflected in our prevention efforts, we can only take responsibility for the fact that they do not then embrace our advice.

Before we leave -- that is fine. Lights up. Before we leave the notion of the importance of culture, I think it worthwhile to highlight how at times at odds American culture is with its emphasis on individualism is to the activities of HIV prevention in communities of color.

For some ethnic group members, ethnically-based values of cooperation and unity may be more powerful motivators of behavior than strict appeals to individualistic actions such as protect yourself. And again, if could kind of comment on the America Responds to AIDS prevention campaign, that is a theme in terms of the very individualistic orientation pervades that whole

campaign.

And then again we say, Individuals have been exposed to these messages. We don't understand why they aren't changing their behavior. That is not -- and again, it is a very American message and it is not necessarily an ethnic message and I think that, you know, again, this issue of culture -- we need to understand how pervasive it is.

When we design approaches that focus comprehensively on the individual -- I am sorry. We do -- well, we need to design approaches that focus comprehensively, not only on the individual, but also the individual as a responsible member of a social or familial network.

We need to think that some people are very invested in their families and this is a very important issue for them in terms of a motivator to change behavior. For example, for black Americans, ethnically-based values of cooperation and unity may be much more powerful than some of the individualistic actions.

For example, one model of AIDS education that appears effective in changing attitudes and behaviors in some segments of the black community is an appeal for change based on a responsibility to others in the community. Men are asked to practice safer sex in order

to survive as a needed father or support for their parents.

Women are asked to be more assertive regarding condom usage in order to stay alive to take care of their parents or children. They are asked to promote condom usage with an -- as an -- almost an act of rebellion as a collective force to be a united unit with a partner to fight racism and genocidal efforts.

African American men and women can be encouraged to practice this reduction or to ensure the existence of the black community and to build a future for others. For example, some have proposed helping black women to view condom usage not as a barrier method which often gets put into a bigger context of a very genocidal framework -- and we also see it as -- to some extent as a method that the woman used as distancing herself from her partner -- but rather, when you put it into a much more Afrocentric context, the use of a condom as a protective barrier against the outside diseases which are proliferated against black people to weaken their health.

The act of using a condom becomes a much more Afrocentric proactive behavior that ensures long health for the woman and for her partner as well as builds a bond that really strengthens unity with her partner. Again, what we see in such an approach is that it is based more

on a model of social responsibility, rather than individualistic preservation.

Let me turn again to the issue of gender because it has been talked about quite a bit here and I think I won't use a table because I don't want people to get caught up in all the numbers. But just to talk about a piece of research that we did that illustrates the care that we have to take in terms of making sure that our messages and that our research is really gender appropriate.

One of the pieces of advice that is often promoted, particularly among the heterosexual population is that a person should know something about their partner. And part of knowing about your partner is asking them questions in terms of their background.

Again, part of the study that I was going to show you is actually a multi-ethnic study by gender in which what we did is ask people about the effectiveness of this. And what you find is that, again -- I mean, as social scientists part of what we know is that early in relationships, women have -- women tend to be a little more honest.

They tend to reveal information about their sexual history whereas men are not quite as forthcoming with this. If we use this as a piece of advice, what we

see is that it works very differently for men than women. It actually puts women at a little bit more jeopardy than it does men, if men are not going to be very forthcoming.

Again, that is just a very thing but I think what it tells us is that as we go through doing our research, gender has to be foremost in our planning, it has to be in terms of our analysis, and it has to be in terms of the interpretation of the results that we get.

Let me also comment on the issue of ethnicity because I think part of what has occurred is that we have been doing in the last probably couple of years more national based studies. And in that, when the results come out -- and I too stand guilty of that.

It is something that I have given much more thought to. And as the results come out, what it will say is it will say blacks. It will say Latinos. It will say Asians. I mean, this is the way that our surveillance procedure is based. But when you do a national study, you have to be careful about what you mean when you say black or African American.

Because what you will find out is that you may be talking about Caribbeans. You may be talking about Africans. And then when we start talking about intimate behavior, we start talking about very different values. Again, I think if there is nothing else I would emphasize,

it is the issue of value and how important value is in terms of understanding sexual behavior here.

So again, as we go through a lot of these studies, we are going to end up with data reported about Asians or Latinos without it being broken down by smaller subgroups, and I think that that is going to be, you know, a problem for us because a lot of these data bases are going to be used for the next set of prevention recommendations and activities and I think we need to start asking, Who are you talking about specifically?

The other thing which again is kind of a recommendation that I am just going to touch upon is that I think that we have to question whether or not there -- that only one large study or whether we should continue in the vein of having large national studies.

I am not as convinced. I mean, I am a little concerned about, for instance, having one national study of teenager sexual behavior and one national study of adult sexual behavior because I think that the issue of region, the issue of differences in ethnic group, the ability to be able to get some of the groups that we don't hear from is compromise sometimes when studies are done on large-scale levels.

We have not heard -- and it is interesting in terms of sitting in New Orleans -- we have not heard very

much, for instance, from communities such as transsexuals, transvestites, you know, the -- I guess in New York they call it the House of Latex in terms of, you know, the variety of different groups there are.

And in national studies we sometimes lose those people and I think that is the group, if anything, that we need to make sure that we are getting some information about and not just sticking to the mainstream. Thank you.

DR. OSBORNE: Thank you. Commissioners have questions? Harlon?

MR. DALTON: I am suffering from writer's cramp. Thank you.

DR. MAYS: It is written, too, so that is okay.

MR. DALTON: Oh, now you tell me.

DR. MAYS: Well, I will get it to you as presented to you.

MR. DALTON: Actually, I wanted to invite you -- first of all, I wanted to thank you for several things, including some very specific examples. For example, when you talked about gender and gave an example of why it is important to focus on it, it was such a nice example when you say to people, Learn about sexual history, that it has a disproportionate impact.

It was similar when you talked about trying to understand the importance of focusing on community,

appealing to caring about the community rather than the an individual focus campaign and that is something that Eunice, among others, has been saying over and over and she must just be thrilled to hear it this way.

I wanted to ask -- just give you a chance to give some more examples of what you mean by importance of value. And I say that because that is a term that has so many other meanings for us. I mean, George Bush yesterday talked about family values or the decline of family values as being responsible for, you know, what happened in South Central LA, for example.

You -- I don't want to put you in the same bed with him. You are talking about something very different and I thought that was a fabulous example of anal intercourse of having different value for gay-identified men than for women trying to avoid pregnancy.

But if you would give us some other examples to help us sink it in. Among other things, you are just helping us sort of -- I don't know that we are planning to write anything about you really are talking in paragraphs here and I want more.

DR. MAYS: I think part of -- when I talk about value, I guess I am trying to talk about it as a -- I mean, part of another role I have is that of a clinical psychologist so I often see people within the context of

when they come in distressed about these issues and you intimately see what happens when you are trying to change behavior.

And then because of the diversity of research activities I have, I see many different groups and what you find out is that a lot of our research has been driven by I think documentation and it is almost like what Dr. Gagnon talked about -- is early on, I think the epidemiologists, who are much more medically oriented, were like in the forefront and our surveillance procedure kind of keeps us in that same thing of when we talk about risk groups, for instance, and we talk about risk behaviors.

But we never talk about the context of risk. And I think if we spent a lot more time talking about the context of risk, it would be easier for people to understand how to change their behavior. As an example, part of what we try and study in our black men study is a little bit about the ways in which they see themselves in terms of what group they identify with.

When we go in, we say that they are heterosexuals, you know, if they are married. Again, what we find out is that you will come up with a finding that says risk behaviors are much higher in poor groups or very specific subgroups.

Then we find out something about the fact that this guy may have a history where he has been in prison, he has been someplace else. He has a -- how do I describe it? It is almost like he is in another world. But we only see him as a heterosexual male and we make these assumptions.

To give an example of one very specific subject, he is in and out of the prison system. When he is in the prison system, he lives a very different life and in that, he has a male relationship. And that male relationship does expose him to HIV.

When he is out on the street, he goes to church, he is a family man. So we put a label on him by the way in which we approach our behavior rather than finding out from him a little bit more about what his world is like, which he values, and what it will take for us to change his behavior.

It is not going to be an easy task for us to tell him within the context of his male relationship to make changes. Why? Because in the context of, you know, that incarcerated environment, there is much that he gets from it.

He gets intimacy. He gets -- so he gets many things. And so the message that we give is a very simple message, but we have to understand what he values and how

to then change that.

MS. DIAZ: Vickie, you and I have been on many different panels over the last ten years in this epidemic trying to make a plea for the greater inclusion of ethnic and racial minorities in research and for funded projects that are directly in the minority communities.

Do you see any break in this, other than your project and a few others that I can count on maybe this hand? Nationwide, do we have a greater amount of ethnic representation in the research that is being funded and how does the lack of that continue to impact what you just talked about today?

DR. MAYS: Okay. Let me talk about that from two perspectives: one of who participates and who does the research, because I think both of them are very significant. In terms of an increasing participation in research, I think that that is occurring.

I think that some of the procedures that have been put in place by, you know, Adam Hahn, NIH, in terms of inclusion of ethnic minorities -- they are sometimes thrown in because people think this will get through the review panel a lot easier, so there are greater efforts.

Now, on the other side of who conducts that research, it is the issue -- and I think Dr. Coates said that sometimes people call and they say, Can I use your

questionnaire? And the issue becomes, is not just the asking of the question.

I can give you all those terms I gave you up there. I can give you those terms. And you can go out and ask it, maybe, in the right way, but then there is the other steps of, have you really surveyed this population well?

Do you have people who are poor? Do you have people who are, you know, diverse? Do you have people who represent the range of what our community represents in there? Not that you have, quote, unquote, blacks or Latinos but do you represent what you know is really in our community becomes the first issue.

The second is, what will you do with this data in terms of how you interpret it if you really don't understand the community? How can I get you to understand the value of the man's life that I talked about when you are interested in making sure it is going to get through the review process?

So it is -- yes, we have more on the end of participation but if you really take a very careful look at what our major studies that help to drive policy, the answer is we do not have as many ethnic researchers. With the add-on component to the grants, they will give you very good numbers in terms of the number of individuals

who are of ethnic background that are now researchers, but in terms of like a MAX [phonetic] study, you have not seen an ethnic MAX study in any way in which, for instance, you can get policy that will be changed immediately.

When you have a five-site study and someone wants to say, How do I know this is true, and you can say, We have done this in five sites. Yet, in other places, what you have is a minority study that is in New York. Then they say, We have to see how this relates.

So we lose quite a bit of time. We don't have, you know, large-scale studies like that that can turn policy around, that can stop the NIH or CDC dead in its tracks and say, We have a result that we think you should pay attention to.

So we don't have that. We don't have that in terms of -- that is what women are complaining about right now is that there is -- because of the budget issue, there will probably never be a women's MAX study in the sense of in the sense of several sites, very powerful, very coordinated.

We have several researchers in different places so I think it makes a big difference. I think it is a critical issue in the epidemic right now because of the way in which our funds are limited and the need to make policy decisions quickly.

We sometimes can't. We have to debate them so long and we have to prove that they are so right because you don't have that powerful kind of set-up in terms of the way in which the research is going right now.

DR. PETERSON: I am not sure how to phrase my question so let me give it a try. It is really more asking for a comment. Listening to you and Dr. Gagnon in particular and reflecting on the difficulty we have had in getting studies of sexual behavior approved, both from the administration -- top levels of the administration -- and Congress and also reflecting on the fact that we seem to be becoming a society that deals only in very simple concepts and sound bites.

