TRANSCRIPT OF PROCEEDINGS

NATIONAL COMMISSION ON

ACQUIRED IMMUNE DEFICIENCY SYNDROME

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COMMISSION MEETING

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Washington, D. C.
April 23, 1991

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NATIONAL COMMISSION

ON

ACQUIRED IMMUNE DEFICIENCY SYNDROME

COMMISSION MEETING

Tuesday, April 23, 1991

8:30 a.m.

Pan American Health Organization
Meeting Room B
525 23rd Street, N.W.
Washington, D.C.

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P A R T I C I P A N T S

Commission Members:

June E. Osborn, M.D., Chairman

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Don C. Des Jarlais, Ph.D.
Eunice Diaz, M.S., M.P.H.
Donald S. Goldman, Esq.
Larry Kessler
Charles Konigsberg, M.D., M.P.H.
Honorable J. Roy Rowland, M.D.

Guests and Staff:

Robert Fullilove
Molly Coye, M.D.
J. Allen
Patrick Chaulk
Harvey Makadon, M.D.
Patricia Franks
Tim Westmoreland
Enrique Mendez, Jr.
Jeff Stryker
Holly Taylor, M.P.H.
Maureen Byrnes

C O N T E N T S

P R O C E E D I N G S

DR. ROGERS: If you will take your places, we will start. First as a preamble, there are two issues which concern all of us -- I am going to give June the last ten minutes of this because I think she has a plan that might satisfy all of us and that has to do with how we deal with and how we put together a minority report, and how we deal with our site visit to Puerto Rico, on which there have been a number of thoughts. So we will stop at 9:45 to discuss that issue.

I wanted to make a couple of preliminary comments and I delayed in starting the meeting because I wanted as many of you here as possible. First, a number of you have asked about Belinda. I went to see her on Sunday. I thought you would all like to know about that.

First, she sent you all her love and her greetings. Secondly, she is not doing well. She has had an absolutely dreadful six months. She cannot eat. She vomits a lot. She has fever. She has lost a lot of her hearing due to drugs. She has had quite disabling pain from peripheral neuritis. To my sorrow, she has lacked the kind of supportive, compassionate care that we are all shooting for.

If you want a really vivid reminder of what we do not have in many areas of this country and what we need, it is to watch Belinda's care right now. I know that is tearing a number of you to pieces and me as well. I am working very hard to get the kind of care she needs and it is very tough in some areas of this country. I just wanted to give it to you in an unvarnished way.

Despite that, her sense of humor is still very much intact. So is her head. She is as wise and as thoughtful and as caring about other people as she always was. Her guts are just as evident as always.

The final straw which I will mention to you is that last week her husband, who is a remarkable young man in his own right, while mowing their property on his big tractor, turned the tractor over, tore up his leg badly and broke his collar bone. Belinda came out to try and help. She had a seizure. He fainted. They both went to the hospital in an ambulance. They are both home but are both having troubles right now.

As you know, they have two little kids and if you want to watch AIDS play out in terms of how dreadful it can be, it is watching what that family is going through.

She sent a couple of messages that I wanted to give to you. First, to my surprise, she had read all of the material that you had sent her. She wanted particularly say that the staff has done a great job and we do not give them enough credit and we should.

She wanted me to say to this whole group, she said, "send them some bouquets. They have done an enormous amount of work for us and I want to be sure that they know that, and would you say that publicly?" And that was one of my reasons for delaying, because I wanted all of you to hear that.

I am going to take about three minutes to give you a little sermon. I have heard from a number of you concerns about this more comprehensive -- I guess Maureen's title is a more comprehensive report, not a final report; a two-year report or what-have-you. I just want to give you my perceptions about that.

First, I want to at least give you my assurance that I think we are on track. I would simply remind you that in December, in January and again in February we went over what we wanted to do; what we wanted to have contained in that report; a work plan; what it should cover; where we wished to go; when we wanted the interim reports; the kinds

of consultants we wanted to work with the staff; when we want a prisoner report -- all of those things were covered.

I think all are, in my judgment, coming in on schedule. We have a prisoner report. I was absolutely delighted with the consultants that the staff have put together and yesterday was refreshing, in my judgment, because they are absolutely first-class people. They have a Karen Davis or a Molly Coye or a Henry Makandon or a Tim Westmoreland working with us. That is a real privilege.

For this meeting we have a whole series of drafts. They are, in my judgment, equal in terms of their quality. But, again, I think we should congratulate the staff. It is an enormous amount of work to put together that kind of material and it takes time and effort. And now the monkey is on our back, that is, to take the time and the effort and the commitment to review those. We can talk about how we can best do that but that is going to take a lot of Commission effort and we need to put that input back to staff so that they can do it properly.

We need to go through the same sort of exercise individually, I think, as we did, in part, with Karen Davis yesterday, which was a wonderful back and forth. I think we

gave her a number of messages and we will see what we get back the next time.

Third, I wanted to say I hope all of you really feel quite good and quite proud about what we have done to date. You should. I am older than most of you; I have had some experience in this kind of thing and I think we are doing splendidly.

I would point out to you that we have four reports out there. Go back and read them. They really have kept AIDS on the national agenda. I am sure each of us would craft each of them a little differently, but that is good. They are punchy. They may not have been as Don's memo said "on the front burner" but they have kept AIDS on the stove.