I mean, it is very easy for our politicians to talk about family values without ever explaining, What do you really mean by family and what are the different relationships that can constitute family and how do they differ geographically or by ethnic group?

And I just wonder how much of this direction of our society towards, you know, a very abbreviated fragment of a concept drives some of this opposition. It is not only perhaps an anxiety about what the answers might show but it is also, you know -- what you are coming up with is too complex. I can't deal with it so we just want to shove the whole thing.

DR. MAYS: Preparing for my testimony, one of the things I did was actually to read quite a bit about the history of public policy and social policy because initially I was going to focus on it much more than I did. I only kind of alluded to it.

But I guess what struck me was the issue of, again, values that permeate our policies and to see how difficult -- how what we are up against is something that people have been up against for awhile. When you talk about that 30-second sound bite and they are talking about families, it is kind of like we begin to know what they mean by family when we look at the policies that are enacted.

We have a sense of it is a very narrow notion of family, that it does not include alternative families, that a lot of times it is not even talking about poor families or else it is talking about poor families sometimes if it is something that we don't like.

So we can kind of see that. Part of what -- I mean, the other part of this is like, well, what can we do? Is this all too big and, you know, how can we get around it? My personal feeling -- and it is not policy recommendation.

But my personal feeling is I don't know if the best source for collecting some of our sexual behavior

data is funding from the federal government unless the federal government is willing to join into a partnership. I mean, I happen to think that when we start talking about some of these national surveys that when you knock on the door and tell somebody, This is funded by -- da, da, da, da, da -- it is like you are going to get the door slammed in your face as if you were trying to sell Fuller Brushes to a community of people who are bald-headed or something.

It is almost that pathetic. Instead, I think we need to think about pressure brought to bear on groups like the Ford Foundation, Kaiser Family Foundation, Rockefeller Foundation. They have supported research and they will go out on a limb a little more.

These are groups that have supported some ethnic research early on, particularly research on racism, where you knew it was going to be very difficult to get it through. I think in those instances, the federal government can be in a partnership but not in a dominating role or we need to think of some very different models that the federal government is participating in, which there is -- and I think this was brought up a little bit earlier, that there are advisory boards or there are some controlling entities that have input into this so that it is not as if it is -- can be manipulated by, owned by and promoted in whatever way by the federal government.

I mean, there can't be contracts. And see, that is part of what happens quite often in terms of some of this CDC funding is we are talking about contracts. I mean, I am funded by NIH and NIAID and for me, I am not in a contract, which is a little different.

I am in an RO-1, which gives me a little more flexibility. I mean, my funding may get snatched later but, at least, if nothing else I have collected data and I may be very poor in the sense of times to come. But that makes a big difference when you can go out and insure someone the integrity of how that information will be used.

And I think those are all the things that go into making a big difference in terms of getting the people that people always say won't participate. I mean, we were able nationally to get over 800 black men who have sex with men to participate in our study.

MAC has never been able to do that. Other people have never been able to do that and they say you can't do it. I think it requires, you know, some commitment, some promise and going to all these sites in terms of getting it so that people can ask you questions, that you can meet with advisory boards and you can demonstrate what it is that you are willing to give back, that you have control over being able to do. And in some

contracts, you can't do that.

DR. OSBORNE: Vickie, thank you very much and let me thank all of our witnesses this afternoon. It has been very rich testimony and very helpful to us. We will break now for 15 minutes and then the commissioners will return for Commission business.

(Whereupon, a short recess was taken.)

DR. OSBORNE: We have a new agenda here for the business session, which we will turn to very quickly. I have a letter that looks like maybe it just came to me but I thought that since we all agreed that one of the reasons for traveling around is that we have our meetings to bring hope to people where we visit.

I don't think that I should be the only one to see this. This is from the Long Island Shelter in Boston Harbor. Oh, did everybody get one? Okay. Good. I wanted to make sure that didn't get -- mine is nicely addressed and I wanted to make sure that it didn't get lost.

DR. WIDDUS: I can just -- there is a list distributed just called, "September Availability Dates." There are six dates in September, potential dates for meeting, where we have got at least a reasonable number of commissioners we know could participate.

I think there are one, two, three, five

commissioners that we have not yet got calendars from. If those of you listed -- that we don't have your calendar availability yet, if you could give to Tracy Brandt during the course of the meeting whether you are available on either the 14th, 15th, 16th or 28th or 29th or 30th, then we can do a complete compilation and tell you which are the most suitable dates for the maximum number of commissioners, either by the end of this session or definitely by tomorrow morning.

DR. OSBORNE: Let me make a side comment, Roy. You know, Detroit has -- the southeastern Michigan/Detroit area has been on our list of places we might want to go and for a variety of reasons that would mesh very well with our being there on the 14th and 15th, that, I would like to suggest, might be a tightened up version.

Mary Fisher [phonetic] wants to get involved in that. I think we would have quite a massive -- knowing how Mary functions in the southeastern Michigan area, I think we would have a very wonderful opportunity and welcome and some chances involved in that.

And she sent her apologies for not being here but suggested that that particular pair of dates would work awfully well for a variety of reasons meshing into the overall issues in Detroit.

MS. DIAZ: For those of us that have not, can

we just put our names to whatever dates?

DR. WIDDUS: Sure.

MS. DIAZ: And give you the sheet?

DR. WIDDUS: Either give them to myself or give them to Tracy Brandt.

MS. DIAZ: My second question is, did we already reference Dr. Sullivan's letter?

DR. WIDDUS: No. We haven't gone on to that yet. I guess the first item is in the package you received, the letter to June and a copy was also sent to David from Dr. Sullivan responding to our letter to him immediately after the March meeting where we asked in that letter for a written response to America: Living With AIDS and a schedule of the meeting once we have gotten that written response in hand.

The written response is in the form of a series of tables with the HHS response put against each of the Commission recommendations. They are grouped by chapter as they are in America: Living With AIDS, so in the code in the table, P stands for prevention recommendation one, et cetera. See the HHS response.

The staff received this at about 3:30 on Friday last week so we have not have time to analyze it carefully. I suspect having looked at it briefly there are a number of areas where we would want to elicit more

details from HHS as to the reasoning behind the statements.

We can do that. I understand from conversations from Secretary Sullivan's office that they are willing to schedule a meeting and I think that they are willing to do that reasonably rapidly, early June being suggested as one possibility, one possible time.

I don't know if, Jim, you have been able to find more out about specific dates.

DR. ALLEN: No. I -- the one date I think that was proposed was not convenient for David and that was June 1, I guess, and I was on my way out of the building to a budget meeting when I got your call, Roy, and I haven't followed up on that.

I will ask Dr. Mason's secretary to take the central role in trying to coordinate everything between all of the different offices, but primarily it depends on Sullivan's and Mason's availability.

DR. ROGERS: Don, as we look at this -- that is putting it rather casually. I said one day out of the month I can't do it and that was it. It is a longstanding commitment. If they do it on that day, it is perfectly fine but I had told Jim Mason I hoped they could make it another day.

MS. DIAZ: Is this a meeting for the entire

Commission? If it is, do you have our dates of availability for June?

DR. WIDDUS: Okay. That is one thing we wanted to do at this meeting is to check whether June 1 -- and I believe it was the morning of June 1 was Dr. Sullivan's proposal and perhaps see if there are other dates where a larger number of commissioners could make it.

We haven't polled you for dates yet but perhaps if you know at the moment whether June 1 -- the morning of June 1 is a possibility, you could just take a quick poll on that.

DR. ROGERS: Roy, may I make a suggestion? It clearly is dependent upon the Secretary's calendar and Jim Mason's. I have told my office, for example, to cancel anything else if we can do it. I think it is foolish to poll the Commission.

Once we get a date from the Secretary, well, that is it and let's make an effort to show up as possible but I think it is silly for us to wrestle with our calendars. We will be out and it will be a year before we get in there.

MS. DIAZ: That is the only date given to us?

DR. ROGERS: I think they are going back for another date so it seems to be kind of foolish --

DR. OSBORNE: That was the only date that has

been given to us, yes. So now it looks like -- then we will just start over, I think. Right?

MR. GOLDMAN: June, I can't make it on June 1 but I share David's view that it is more important that it happen quickly than any one or more of us can or cannot attend and I would urge that the meeting be done as expeditiously as possible and if the choice is between June 1 when David can't make it and I and perhaps others and July 30 when more people can make it, I would rather have it June 1.

DR. ROGERS: And I made that absolutely clear.

DR. OSBORNE: Well, that is, I think, how we will leave it for the moment. I think if people get a chance to go through this and see things that are particularly troublesome to them or so forth, maybe the thing to do is to drop Roy a note so that we have a process that allows you to -- all of our heads to be put together to spot thoroughly -- good spots or thoroughly unsatisfactory spots in the telegraphic response and at least inquire about whether that is well-represented of what is going on and what to do next. Yes?

MS. DIAZ: Just a brief comment. When I came in late last night, it was such an important letter that I did take an hour to look at it. And it just appears like most of the responses to our suggestions and various

recommendations are answered -- all answered as -- in fact, there are some right here. We are doing this.

DR. ROGERS: We are already doing it.

MS. DIAZ: We are already doing it and we are doing it well. So basically what do you folks value? And you know that makes me a little disconcerted at 11:30 or 12:00 last night because I thought, here, we have our hopes on this meeting. We just get there -- a show and tell and we are already doing it and thank you for being here and for saying what we are already doing.

We are really wasting our time. A lot of us would have to change schedules and we have got an important thing in Puerto Rico the next morning. And I don't know if I am up to going there and hearing about the fact that it is already being done and there was just nothing to offer.

I mean, basically I would think that any thinking person says, What has our Commission been about for two and half years if this is already being done in every category. Excuse me but this is just a gut feeling at 11:00 in reading this and where everything was being done and has been done and there was just nothing that we have contributed. That was very upsetting.

DR. ROGERS: Even if it is your gut, it is right on target. It is a dreary document and I think it

is quite predictable. If we are already doing those things, what are you bellyaching about? It is a beautiful summery. It seems to be one reason for each of us to think through those -- we shouldn't make the mistake, which we did to my sorrow when we met with the President.

This time we should know exactly what we want to say. BS, you have not done a damn thing and here is what you haven't done and we really all should feed that into Roy so that when we have that session, instead of getting a snow job, we are able to say, No, I am sorry, Mr. Secretary. You have not done this. You have not done this. Here is something that is critical.

And so I think it behooves everybody to look at that --

DR. DES JARLAIS: There is an occasional flavor of, based on some statistics, that here are not doing something and we are not going to do it no matter what.

DR. ROGERS: Yes. There is some that we are not going to do, too.

DR. DES JARLAIS: Yes.

MS. DIAZ: Yes.

DR. ROGERS: There is some of those which we can argue whether or not -- but the ones that worry me the most are the ones that are the biggies, where they say, Oh, we are already doing that.

MS. DIAZ: Exactly.

DR. ROGERS: They are simply not. And we ought to think -- craft very carefully what we want to say there so we don't just get that polite session.

MS. DIAZ: Roy, will we be able to talk about how we were going to ask for that meeting like on the phone before we organize for it because I agree with David. It is going to need a lot of preparation and we could have the biggest waste of time just coming to hear a reiteration of that.

But will there be a little preparation, maybe, like on the phone whoever the commissioners are that are going to be there?

DR. WIDDUS: We could certainly set up a conference call to discuss specific recommendations, get your comments of those things that you really want to in depth at the meeting.

DR. OSBORNE: But I think you better not count on that. I know I, for instance, am booked solid between now and June 1. And so I think people are going to have to -- what we -- if June 1 happens, what we probably will have to do is to try and get together just beforehand so that we can do what you are talking about at the last minute which is why I was suggesting that if people have focused comments that they should be directed at the staff

so they can be collated.

We can know that quite a number of people are concerned about a given point and that we can make whatever time we have beforehand as admissioned as possible. But quite frankly at this stage, I don't have -- there is nothing left between now and then and --

DR. ROGERS: June, I am thinking out loud here but we are a compromise people. If we each do try to put to Roy those things and Roy, you craft some bullets that can all -- can get out to all of us so we can know --

DR. OSBORNE: Yes. Talking points. I think strategically --

DR. ROGERS: I would hate to try to plan just an hour before we see them because they are pretty smooth and I think we ought to know exactly what we want to get across to them.

DR. OSBORNE: Right. No, what I had in mind was that if we all have collated a set of things that need to be talked about, then in an hour we can probably dole out the sort of talking assignments so that one person doesn't have to carry the whole boat. Don Goldman.

MR. GOLDMAN: As a product, I would hope that -- and I realize it is relatively a short time if we have a meeting on June 1 but I think it would certainly be useful to create a document which in a sense reproduced

the summary but had a third column and the third column would be the Commission response to the HHS status.

And I think that might be a useful document to have for a number of different reasons and preferences, including media use and --

DR. OSBORNE: That is a good idea.

MR. GOLDMAN: -- if we did that, we could then choose and select among those as to which ones to make forceful presentations on, but I think we ought to create that kind of -- that kind of document would be useful and I will certainly contribute to Roy my suggestions on specific points.

I may not deal with all 30 of them because some of those are more -- I am more into than others but certainly I will make some comments on the financing ones that I really am familiar with and I would hope other members of the Commission would do likewise, including those who are not here, so there has got to be some way of communicating with those who are not here as well.

MR. ALLEN: I have some questions.

DR. OSBORNE: Scott.

MR. ALLEN: A point of clarification on what is the format of this meeting.

DR. OSBORNE: We don't know.

MR. ALLEN: Who is going to decide that? Is

that going to be Dr. Sullivan or are we going to have dialogue or are we going to be there to listen? That is something that I think it would be helpful to understand. Is it just going to be an hour and all that is something that I am not clear on and I would like your suggestions on -- about media.

And that is a question that I have. What kind of visibility is this going to have from our perspective? Is it a low-key behind-the-scenes or is it up front, high-visibility? If it is high visibility, the strategy of whoever can make it as long as there is a sense of urgency -- to do that quickly may not be the best strategy.

If we are looking for visibility, we may want to have as many commissioners there as possible, if that is the case. So I am a little confused on what we are looking for.

DR. WIDDUS: My discussions with Secretary Sullivan's office last week -- I indicated to him that I was anticipating they would extend an invitation to all commissioners. They didn't specifically respond to my conveying that to them.

DR. ALLEN: Roy, who were you talking with?

DR. WIDDUS: I am blocking on the name. It begins with H, I think.

DR. ALLEN: Glen Harrelson.

DR. WIDDUS: Yes.

DR. ALLEN: Okay. From the executive secretariat.

DR. WIDDUS: I indicated to him that that was the format which we were anticipating but he didn't respond.

MR. ALLEN: So you are saying that maybe not all commissioners are invited to begin with?

DR. OSBORNE: Jim?

DR. ALLEN: Let me -- I would suggest that you get from the two of you a clarifying letter in the mail as quickly as possible and lay out what your expectations are in terms of what you want to accomplish and who you plan to have attend. I also suggest that you follow up with Don's suggestion and select those recommendations or areas because sometimes you could group recommendations into topic areas that you clearly want to address.

And I think you ought to lay that out also in the letter because that might well influence who from the department is selected. And clearly the Secretary and even often at the assistant secretary level, they will not have the detail of knowledge that is necessary to provide the responses that are needed so that -- I think they are going to need to bring in a range of appropriately-

selected staff.

I would stay away from areas such as the clinical trials where there clearly has been a lot done. I mean, the NIH was in the process, I think -- has hastened it following the meetings with the Commission and clearly has done, I think, an outstanding job in terms of outstanding -- in terms of expanding the scope of the clinical trials.

There is a lot that needs to be done but the basic restriction now is one of financing. And I think you ought to focus on those areas that are the most important to you or where you feel that there really hasn't been the kind of response that you would have hoped to have stimulated with your report.

DR. OSBORNE: Jim, I don't want to put you on the spot but a number of Scott's questions are ones that, if anybody here can answer them, you can. Otherwise, they can't be answered. What would be a reasonable expectation for length of meeting? What would be a reasonable expectation for format? I have my own set of guesses but they may be jaded.

DR. ALLEN: Well, the -- to -- for the Secretary to have a meeting that lasts longer than an hour is unusual and given -- particularly if there are a number of commissioners coming in, that probably is not going to

cover what you need. It may be that if Secretary Sullivan were there for the first hour and then there was a continuation of discussion with people at the assistant secretarial level or whatever, that is not unheard of and I think you ought to ask for that, if that is what you want.

And I think you ought to lay it out very clearly. You have got the opening here. The letter is fairly nonspecific in its response and I think you ought to lay out what you want and get it back to them very quickly.

DR. OSBORNE: Other commissioner comments about that? I guess I am going to put the obvious question, since nobody else has. There is a hazard to doing this because I will give my jaded answers. We are playing his rules at his house and there is a real sharp limit to how much we can do under the circumstances that has not already been done.

And I think given that, given David's unavailability, I am very much of two minds about whether it is a good idea to keep pressing on this particular meeting at this particular time. I am not sure what we are buying with -- our sense of urgency was back in September when we issued the report.

The chief thing I see we get, whether we want

to buy it or not of having this meeting now is that we can no longer say they didn't respond. And yet it is something of a nonresponse and whether we buy useful time by hurrying now to meet a narrow window which doesn't coincide with, you know, David and Don, I don't much want to be doing that or whether having -- we can officially say we definitely want those people to be with us; therefore, June 1 doesn't work, therefore, we are going to look for another date and in so doing, begin to get an opportunity to regroup or decide -- I mean, I am very concerned that we are going to put ourselves through hoops to do something that in fact puts them in a better position and us in a less good position very quickly.

DR. WIDDUS: That was my concern.

DR. OSBORNE: Yes. And I share your concern. I don't know as I --

DR. ROGERS: Well, June, if we follow Jim's thing -- again, thinking aloud -- if we crafted a fairly careful letter saying we are delighted you wish to meet with us. We have seen your initial document. We find it quite unsatisfactory in five areas or four or three.

And here are the things we specifically wish to bring up with you. We put that in the letter. And that at the closure of this -- again, I am just thinking out loud -- we will wish to meet with the press to report

where we have come out with this. I think that would begin to take it out of their house and out of their hands in ways that we might have some better control.

Yes, a good letter which said exactly what we wanted to discuss and that we were not satisfied with what we had would at least begin to set the stage for something. And I think could change the date.

MR. GOLDMAN: Yes, I see where you are going and I agree with you in one respect and that is that at least from a brief review of this response, now that we have gotten it, it seems to me that any such meeting will have as an equivalent audience the media as well as the attendees at that meeting and that we want to be thinking along those lines.

I am not prepared at this point in time to decide whether or not a letter ahead of time or a press conference at the same time or the day before, the day after or a written document or what is the best way of dealing with that. Thank God we have people like Tom who can help us make those kinds of strategic decisions and all the staff.

So I am not sure whether or not I know enough information now or thought through it enough to agree with your particular tactics, but I say -- but I think that that objective -- and so I am not concerned -- I am not as

much, frankly, concerned about the results of the meeting.

My question is whether or not we will have enough time between now and then to put together the kind of documentation that can deal with the public interest in this area through the media.

DR. OSBORNE: Maybe that -- I mean, I think perhaps you sharpened the point I was trying to make, which is, if this is a strategic meeting rather than a working meeting, then doing it in a hell of a hurry and with some of the key people missing doesn't strike me as the way to do it.

I mean, I really am sorry that I don't have the time between now and next -- to do what we are now talking about, which is very much a strategic thing rather than a sit-down meeting. And that -- you know, that is -- I am sure David feels the same way, the one day in June that he can't do it is the one day that is available at the moment, and so we are sort of limping in with wounds that we don't have to have and what already is a fairly tough game. Mike, you wanted to comment.

DR. PETERSON: Yes. I was just wondering. I think the idea of having a well-crafted responsible third column in the appropriate areas is certainly the way to go. I am just wondering, what is the advantage of having the face-to-face meeting?

I almost see keeping it in the Commission's ballpark by having press release of the response or something and avoiding the face-to-face meeting because I think that is a no-win situation from the Commission's perspective.

DR. OSBORNE: Here is a guy who is playing my game. That is -- now --

DR. ROGERS: It would save us lots of trouble.

DR. PETERSON: It saves lots of trouble and it doesn't have to be done in a week and --

DR. OSBORNE: Yes.

DR. PETERSON: -- there are advantages to that.

MS. DIAZ: I would disagree with that point of view. I think that, you know, in reading -- it was very late last night and I want to do it again tonight to see if I am missing something. But a lot of it is interpretation of words. Apparently, the department feels they have got comassive [phonetic] and global prevention plan -- they have a national plan.

And we see it differently. And I think that Dr. Sullivan is very much a part of this Commission. We have seen his face altogether maybe three times in the length of our work. And I think we owe it to ourselves and to the department to be treated with the respect that a face-to-face meeting -- I mean, we are not ogres.

We are not going -- we have a different point of view. If they say recommendation 1 is being done with, we would like to say our interpretation of recommendation 1 may be different than the department's and this is what we are recommending. We ought to make those things defensible in person and not through a paper war that starts back with column 4, the department answering the third column to the Commission.

We could go on through the length of our existence responding to each other on columns, whereas if the public -- if the media asked us, Have you sat down with reasonable people like Dr. Mason and Dr. Sullivan to express your point of view? You don't agree there is a national plan because what the Commission sees as a national plan are X, Y and Z components, which the department understood to be P, Q and S.

And you know, it seems to be like we shouldn't get into this kind of game. I mean, that is what the department does all the time. That is what bureaucracies do, the paper game back and forth. And we are not part of the bureaucracy so I would say let's go at it as good working citizens that we are, you know, appointed by people that entrusted in us a responsibility to deal face-to-face with these issues.

If our positions are defensible, I would agree

with what Jim said. If we are not ready for June 1, if three of the major players, or four, are not going to be there, there is no reason to have this meeting.

DR. PETERSON: I think -- let me just respond to that if I may real quickly. I think another strategy that we may want to use is to go ahead and invite staff who actually -- you know, the front page was signed by Secretary Sullivan and the rest of it was not put together by Secretary Sullivan.

He is not the expert on this issue. I think you need to sit down and talk with the experts so that you are not back and forth. Here is the Commission's response to Secretary Sullivan's letter and then you get Secretary Sullivan's response to the response.

I think the way to avoid that is to sit down with the people who wrote the back end of that, understand where they are coming from and have them understand where you are coming from and when there is not common ground, then put together what you consider the final response where differences exist and use that as the final word on the subject.

I personally don't see any advantage to getting together with Secretary Sullivan. It is like holding the Secretary of Defense responsible for something that was done in a staff office. You are not going to get the

knowledge that you need.

DR. OSBORNE: Harlon and then Scott and Don.

MR. DALTON: It would help me sort of understand this conversation that we have had over a couple of meetings -- because I think the question is what is it that we are trying to accomplish? One of the things you said is that they owe us the respect of a face-to-face meeting and if what we are after is respect, that kind of respect, then there is an argument I think to be made for essentially forcing the meeting, whatever comes out of it.

I guess I personally wouldn't find that particularly respectful because they would have to meet because we insisted on it and that wouldn't be a measure of respect so much as just a measure of the politics of the situation. At least, I understand that.

If what we are looking to do is to change their policy to shift what those responses say, then there is a question of what is the best way to go about that. I don't that a face-to-face meeting with the Secretary is the best way but I also don't think that we in fact are going to change either their true perception that they are doing what we already said or if they don't think they are doing it, nevertheless, the fact -- I don't think we are going to change the policy in any significant way in a

face-to-face meeting or otherwise.

The third thing that we might want to accomplish is to point out what the shortcoming are in the current national response. That is the third column that Don was talking about. And if that is what we want to do, then I think the simplest way to do it is just to do it as Mike Peterson pointed out.

Here is what we said, here is our response, here is the shortfall and figure out the best way to publicize that. So I guess the questions is what are we trying to accomplish? You know, I think we have been disrespected and I don't think that this -- I don't think the meeting would make a bit of difference and as for -- and I don't think we are going to really change their policy.

If we do, it is not through those kinds of one-shot meetings with the Secretary. It is just a constant kind of interchange that we have been doing all the way along. So I think our best shot is to focus narrowly on the third goal of trying to plan what the shortfall is and I think having a meeting makes it more difficult to do that than not having a meeting.

DR. OSBORNE: Scott.

MR. ALLEN: We would disagree on several points. One is I think the media is necessary because

Secretary Sullivan is responsible whether he just signs the first page or not. He is accountable as secretary, I think. So is President Bush -- is accountable for the way we are responding to our health.

I think the meeting also and the visibility thereof is important because we are not the only players in this epidemic and if we can be a conduit to the communities that need some type of focal point of saying we need a response, this is also an opportunity to help initiate that.

I think -- we are not just batting around paper trying to solve an epidemic. We are trying to get a consensus in our country as well. So the visibility -- the higher the visibility, the more people come to the table to deal with this issue and to deal with this response, where if we do it by paper, we can play the game and we can do it in a quiet fashion and I think it would be just as ineffective as it has to bring -- my feeling, my strategy would be to bring more people into the dialogue.

And so I think the meeting would be helpful in that and the dialogue of what Eunice -- I agree that it is more than just saying, okay, this is what we are saying, this is what you are saying but let's really talk it out. Let's really -- let's see if we are all on the same page,

not less the columns.

And so that is kind of why I would prefer a meeting with the Secretary and then moving on to the people that actually did the policies. Beyond that -- that is a personal opinion.

MR. DALTON: Just one other quick thing. One of my concerns, Scott, is that if we do have a meeting with the Secretary and then after that we decide that they haven't -- if we are in the same -- if we have the same response that Eunice had last night after meeting with the Secretary and then we publicize that, then I think it is much more awkward because we have just had this meeting with him in which he has been courteous to us and gracious, which he undoubtedly will, and then we slap him -- and I think that is harder to do and creates more hard feelings than if we just simply respond based upon the information that we have.

It feels much more like a personal response to him. Now, if that is what we want to do, that is one thing, but we need to think about that. If you want to have a meeting with him because that ups the ante and increases the publicity around what we have to say, that is perfectly comprehensible to me but I think that the down side of this is pretty great.

DR. OSBORN: Don?

MR. GOLDMAN: I think it is very difficult to say that we refuse to meet with him. I think we can't say that we refuse to meet with him. He has requested --

DR. OSBORN: No. And in fact, that is a short version of what I was thinking. Here, timing is all and the question becomes a matter of, do we urgently want to meet with him June 1 when we don't have our ducks in a row.

MR. GOLDMAN: But the question is if it is a choice -- if we -- if he can't meet with us any other day other than June 1 until September -- that is a choice between June 1 and September -- I don't know what the answer to that is.

DR. OSBORN: I don't think we have established that, have we?

MR. GOLDMAN: No, we have not.

DR. OSBORN: I mean, I think that it is significant that a number of key people, David most of all, who is the closest, and I can't make it on that particular day and that our time constraints are fairly substantial because I at least will have to leave in time to get to Puerto Rico because we are releasing a Commission report the next day.

So it is not by any description a good time to be doing it and then in between now and then, to try and

do the staff work which, if that is going to be the chief strategic component has to be done well, when everybody is fully booked between now and then --

MR. GOLDMAN: I don't think there is any disagreement that we should use our best efforts to try to change the date to a date that is more convenient, particularly if you weren't there.

DR. ROGERS: I wonder if we couldn't have our cake and eat it too. Let me try this out: that we do in essence follow the line initially that you and Mike are suggesting, with a nice letter to the Secretary saying, Thank you. We are delighted that you wish to meet.

We would like to meet, too. You have also sent us a response to our thing, which in many ways we are concerned. We are putting together and will put before you our third column so that it is clear the areas that we wish to discuss when we get together with you.

And then let's -- so that it is clear and that there will be --

DR. OSBORN: And in that letter make it clear that we want as many of the commissioners as possible --

DR. ROGERS: Yes.

DR. OSBORN: -- to be able to make it.

DR. ROGERS: Yes. We could put all of those things in there but then, it seems to me, we have got

something that is clearly to the Secretary so that we don't slap him. We say, We disagree profoundly on a number of things. We in essence say, here are a series of things on which your perceptions are not ours.

And that is the things that we wish to discuss. And then it will not come as a surprise to them if we are totally unsatisfied when we meet with them. We can then go out and say that was a very unsatisfactory meeting or we agreed on some things and we didn't agree on others.

And at least we have played it in an honorable fashion. And I think that would push the meeting out a ways but it would be foolish for us to go in under only their ground rules. I think we would end up kind of like we did on the other one, where we were all so disappointed where we felt we had a big shot and we didn't come out with very much.

DR. OSBORN: Jim, Larry --

DR. ALLEN: Let me just point out that this is sort of like leap year, a special year that comes once every four years. Mike and I were comparing notes a little bit earlier in terms of what is happening and the -- I think both of us clearly conceive the conventional wisdom of long-time residence in Washington is true and that is that there is a window of time in every administration when things get done.

And it normally starts sometime nine to 12 months after a new administration takes over and then it closes down as the campaign gears up. The veterans that I have talked with have been murmuring that the window seems to be getting smaller, that the period of time during which things are accomplished are getting shorter.

It has already slammed shut. The senior members of this administration have been in place by and large for three years. There has been very slight turnover. We are likely to see that accelerated. Some people may leave between now and the convention.

Probably if they haven't left by the time of the convention, they won't leave until after the election, but you have got people in place who, mentally at least, may be moving on and something just at least to factor into your considerations in terms of importance of what you want to accomplish.

DR. OSBORN: Larry?

MR. KESSLER: I just -- I think that if we do this column three, it will automatically have the effect of pushing back a June 1 date because they won't have time to respond or even to answer internally the third column so they will probably push it to July.

But then you enter that other problem. We may not have people to meet with us.

DR. ROGERS: But it would permit us to keep it on the public agenda, wouldn't it?

MR. KESSLER: Well, I think we ought to be as feisty as possible and -- you know, until we are convinced. I mean, if they are right, they have to do more homework. If we are right or if our doubts are accurate, then the ball is in our court at this point.

DR. DES JARLAIS: Yes. I am having concerns about how the public and the press will or will not be involved in this, that as I read through this, the places where it was clear that the administration was not doing what should be done, it was Congress' fault that what should be done was not being done.

The administration had asked for so many dollars and Congress hadn't even appropriated that and various things like that and I think one of the things that we probably ought to do our utmost to avoid is getting AIDS caught up into the administration blaming Congress and Congress blaming the administration, which is probably going to be the dominant theme of the election campaign.

So that if we are planning on saying we want to meet with you and then we go to the press and say, Well, we are dissatisfied, the administration response is probably going to be, Well, we did a great job and where

we didn't, it was Congress' fault and that that is probably going to be a rule situation for the Commission and for the epidemic so that we really ought to decide whether we want to sort of get into that publicity game and if we do, I think we really need to be very, very well-prepared that that third column is not just the third column but it is almost the whole Commission report.

Or the other strategy is face-to-face meeting that essentially would not be followed by a press conference but would be an attempt to move things along but not to hold a press conference afterward with the idea that they are going to go in basically on a defensive mode saying not only did we do a great job but where we didn't, it was somebody else's fault, that we sort o have a choice between going to a confrontational meeting and then getting really sucked into electoral politics or an essentially semi-private meeting where we would attempt to move the agenda along but without the threat of, you know, the press conference starts 15 minutes after the meeting is over.

MR. DALTON: Yes. I am just thinking about what Jim Allen said. I also was listening to you, Don. And I guess it has been in the back of my mind all along, which is the election campaign. And I think under any of these theories of what the meeting is all about, we are

not going to get what we want, largely because of the leap year.

That is, even if there was a willingness on the part of gnomes within the bureaucracy to do something different than what has been done already, it is not going to happen between now and November or now and January. Even if a light bulb went on in the Secretary's head, that is likely not to be very useful between now and January and he is likely not to be there come January.

So it strikes me as sort of wasted effort unless we can pinpoint what the benefit to us is of doing it. And the only benefit that I can imagine is keeping this issue on the -- alive on the front burner of the public, but even that, as Don Des Jarlais pointed out, gets a little bit complicated in an election year.

It is transmogrified into Congress versus the administration. So I must confess, I don't see a lot to be gained by going much further.

DR. OSBORN: Diane?

MS. AHRENS: I like David's compromise and I do think the face-to-face meeting is valuable. You never know what impressions one makes or we would make when we sit down with people. You might not know for six months. You might not even know for a year but it is not just a we-they situation and anyway, I think David has a good

compromise and I would just like to add to it.

I think we should ask for a meeting in June. June 1 is not a good but June, I think, is a good time and I think the -- the word is closing. I think by July, certainly by August, it will be closed. So think there is no point in pursuing it if we can't try to set something up in June.

The other thing I would like to suggest is that we decouple any kind of press conference from this meeting. We can always have a press conference if we feel it is important but to go into this with anticipating or allowing them to anticipate that we may come and then talk to the press I think is just a bit of a threat and it is not conducive to the kind of conversation I think we need with them.

So I would not think that that would be a good approach.

DR. OSBORN: David, maybe I could ask you to rephrase -- I mean, reframe the suggestion you made and see -- I can't tell but I think we may be closer to that --

DR. ROGERS: Okay. I will try. I think my suggestion would be that we ask the staff to proceed with full input from us to try and develop that column three -- I will use that as a shorthand -- that we at the same

time, thank the Secretary for his letter, indicate that we are developing this in response to the document he sent us and that we will share that with them but that we would welcome a meeting and we will by that time have crystallized, thanks to his document, these areas on which we have concern and which we would like to get specific clarification.

DR. OSBORN: And we specify --

DR. ROGERS: And we could ask the staff to kind of -- yes. And that it would be the Commission meeting with them and we would ask the staff to proceed with the development of that now. And that would -- and we could make it to June -- something like that.

MS. DIAZ: I would just strongly support one thing. She said, urge again a June date because if we go from the records, taking the department six months for the first cut of responses to our recommendations --

DR. ALLEN: It took two months to get the responses together but it took the rest of the time to decide to get it released.

MS. DIAZ: Okay. So I am just thinking, you know, if it take a minimum of two months, you know --

MR. ALLEN: Yes. I wasn't even thinking of a press conference as much as is the meeting going to be open to the public? Is it by law open to the public and

if so, there will be press there. I am not saying --

DR. OSBORN: It is not by law open to the public when the Secretary calls it.

DR. ALLEN: The Secretary is inviting --

MR. ALLEN: I see. Okay. So we don't have to --

DR. ALLEN: To his personal conference room there will be no media there.

MR. ALLEN: Okay. But anything we put out is a public document so when we respond there will be a public document. This will be a public document.

DR. OSBORN: No. If we write a letter to him and the correspondence, that is probably subject to the Freedom of Information Act.

MR. GOLDMAN: It certainly is.

DR. OSBORN: Yes. But it is not public document a priori, in the same way that our meetings are automatically open. I think there is a little bit of a difference in there. But if it is done --

MR. GOLDMAN: Well, we may not be able to get it published by the government printing service.

DR. OSBORN: Yes. I haven't -- is anybody very unhappy with that? We have got a big agenda here and we have talked this one through pretty thoroughly. It is clear that there are some ways to win and lose. Tom, do

you have a comment? I am sorry, Don?

MR. GOLDMAN: Yes. I just have one request and that is do you think it would be possible for as soon as possible that a draft of the proposed letter be circulated so that if any of us have any questions or comments on it --

DR. OSBORN: Well, I think the proposed letter was going to follow all of you sending in any concerns you have and the suggestions. So that is the first rate limiting thing. Then I think the staff can go to it with whatever other drafting is needed.

But the main thing would be -- why don't we say by the end of this week, anybody who has comments about what they have gotten no matter whether they do it on airplanes or whatever, by the end of the week the staff should have in hand whatever -- preferably -- I mean, if you did it tonight, you could hand it to them tomorrow and not bother with faxes and stuff.

DR. WIDDUS: Okay. One other option is to send a first response indicating what David said and then also indicating in that that once we have assembled column 3 --

DR. OSBORN: Yes.

MR. GOLDMAN: That is what I thought that you were talking about doing --

DR. WIDDUS: Yes.

DR. OSBORN: Yes. I will be a two-stage correspondence.

DR. WIDDUS: You can have a draft of the first response by tomorrow morning.

MR. GOLDMAN: Okay.

DR. OSBORN: Tom?

MR. BRANDT: Two tactical questions: one, follow through as David's proposal. In the meantime, sometime between now and when the meeting occurs, if they ponder [phonetic] the Secretary's letter, let's get to the press through some vehicle beyond our control.

Then I would assume that you would -- then how are we going to deal with it? Do we want to minimize that and say that we will follow the meeting of the Secretary and we will comment before the aftermath? Or do we --

DR. OSBORN: Especially if we have asked to meet later in June. I would say that -- we say that we are preparing a -- working hard to prepare a thoughtful response. We want to meet with the Secretary. We have asked that that happen before the end of the month in terms of -- in view of the time lapsed and that further comment would be after that round of exchange. Right?

MR. BRANDT: The second tactical decision we might want to make, that after the meeting with the Secretary, if we decide that the -- that exchange has been

far less than fulfilling, the Commission, I think, has an opportunity, if it wants to use it, to almost have a -- to do a press initiative merely to what we did when we released the original report last September.

And I think the polling is showing now that the country is -- feels very strongly that not nearly as much has been done about AIDS as should be done. I think if the National Commission at this point decided to call its second major press conference to say that, in fact, we have read the administration's response, I think that would also have measurable impact on the discussion of AIDS in the political process.

And we may simply want to discuss options and when we want to move that aggressively and [unintelligible].

DR. OSBORN: Yes. Let's -- I think that sounds like the general line of thought and we can keep -- there will be good things happening along the way. The Puerto Rico report is coming out. One hopes that that will get good visibility and I think the [unintelligible] may be closer than one would have thought with that again.

So we will be beating the drum along the way and we can time that as best we can figure in the context of this earlier discussion. I want to move this along if I can. And David, I wonder if you could give us a status

report concerning your recent conversations and then we want to look at the --

DR. ROGERS: This relates to a report that I think you have seen that Jeff has already worked on.

DR. OSBORN: Item 3. Is that right?

DR. ROGERS: Yes. Well, this was really to bring you up to speed on where CDC stands on its putting forth recommendations on the HIV-infected health care professional in the health setting. And you may -- well, I won't go through the -- all that has transpired before but there have been a series of iterations of that which were progressively improving and I think I reported that to this group before.

And I have met with Bill Roper. I met with Jim Mason. I met with Jim Curran. Jim Allen has usually been with me. To my sorrow, I got to document I guess at the end of the week which is the latest of theirs and I thought I would simply report my conversations with Jim Mason about it.

And I will tell you exactly what I told him because I am going to use the same notes. I said to my sorrow I was even more worried than I had been before and I thought Jim Mason and the Secretary have been very poorly served by their CDC colleagues, that they were putting forth a document that mystified me.

It was well-crafted. They had not taken many of the words that a number of us had suggested, a number -- and then reversed the order, but that they had increasingly moved in directions that we had strongly not recommended and that my bottom line was that they were going to move us toward a tragedy, that it was going to lead to mandatory testing of every health care professional in the country, certainly every MD in the health care setting, that it was going to escalate public fears, that it was going to cost enormous amounts, it was going to do enormous damage to our contention that -- that health care workers should take care of all HIV-infected people and the major tragedy was it wasn't going to enhance patient safety one whit.

The why -- their document now first takes the Hepatitis B model, which was always a perfectly appropriate one but always had good caveats in terms of this is a model that we might use but it is not HIV. That has almost been eliminated. Now it is written as though it is perfectly appropriate to take Hepatitis B and reason from that to what is going to happen in HIV and it will scare the hell out of the public, that part of it.

Secondly, in terms of testing, it recommends not only any at-risk groups but then goes on to anybody who has had any occupational exposure. So in essence, it

is recommending HIV testing of virtually everyone in the work place. And then third -- and there is just one recommendation that is operative here which is going to seal the fate of that mandatory testing -- is health care workers who are infected with HIV and who perform surgical or obstetrical procedures should not continue to perform those procedures until they have sought counsel from an expert review panel.

The -- yes, I will come to that. I had some other concerns which -- it is, again, a very slanted document. And the thing that has troubled me is every document has clearly decided they just must justify the testing of health care professionals and eliminating them from the health care setting irrespective of what the science evidence is.

They don't reference any of the thoughtful papers that have pointed out that might be a very bad way to go and I showed them what those were. They have some really very careless science statements in. They have continued to -- the one point I have made to Jim on several occasions is if you are going to use the Hepatitis B stuff, which they do, and they run you through a terrifying series of things, finally saying that we continue to see one to two cases of Hepatitis B per year despite the use of universal precautions -- they have in

their own document -- I said, Okay, then go ahead and use your own figures.

They point out in paragraph B-4 that it is about 1/100th as infectious. And I said, Jim, would you like to make those calculations? And he said, Okay. I see what you mean. That means we would prevent one case of HIV in 100 years. And I said, Yes, and you better multiple that by the fact that ten times more health professionals have Hepatitis B than HIV.

And so your entire series of recommendations might prevent one case of Hepatitis -- of HIV in 1,000 years. What I have suggested to them -- and he promises -- and I have suggested this before and we have written it. If I sound annoyed, it is because I feel somewhat betrayed because in Jim Mason's office with Bill Roper, Jim Curran, with a lawyer for HSS -- they finally agreed that they would back off of what they are now doing and we wrote it for them and they have paid almost no attention to it.

I suggested that they write a document that really did try to reassure the public, that they completely reverse view, that they in essence write a document saying CDC has been our watchdog protecting patients for the last umpteen years, that they now have eleven years of experience with this epidemic, that they

have watched at least hundreds of thousands of procedures go on, millions of patient health professional contacts, that it is -- that it has now been two years with Dr. Aker that they have gone through almost 40 look-back studies, over 15,000 patients without one single proven instance of a health professional infecting a patient; ergo, that they should then say we go with universal precautions and number two should be -- something that they have totally ignored really, almost, in their document -- which is we should get rid of procedures in which health care professionals injure themselves.

I said, For example, you have got a lot in here about vaginal hysterectomies. My bet is about 90 percent of them shouldn't have been done anyway and that the other 10 percent, don't do them. Do it another way where health professionals don't stick themselves.

And you haven't even mentioned that in your document. And that, third, on the basis of the scientific evidence to date, that they really have seen nothing to suggest that restricting the practice of infected health care workers will improve patient safety.

And last, I said, for God's sake -- and I have said this to them many times -- have you checked it with lawyers? The answer, I am afraid, Jim, still is no. I did try a couple of the statements out on -- I don't know

why this militant refusal to check it with CEOs of major hospitals or lawyers.

For example, they have in their document -- just find this one here -- "the current assessment of risk that infected health care workers will transmit HIV to patients during invasive procedures does not, however, justify mandatory testing of health care workers."

I tried that out on a lawyer in New York who simply laughed and said, in no way will we go that way, not unless there is a specific recommendation against mandatory testing. Dr. Mason has said that they will run this through the -- some of the CEOs of -- or the leadership of the American Hospital Association and some of their lawyers.

I don't think it is going to come out immediately. I have written a letter that in essence tells you what I am telling you to Bill Roper. And it is my fond hope still that they will back off but it has been a most puzzling exercise and I think it is going to put us in the soup in terms of what it does for health care professionals in this country and I hope -- one final comment.

I told Dr. Mason that the Commission was in the process of doing a document on the infected health care worker. He asked when it would come out. I said, Well,

we had been delaying it because I have been assuring the Commission that the CDC was coming out with some much more responsible guidelines.

He paused and then said, Well, maybe it would be good if your document came out first. I thought in that -- though I am interpreting here -- that he was in essence saying we need all the help we can to back off the more sensible kinds of guidelines and perhaps that is what we should do.

I am not pleased with the present posture and I am totally puzzled as to why the stance that they are taking.

DR. OSBORN: Any comments?

MR. KESSLER: Is it -- do you suspect or feel that it is simply political, that somehow or other --

DR. ROGERS: I suspect some of it is political and Dr. Mason said, Well, they are afraid that at some time a case may happen and then they will be blamed for not having predicted. That I am completely sympathetic with, but I did say, Well, I will view you as totally irresponsible if you put out a document that has this kind of statement where you can say, But we suggested they not test mandatorily and that is what happens.

But I really think you have got to do a more responsible job than you are doing right now. I don't

know why they have come out with a document that really -- I would kick a kid out of medical school for some of the science that is really not very good.

MR. KESSLER: Well, the other thing, I guess I would like Don to comment on is whether or not -- if this thing went ahead, whether it really wouldn't muck up the works in terms of ADA and a backlog of cases that would result from mishandling, especially at the local level, based on this increased hysteria, anxiety, fear of litigation.

I mean, it rapidly escalates to a union bargaining position.

DR. ROGERS: The thing I have made consistently clear, Larry, is that if I felt there was any science evidence that this was occurring, it seems to me uppermost must be how do we best protect patients in this country in each and all segments? And I think the evidence is increasingly overwhelming that it is through universal precautions or the changing procedures period.

That this will do nothing for it; indeed, it is going to drive it the other way by virtue of -- and the worst is the message it sends to health professionals which will be awful in Boston and New York and so on, which is don't treat anybody which is HIV-infected or even whom you suspect to be.

You may lose your professional life and it escalates these public fears, which for awhile -- as you know, it looked like the public general feeling was the way to get AIDS is to go see my doctor or my dentist.

MR. GOLDMAN: Well, for someone that perceives themselves not to be engaging in any behaviors whatsoever that put themselves at risk and engage in the denial of that or -- maybe the accuracy but often in denial of that, in their perception, that is the only other way they know how to get it. And so from that perception, they are correct.

DR. ROGERS: Are they?

MR. GOLDMAN: Are they? I don't know. But if there is no other way, I mean --

DR. OSBORN: Let me point out that we are about to turn to our report on that so I don't want us to spend very much additional time on this. This is awfully background to how we proceed with the report, which is the reason for going first with it. But we do need to get to that quickly. Eunice?

MS. DIAZ: I would just like to say I think it is a pretty good idea for us to rush our report if that is the indication he gave you and there must be a very subtle message there.

DR. ROGERS: I thought there was and I thought

we could do a public service by getting our report --

MS. DIAZ: We really could. We have discussed this issue --

DR. OSBORN: We had wonderful hearings.

MS. DIAZ: -- witnesses. And I think we have to be gutsy and bite the bullet on this and go forth but really fast.

DR. ALLEN: One of the concerns, certainly, that has been very prominent within the internal discussions that has nothing to do with the science is the Congressional legislation that is on the books and the Treasury and Postal Appropriations Bill, which lays out the -- picks up the language from the July 1991 recommendations, talks about states needing to put into place measures to --

MS. DIAZ: Or their equivalent.

DR. ALLEN: -- or their equivalent. But it couches it in terms of exposure from procedures, which is a concept that CDC now agrees was invalid and clearly does not take into account all of the many factors that perhaps are important. But the legal counsel talks about, you know, the Congressional response and Congressional expectations and all.

Certainly, I think, having the Commission document out and using that as a base for talking about

the low degree of risk could be very important in terms of helping to educate the Congressional side. But that, again, is something that probably ought to be done very actively both from HHS as well as, perhaps, the Commission and others.

DR. OSBORN: Okay. Well then, let's go to it. The -- Jeff is here and thank you for a wonderful effort and a very beautiful -- I thought a wonderfully-written document which -- with a brisk introductory thing that David says he is armed for bear to do. I bet he is, too -- is I think that what we want to have is anybody's concerns, cautions, worries, not editing changes unless they are awfully important, especially with the sense of hurry that was just articulated and nicely done.

MR. GOLDMAN: Yes. I think this is a terrific document. I think there is another document that is needed, however, and that is a summary document, is a summary document which is in the typical style of what David has done, a two- or three-page document that basically summarizes the recommendations of the Commission that are set forth here and this is a yawn, except in the academic world.

DR. OSBORN: Why don't you make your offer to sum it?

DR. ROGERS: Yes. Jeff and I have talked a

little bit about this. As I said, we each have spent hundreds of hours on it and I thought from that fine document that the two of us in fairly short order could write that executive summary that did contain recommendations.

And I think Dr. Mason was asking for that kind of note. So I think it serve that purpose too.

MR. GOLDMAN: I have one editorial suggestion or change and that is that on page 15 where it suggests the compliance with universal health -- universal proportions in all health care settings, we ought to -- and it talks about including patients, physicians, dentists, ambulatory, surgical and hospitals and clinics, it ought to also include homes where health care procedures are provided for such patients.

And if you would make that change, I would appreciate it.

MS. DIAZ: Just one comment. I really liked the document. I don't know if we have stressed enough the importance of getting those recommendations that are also stressing the necessity for a companion program in public education to 12 years and really get the support of the public behind something like that.

And I thought that if just a little tiny bit could be added because if you remember, when Roper came to

testify, he said they were going to do it. They have backed away from it. And here is our chance to say, you know, they have plans for public education program on this, so when you do get some guidelines, let's accompany that with education for the public, which they direct.

DR. ROGERS: Good. One of the mysteries to me -- and responding to June's comment -- it was CDC that then was often paired with that first document and Congress responded in a way that was not surprising considering what they had before them. And now the circular reasoning of CDC said, Well, now we have to compare them with what was said by Congress.

My reaction was, Hell, Congress said what it said because of what you gave to them. Why don't you learn from that and get more responsible about what you give to Congress.

MR. GOLDMAN: I don't think there is any question but that the intent of Congress was that CDC should do that which protects the country's public health and which reduces risk of the spread of AIDS and other infectious diseases in the health care setting.

And therefore anything that CDC does that acquits that philosophy would be certainly in keeping with Congressional intent.

DR. OSBORN: Well, I think there is a lot of

question about that but let's not get into it now. Having been just outside the Senate chamber while that thoughtful set of deliberations was going on, you are wrong. That is not why Congress acted.

MR. GOLDMAN: You did not -- well, I won't -- you did not think I was serious.

DR. WIDDUS: Saying it doesn't make it that way.

DR. OSBORN: Okay. Other comments.

DR. ALLEN: On page 21 and 22 where you quote the results of the published look-back studies, that can be updated now based on the new MMWR that was published.

DR. OSBORN: Harlon. I am sorry.

MR. DALTON: Oh, no. I did say I would pass. I take it that if we have something that is not editorial but it is not as significant as what Eunice and --

DR. OSBORN: Is that okay with everybody else?

MR. DALTON: -- we can just give to Jeff.

DR. OSBORN: Yes.

MR. DALTON: Yes.

DR. OSBORN: And let's write on Jeff's copy so that he doesn't have to collate and that will speed things up, too. So you -- everybody who has specific but not earthshaking things that they would like to see, deal with Jeff directly and that will be very helpful and speed

things up.

DR. ALLEN: I have one other comment. On page 14, I think given the publication in the annals of the immunological investigation from Aker ought to be looked at very closely. Certainly there is some discrepancy in terms of what they report formally from their investigations and what is here on page 14 in terms of the infection control practices.

And I would just -- you have got in italics here the potential for patient-to-patient transmission. CDC investigation, of course, says they don't think that there is any proof of that whatsoever. The downside that I see that at least emphasizing patient-to-patient is that that provides a theoretical risk of physicians saying, I am not going to take care of HIV-infected patients because if there is any transmission subsequently, people are going to invoke this.

And, you know, I think that there is an equal downside to this as to overemphasizing the risk of transmission from an HIV-infected health care provider to the patients. As a matter of fact, there is a lawsuit now from an HIV-infected person claiming transmission in a dental office even though the dentist and his staff are HIV-negative.

But he is saying, again, it was patient-to-

patient on instruments and he is bringing a lawsuit.

DR. ROGERS: Jim, this is probably slightly manipulative but -- slightly. Dr. Mason did say he had asked for the leadership of the American Hospital Association. Did you take back to him the sense of this Commission, because that would be a very wise thing for him to do.

DR. ALLEN: Yes. Fine.

DR. OSBORN: Okay. So we have a document and we are going to have an executive summary of two or three pages that Jeff and David are going to work on. We will see that but we will also look at it with full knowledge that there is -- the time is, in a certain sense, of the essence with this, that we are sort of assuming that it will probably be able to come out, given what Jim has said informally, but we don't want to run that risk.

So we want to get this report on the streets as fast as possible and therefore, with the executive summary in particular, unless you see something that is really quite troubling that it might be well to leave it alone so we don't have to get ping-ponging with everybody traveling around all the time.

MR. GOLDMAN: I have no -- I trust everyone implicitly. I would still like, however, before publication the opportunity to see the document, A, in its

final form, and B, particularly in connection with those sections that are bracketed that says, This has to be written yet, I am hesitant to simply give some -- even as much as I trust Jeff, and I do, as a writer, probably as much as anybody around here. I just am not sure whether --

DR. OSBORN: Yes. No.

MR. GOLDMAN: -- unwilling to go that far.

DR. OSBORN: Didn't mean to finesse that much, Don. I just meant that, in terms of additional input, I am trying to use moral suasion to get people to restrain. We are all used to editing things and so forth and we will, yes, of course, go through the processes of seeing these things again.

But what I am trying to avoid is the recycling phenomenon if we all want to see everything at the very end of everything. That is the only thing I am saying. Okay? Okay. The National Conference of Black Mayors resolution, which you have in your packet, I have a suggestion about this.

DR. WIDDUS: One of the things that I meant to do in the memorandum updating you on various activities is to indicate that Eunice Diaz represented the Commission at this meeting and we had very good feedback from various people that were at that meeting in regard to the way she

represented the Commission.

I apologize to you as to not putting that in the memorandum. You may want to add something about the meeting in general, as well as the resolution.

MS. DIAZ: It is a very active group and certainly good representation from mayors. Lots of people also from Kansas and Missouri AIDS organizations and the media who were invited by the organizers of the meeting. And I thought it was excellent dialogue.

We had an opportunity to discuss our major Commission work and recommendations. This helps us strongly as we wanted to get a message to elected leaders and also a message to the Commission that they have still many areas of concern which are nothing new that we did not hear at the hearing for Afro-Americans.

And still situations that come to mind that are in terms of this epidemic and they said that they would be coming forth with this particular resolution. I was not there when it was drafted but the tone of the questions and the concerns that are listed in the community are very much expressed there and I think they are things that we have to deal with.

You notice that part of the request comes to the Congressional Black Caucus as well as the Commission. And they wondered if in fact the National Commission will

be having additional hearings or an opportunity for a larger segment of the black community to be represented in future Commission hearings and since we at that time didn't know whether we would be going on with hearings for an additional year, I urged them to just express these concerns to the leadership of the Commission and it certainly would be open. And this is what came forth.

DR. OSBORN: Well, the suggestion I was going to make about it -- or maybe I will make it as a comment and an inferred suggestion. All the way through the life of the Commission, I have been uneasy about our -- people constantly want to press us into the role of a science court.

People have a perception that we are biomedical, which some of us are and some of us aren't, and that we could be judges over issues of science as opposed to issues of policy and whether things are going -- proceeding appropriately or not. As written, this presses us into that role.

I don't think much change is needed to avoid that potential pitfall, but I think it would be an awkward and unfortunate stance for the Commission to be the group that comes down answering some of these questions definitely because some of them are in fact scientific questions and we are not properly constituted.

Now, what I would suggest we do is to endorse their wish that such a dialogue happened, offer them our full participation and staff recommendations and so forth so that we can be as helpful as possible in making sure it happens well, and then be part of it but as witnesses and commentators from our several roles rather than as sponsors.

It is a minor change but what it does is to avoid the problems that would come. See, the issue of the origin of the virus, first of all, is an unanswerable issue and secondly, the extent it could be, it would be answered by virologists, geneticists and immunologists.

Now, I am a virologist but I am not doing virology right now and David and I are both -- would probably be called immunologists but, you know, there are a lot of other folks around who would be better, you know, and that is not what this -- I always talk about us as a citizens commission because by and large, our own specific expertise, when it does come in, is enriching but not determinative of an issue that we here as thoughtful citizens of the country.

That what the -- I think our intent of creating us was. I think this is a -- to the extent these are driving questions, they are very appropriate for the Conference of Mayors, for the Congressional Black Caucus

to raise and ask us to help answer.

That I think we have no problem with, so it is a fairly small shift in gears, but for us to hold a hearing and then come out with a statement at the end sets us up to be in the same other side of this trust wall or else taking a role that we are not fully -- that could be shot at from all science.

Does that make sense, what I am saying? So I think we could very easily participate in this in a very full way and offer a lot of staff and help and testimony but just a little bit of shift in how it is resigned.

MR. DALTON: Yes. I missed the first part of the discussion but I think I get the drift.

DR. OSBORN: You didn't, actually. I waited until you came in.

MR. DALTON: All right. I guess my sense is that there will be no this unless we do something; that is, they are calling upon us to do something together with the Congressional Black Caucus, which lateral organization [phonetic] on its own hasn't so far seen fit to do this either or for that matter, to conduct hearings about AIDS.

So realistically, it is not something that is going to happen to which we could provide witness testimony. I do think that we ought not to conduct a set of hearings with CDC or by ourselves on these particular

questions, at least as framed, but it occurred to me this might be an opportunity; that is, if instead of taking this resolution on its own faith or all its particulars, if instead we looked at this as an invitation by the black mayors across the country for the Congressional Black Caucus and the Commission to get together and hold hearings on the state of AIDS in black America and if that were of interest to the Congressional Black Caucus, then we could frame the issues slightly differently so that the mistrust generated by what happened with KEMRON [phonetic] et cetera is one of the issues.

Then that is an invitation and opportunity and the way to deal with that is maybe to sound out the Congressional Black Caucus about whether they would like to do this together with us. Now, maybe they haven't done it in part because they don't have the technical expertise or at least are not confident they do.

But I think that would be a terrific thing to do together.

DR. OSBORN: Well, I like that better than my idea. I was just eager that we not end up --

DR. ROGERS: We don't need to be trapped at this -- we need to say "State of AIDS in Black America."

DR. OSBORN: In Detroit on September 14 --

MR. GOLDMAN: Yes. I think that is a

reasonable idea, though I might even like to expand it and include some others other than us and the Congressional Black Caucus.

DR. WIDDUS: Who would you include?

MR. GOLDMAN: Perhaps black mayors themselves, who called for the resolution, to ask them to participate in it and perhaps some white mayors, too, because there are white mayors of black -- of cities with black people living in them.

MR. DALTON: Well, yes, this is true. Wait. I guess I want to distinguish between who it is that are the sponsors of the event and who might offer meaningful testimony. The Congressional Black Caucus, the one event that they did hold -- there were three people who showed up, one of whom was a white female Republican who calls herself an honorary member of the Caucus.

So I am not saying that white folks have no role to play, but if you say white mayors, then it is no longer the National Black -- then it is the U.S. Congress of Mayors or something else.

MR. GOLDMAN: What I am saying is maybe --

MR. DALTON: It is a totally different --

MR. DALTON: -- maybe they ought to be invited as well.

DR. OSBORN: They could be invited but the U.S.

Conference of Mayors invited me to come talk to them. They have an AIDS task force and the only two who were there -- the only two mayors of major cities who were there were the two who were the chair and co-chair of the task force.

So if you go through the U.S. Conference of Mayors, you get lost. This looks to me like a group that would show up almost -- you know, in great numbers and from Eunice says -- and I like Harlon's suggestion. We do have to watch when we want to do what because if this is asked with some sense of urgency, we are already getting into the fall with -- you know, we got all the way through to September scheduled, unless we add something. And I don't know if you were thinking about.

MR. DALTON: I wasn't imagining that it could happen under any schedule faster than that.

DR. OSBORN: Well, I wasn't joking about this being an appropriate topic if we want to have that as a topic for a Commission hearing and I had already made the pitch that Detroit in September. Alternatively, Cleveland, of course. Lou Stokes is head of the Congressional Black Caucus or was last time I looked.

And that is his area so we could do it either way. I -- you know, Detroit has a number of things to recommend it.

MR. ALLEN: I have a question on where we are with respect to the minority report.

DR. OSBORN: Yes. The minority report on Communities of Color is likely to be coming out -- what the --

DR. WIDDUS: I would guess that the earliest possible release on an optimistic schedule would be late July. More realistic release date -- or more realistic date at which -- by which we would have finished the report would be early September. We can adjust the release to the timing when we want it but the document wouldn't probably be ready until rather late July at the earliest.

I am suggesting if we want to release, forget August because nothing much happens, particularly in D.C. in August, that we could adjust the release of the report depending upon whether we wanted to have this hearing before it or not.

DR. OSBORN: Harlon, do you have any thoughts about that, as one of the key participants?

MR. DALTON: Well, I guess I do think that July is probably the earliest realistic date so I agree with that.

DR. OSBORN: How about -- with the kind of hearing you were describing vis-a-vis the report, which

comes first and how do they line up together and all that kind of stuff?

MR. DALTON: I think if we had the hearing and then we ought to use the report to kind of prime the hearing and so it is just simply a matter of talking to Tom and other people about what the timing -- what release date meshes best with the date of the hearing.

I think it would make sense -- that is, I think it would make sense to use them to reinforce one another.

MS. DIAZ: Just to play the Devil's Advocate, what if we get asked why are we holding this hearing in Detroit in September when we just issued our recommendations on communities of color? What would be our response?

DR. OSBORN: Well, that is quite a different general topic from the status of HIV epidemic in black America. Communities of Color report is intended, I thought -- it has subsections on specific communities of color but it is an effort, as I understood it and got -- was involved at some extent to try and have an overview of which this then is a development.

MR. DALTON: I think we could -- yes, that the hearing would be the next step. I mean, this is the Congressional Black Caucus getting involved in the National -- and the black mayors across the country

wanting to sort of move on the issue so that affects me as a perfectly acceptable response and indeed I would hope it would be true.

DR. OSBORN: Well, we didn't have a topic picked for the September meeting. How does it sound to you if we took this as a stimulus to start working on a September meeting, quite likely in either Detroit or -- Fran is waving.

MR. DALTON: The Congressional Black Caucus needs to be --

MS. PAGE: The Congressional Black Caucus legislative weekend is in September and it is going to be held at the Washington Convention. I can't remember the exact date but I think it is the third or fourth weekend.

MR. DALTON: Are you suggesting that that would be good --

MS. PAGE: No, I am not.

MR. DALTON: You mean because this is too substantive of an event to -- I am just trying to --

MS. PAGE: No. Because they go -- the Congressional Black Caucus already is planning certain events around AIDS proposals. I know what the black women's agenda is and I know it --

DR. ROGERS: Fran, can we --

MS. PAGE: Stokes is going to be doing

something on that Friday also so whatever we use, if we plan to do it in September, I wouldn't do it during this time.

MR. DALTON: My thought is we shouldn't be doing it unless we are doing it with them anyway, so it is not like that could happen. We couldn't very well do something in tandem with them if they are not doing it with us. But I gather what you are saying is they are not likely to want to do it in September.

MS. PAGE: They are not likely to do it during their time. This legislative Black Caucus weekend is their time.

DR. ROGERS: Why don't we join forces?

MR. DALTON: Fran, would there be any advantage to having this done before as opposed to afterwards?

DR. OSBORN: Let's -- I tell you what. Let's talk about -- how can we do this? It needs a little bit of talking. For instance, I am not sure the Austin topic is firmly pinned down but I don't know whether that is the best place to try and do this in July and then regroup on the other.

We don't have August hearings scheduled. That is another possibility, although normally that drops attention quite a lot to do things in August and everybody has vacation plans and --

DR. ROGERS: June, let me precipitate that. I hope we don't just give up by this because maybe they just want fun and games but why don't go to their party? You know, if they want to talk about AIDS and they want -- and the mayors want this, why don't we try and say why don't you do part of this?

During your black caucus, we will join forces with you.

MS. PAGE: That is different from the mayors, though. The Congressional Black Caucus --

DR. ROGERS: Wouldn't they allow the mayors in for a day?

MR. GOLDMAN: David, this resolution of the National Conference of Black Mayors calls upon the Commission and the Congressional Black Caucus to hold public hearings.

DR. ROGERS: Yes.

MR. GOLDMAN: Joint public hearings.

DR. ROGERS: Yes.

MR. GOLDMAN: I guess the first step before we do anything is why don't we be in contact with the Congressional Black Caucus to see whether or not they are interested in holding joint public hearings in a shared, cooperative way?

DR. ROGERS: Good. That seems like an

extraordinary sense of blind ear.

DR. OSBORN: Well, that is what my initial caveat was about, though. If we take this word for word, we are back in the soup I was worried about. We don't want to work right off this piece of paper. We want to respond to the spirit of it but Harlon's suggestion of rephrasing the themes is terribly important to keep us from turning into a science court.

And if we jointly hold hearings with the Congressional Black Caucus, that puts us in a situation in which we are -- we may have -- we have got to be real sure that we have control of the theme or we have to be real sure that they sponsor and we participate, deeply; one or the other of those.

I really would be uneasy to have us jointly sponsoring with this document as a major reason why.

MS. DIAZ: I think basically what has been done in that document is to throw for our consideration or anybody's consideration that concerns have existed for ten years.

DR. OSBORN: Oh, yes, Eunice. I don't have any unease about -- I don't feel like I am end-running them by suggesting that. I am just worried that if we get working off this piece of paper, it will look as if we did. I am very concerned that we accept the spirit and watch out for

obeying the letter because it has got pitfalls I am sure they didn't intend but later on could turn out to really jump up and give us trouble.

DR. ROGERS: June, would it be accepting the spirit to in essence consult with the black caucus and say we would like to be responsive. We think the agenda should be quite different. It should be the state of AIDS in black America. Would you like to join forces with us? Or could we do it in some way --

DR. OSBORN: Do you want to sponsor or do you want us to sponsor? I think -- Don?

DR. DES JARLAIS: To me, this document really says there is a big problem about trust and mistrust out there.

DR. OSBORN: Exactly. That is exactly how it is written.

DR. DES JARLAIS: The state of AIDS in black America doesn't address that issue very much --

DR. OSBORN: That is right.

DR. DES JARLAIS: -- any more than dealing with KEMRON in terms of the immunology of alpha interferon is going to address the mistrust issue. I mean, if we really want to address the mistrust issue, we would have to involve these people, the black caucus, maybe several other important groups.

And we would have to expand the hearings beyond AIDS because AIDS is only one little tip on that iceberg. It clearly ties in with the conspiracy theories of it was the drug use in this country and lack of prenatal care and all sorts of other things --

DR. OSBORN: But that --

MR. DALTON: First of all, I just want to say, the state of black America -- all I meant was something broader than simply talking about the origins of the virus in KEMRON. But it seems to me if you are going to talk about AIDS in black America, mistrust is a huge piece of it.

I mean, when we had our hearings in Baltimore, four topics, one of which was mistrust. So when I talk about the state of AIDS in black America, a lot of what we are talking about is mistrust. Moreover, Vickie in her testimony earlier described the ways in which viewing the kind of outside assault on the community can be harnessed as a way of kind of taking collective community ownership of the disease.

I mean, the way that I always respond when people talk about these issues is not the debate as a scientific matter but the issue as one more reason why we need to take hold of this thing. So all I am saying is that I don't -- that we are absolutely right that we

should not ignore and Eunice is right that we should not ignore that what is being said here is profound mistrust by a lot of things -- and Tuskegee is mentioned, of course, et cetera, et cetera, as a metaphor as well as specific reality.

Yes. We shouldn't duck that. I am not saying we should whitewash that, to coin a phrase. What I am saying is that we might want to use this as an opportunity -- as just an excuse for getting the Congressional Black Caucus energized around these issues and conducting some business that among other things deals with this issue but not with the idea that we are going to settle the question of where the virus came from and not with the idea that we are going to settle the question of whether the white health establishment treated it with any seriousness and dignity African doctors or on KEMRON.

I haven't got any answers to those but that -- but I am saying rather than have that be the focus, that is part of what gets discussed.

DR. OSBORN: You are actually making -- at least, to me, you are making something of a case to me for really exploring whether the Congressional Black Caucus would like to sponsor this with us as participants because if we want to get -- I mean, there is an argument you could make that the AIDS Commission should not be the

sponsors of a major discussion with distrust as the main theme because it always seems to almost feed into some people's paranoia at least.

So if indeed that seems to be the sense of the matter, then I would be inclined to go back to where I started, which is let's offer them all of the encouragement, support, participation, collaboration that we can in an initial contact with the Congressional Black Caucus and if they want to have it be this broader set of topics, I would be very supportive of that and we can -- we have, of course, had a hearing that brought out a couple of hours worth of very powerful testimony on the issue of mistrust and we did in fact go back to that and also ourselves talked about what we have heard and seen to the extent that is useful. Eunice?

MS. DIAZ: I respect that opinion but the urgency that was felt or communicated to me so that these people would -- after this presentation -- I think Harlon had been there the year before. They thought about it. They know what is happening in their communities.

Some of these were mayors of smaller towns really wanting to get some of these answers and in their minds be responsible to the constituents. I think for us to say, you know, someone else should do it -- they saw in this Commission a body, for whatever it may mean, that

advises the President and Congress and they felt that the request was appropriate to us.

And I really would urge us to go the other way around and let's joining hands, if possible, with the Black Caucus and being able to see how we can best do it. Maybe a more creative suggestion will come up from both groups getting together to say -- but for us to say, you know, we can just testify.

We did a couple hours worth in Baltimore. The feeling that was expressed to me, not openly at the meeting but afterwards, is that there was a feeling that that was a short amount of time of this Commission in terms of the magnitude of the problem, they felt, so they wanted to express it on paper to give some kind of attention of this Commission to a broader addressing of issues in the black community.

So I think Harlon is right that this is just a tip of the iceberg. It is not representative of the mistrust but some questions that they have. A lot of questions came regarding the development of the new vaccine. And I think that basically they are wanting to open additional dialogue with this Commission in listening to expert testimony, that we would be forum in listening, not to resolve the issues but some very pressing concerns that still exist.

And so that is why this resolution was sent to us. It could have been sent to other groups but it was to us and I think that we have a responsibility to answer and I hope the answer is not someone else would better do it. So I think that that would be taken very seriously by this group as a coopting of our responsibilities.

DR. ROGERS: Could we respond, Eunice, saying that we hear them loud and clear and we will be exploring with the black caucus how best to go about --

MS. DIAZ: Yes. That is exactly --

DR. ROGERS: Because that would give enough running room to be responsive where June was concerned in terms of how --

MS. DIAZ: We may not be the best. You know, to tell them go with it to someone else because we are not going to do it, I think would not be taken too well.

DR. WIDDUS: In light of the need to break fairly soon in order to go to the reception, I am going to proceed fairly rapidly through Items 5, 6 and 7 and suggest that if we -- if any of you want to take a -- or get full reports on meetings, you can get them from individuals that were involved in those meetings.

We will come back to you on dates for September when we have analyzed what we get back. Item 5 are the plans for the release of the report on the HIV-AIDS

epidemic in Puerto Rico. That is scheduled for the morning of June 2 in San Juan, Puerto Rico. June, Eunice, Don Des Jarlais and Larry Kessler will be Commission representatives along with Owen Kurnick [phonetic], who will be in Puerto Rico for other activities. In other words, we are not paying.

MR. KESSLER: Who pays his way?

DR. WIDDUS: He does. I checked on that. I think that will be -- we have the report at the printers at the moment. We pushed it through and I think you will be pleased that we are managing, from now on, I think, to get a very nice style of document produced in house. I think you will be pleased with the product.

And I thank you, by the way, for being responsive on our last minute request to you for comments. We managed to incorporate, I think, everything pretty well. The reports on recent activities, a number of commissioners visited CDC on the 20th and 21st of April.

The commissioners that visited were Eunice, Larry Kessler, Don Des Jarlais and Diane and Scott. I am sorry. I just didn't have it written down in front of me. I think that was a very useful meeting. CDC sent her a letter of appreciation. They really enjoyed being able to talk to the Commission about some of their concerns, some of their approaches to the problems, and I think it was

useful for the Commission to convey some impressions to CDC.

We have a -- quite an extensive set of documents collected from those CDC visits which I think it important for you to have a full set of those as reference documents. And the list of those documents is in the package of materials. We have not distributed yet because we are waiting for one further contribution which is the summary of AIDS activities from the National Center for Infectious Diseases.

We anticipate having that this week or early next and will send out to you a set of these documents. They detail the budget that CDC devotes to different aspects of AIDS, their strategy documents, their health activities and their activities on women.

So I think this is a good comprehensive reference source which will be sent to you in a binder in the next week or two. The other meetings that have been held recently were a meeting with various associations in Washington that are connected with state or local health activities or represent elected officials.

Joey Connersberg [phonetic] was instrumental in requesting that meeting and getting it set up. Diane Ahrens participated also. The groups represented were the Association of State and Territorial Health Offices, their

executive director and their AIDS director; the U.S. Conference of Mayors, which is the sponsor-apparent group of the U.S. Council of Local Health Officers, including all their AIDS personnel; the National Association of Counties, the National Association of County Health Officers, representatives of the new National Alliance of State/Territorial AIDS Directors.

We shared information about what each organization was doing and then identified possible areas for collaboration or issues that were of concern at the state and local level. I will just run through a number of them: the need to motivate state elected officials and local elected officials to take up AIDS; the coordination within federal agencies, between different federal agencies, including the overlap between prevention and early intervention, which falls between CDC and URSA [phonetic]; the need for improved channels of communication between CDC, URSA and state and local entities; the need to -- for the federal agencies to provide better information to state and local bodies on funds which were flowing through various channels to CBOs under their geographic areas, which was a major concern because I think it was discovered at the CDC meeting that there were probably about five or six different mechanisms through which funding can flow through CDC to local -- to

community-based organizations and those community-based organizations are not necessarily always operating within the broadly defined, comprehensively worked out local mechanisms.

The need for technical assistance in prevention came up, particularly what constitutes good practice, as Tom Coates was talking about in terms of designing prevention interventions.

And finally the -- a major concern of these organizations was the need in talking about how to get things done to take into account the fact that the public health infrastructure has been consistently underfunded in the last few decades and that should be a message relayed both to federal officials and to state officials.

The sense was that a follow-up meeting would be useful and we may schedule one of these for further discussion of what collaboration or what particular Commission products would be useful possibly sometime in mid-summer. I will turn to Don Goldman for a quick review of meetings he has held recently with Congressional staffs and the Social Security Administration. Could you summarize, Don?

MR. GOLDMAN: On April 30, I met with a number of members of staffs for both the Senate and House as well as having lunch with the assistant commissioner for

disability. And as Jim Allen said earlier, at this time of year, nothing is happening. I neither anticipate any legislation nor any administrative action until the fall under the best set of circumstances.

DR. ALLEN: Next spring.

MR. GOLDMAN: What?

DR. ALLEN: Next spring.

MR. GOLDMAN: Next spring probably would be even more likely but there are some things going on that may speed up some processes, particularly in terms of administrative processes. But essentially, nothing is happening and where things are going and where they are likely to end up, I have no idea.

MR. DALTON: When you say administrative processes, do you mean that the new regulations are not likely to be issued until --

MR. GOLDMAN: In her testimony before a recent House committee, Gwendolyn King indicated that with 3,500 sponsors, it would take them until the end of the year to collate and to analyze the responses and it would take until December to do that process.

My understanding is that they now anticipate that as a result of some of the pressure that has been put on them and put into some of the efforts of this Commission, that they have now indicated informally that

they hope to have that process done by September with a document ready to go from SSA to Secretary Sullivan sometime in the fall which means sometime between September 21 and December 21.

At that point in time, that document would then have to be reviewed by HHS who would then go to OMB and go through the budget process. Jim is probably correct in terms of a final regulation coming out of it in the spring.

MR. DALTON: And my only other question is, did you -- that was said at lunch that the Social Security Administration might in fact change its practice between now and the spring as against the regulations. Might they unilaterally change the functional test or --

MR. GOLDMAN: I don't think so, although I would be happy to discuss further strategies with you as to what can be done on a true basis at a later time.

DR. OSBORN: Okay. We are getting so close to the time when we should be at the reception that to keep going --

MR. DALTON: There is just one thing about the amicus brief --

DR. OSBORN: Oh, please.

MR. DALTON: Yes, which -- the next item gets me in mind. I guess all I wanted to say is that -- I

don't know how many of you know but this case that we have filed, the amicus, originated at Yale Law School, in fact, two doors down from me.

In fact, at request of the Commission, participating in amicus didn't come from me. I am sure whether they knew I was on the Commission or didn't care. But a call came into the office -- probably of both and I found out the way the rest of you did.

Nevertheless, I was delighted to be involved. The -- this past week, the case was argued in the U.S. Court of Appeals and the day after the -- my colleague came running up to me in the hall and virtually tackled me and wanted to tell me -- first of all, before that he had said how terrific he thought the brief was and how helpful he thought it would be.

At the oral argument, the judge did something that was really quite unusual, which is to publicly laud the brief on the part of the plaintiffs as well as the amicus brief and said that he -- one of the judges on the panel said he found it to be quite helpful.

And so Harold Coe, the principal attorney in the case said to me that he thought that that was indeed the case that the issues raised in the way in which they were raised were in fact very helpful to the Court's understanding of what was really going on.

So I am -- and the oral argument, apparently seemed to go rather well in the sense that the Court focused on the real issues in the case, including those involving HIV. Also, the Government filed a reply brief -- I brought you a copy, Don -- in which they at least make an effort to reply to our brief, which shows that they thought it was worth commenting on.

MR. GOLDMAN: Also, I promised Roy -- which is another issue that I think that while we get into this case, I volunteer and hopefully at least by the time of the next meeting, I will have provided to Roy a draft of what perhaps a Commission policy ought to be in terms of being able to deal with requests to file amicus briefs in a more generic basis.

DR. WIDDUS: We need to be departing for the reception.

(Whereupon, at 5:30 p.m., the meeting was concluded.)

CERTIFICATE

HEARING NAME: Sex, Society, And the HIV Epidemic

LOCATION: New Orleans, Louisiana

DATE: May 18, 1992

I do hereby certify that the foregoing pages, numbers 1 through 165, inclusive, are the true, accurate, and complete transcript prepared from the verbal recording made by electronic recording by Sandra McCray before the National Commission on AIDS.

Kendra Kahn 05/23/92
(Transcriber) (Date)

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The School-Based Adolescent Health Care Program