We have had a Chairman who has put lots of hours into this, has been out there as a thoughtful, articulate spokesman for us. I think we are doing well.

As a modest confirmation, I hope that next week we will have a letter from the President saying that we are doing well and we are being extended for another year. "Don't screw it up" -- I guess his letter will not say that but I think it will say "keep up the business."

In terms of trying to decide in my own mind why

there are some feelings of unease about the final report -- not final report, comprehensive report, my own thesis goes as follows: I think all of us feel individually an enormous responsibility for what we are going to get out there. All of us care enormously about what it is. That shows in all of our interactions. Everybody cares an awful lot about this particular issue. My guess is that each of you feels a little bit as I do, that you are scared to death in your own heart that we cannot deliver everything that we would hope to deliver on that, that we cannot live up to all of the expectations that are out there for us, and that a lot of hopes are riding on us. So we are all feeling tense and worried about whether we can do it in the way we would all feel proud of.

I think we can -- I think we can. I have just enormous affection and respect for this group. But I think that there are some things that we each ought to think about. One is that we take very, very good care of each other. This is a very demanding task. We are going to have a lot of work to do and we have to be very careful of each other's hopes, feelings, value systems -- everything that we care about.

Secondly, I think we have to take very good care of

the staff. We are fortunate in having a very good staff. They work very hard. And we have to be as careful as we can to give them both a series of consistent messages and the kind of support they need. I have often thought that it must not be an awful lot of fun to work for this group because we have a million different agendas and we beat the hell out of them a lot of the time. I think we should remember that they need the same kind of support that all of us do.

Third, we have to trust the process. In my judgment, that process demands that we all do our own homework, that we give the staff the very best advice we can with the material coming to us. That is going to require that sometimes each of us will have to sublimate our own individual agendas to try and get as good a group kind of thing as we can together; that we show up on time at meetings; that we stay the distance at these meetings; and that we feed that stuff back to staff. All that is going to take a lot of time.

I would think this would be the first of a number of sessions. So we will try to swiftly group as a group and say, "here's what we want" and give the staff the best guidance that we can. End of sermon.

As you know from my note to all of you, if we could each arrive at some general kind of group consensus about the four issues that have to do with that report -- and, to my absolute delight, Don Goldman put together a memo that I find is just elegant. I feel that he has done most of our work for us. That is quite a remarkable document. It is simple and straightforward and I, for one, would agree with it in its totality because he has given us a way for each of us to paint our individual picture, as well as doing some group kind of thing, that I thought might come out quite well with nifty ways of preserving our individual identities but putting together something that we can do as a group. I hope you have all read it.

So that is the end of my rather long preamble. I was stewing about it so I got up early this morning to kind of give you that general overview of what I think we are about.

With that, maybe we can turn to what I promised you in this session, which is those four bits: Who is our audience? What are the areas that we should give staff clear messages that we want in that? Some thoughts about the length and perhaps the style of the shorter piece, the

executive summary. Then some thoughts about recommendations. As I say, I thought Don solved most of that for us. So the field is yours. So go to it.

MR. KESSLER: David, I think your summary is excellent. The only thing I would have added to it is that in a way it is timed also to circle the wagons and to be careful about how outside forces want to use us. In a negative way, I have had several calls from groups that want to lobby the Commission or lobby me, and I suspect others have had too, about seeking to have specific input into the reports and bypass the process of the hearings, the site visits and so on. I find that not helpful and I have suggested back to them that if they have something constructive to add they should put it in writing but not to lobby in the strictest sense.

DR. ROGERS: Yes. I thank you for that. We will get a lot of that. There are lots of groups who care intensely about it and they are going to push hard, as is appropriate. But, again, that was one of the reasons for saying that we have to take careful care of each other and the staff, besides the process, as we move to something which is bigger than the sum of its parts.

DR. KONIGSBERG: I guess my concern, which is sort of the flip side of Larry's, is the groups which do not seem to care about what we are doing. I guess that gets into the issue of who our audiences are, the next level below Congress and the President. I think I have expressed to a number of you individually and perhaps collectively that state and local health officers, for example, are not viewing this Commission as being particularly relevant. I think that may extend even to government more broadly.

That concerns me and I think we can do something about it when I am in an optimistic mood, which I am this morning. But I think that is an opposite situation. Those groups, instead of "lobbying" us are just sitting out there saying, "so what?" with regard to the Commission. They are not necessarily saying so what to AIDS and HIV. Then there are other audiences that do not want to hear about AIDS, inside and outside government. And I am not really sure how we deal with that.

DR. ROGERS: I think that is an important point. There are all kinds of views on the Commission. I get, in general, rather positive views from people in government as well as without it, and health officers as well. But there

are appropriate concerns. I mean, we have put out some tough stuff and some agree and some do not agree. Any more general comments? Diane? Harlon?

MR. DALTON: You said a couple of times that we should trust the process. I am not really clear about what the process is. I just read through Maureen's most recent description of our meetings through August and I saw a memo, I guess from Karen, to the consultants. I just do not know when we get back, for example, the sections of the final report that we are going to look at today and that we looked at yesterday. I cannot imagine that we are going to do all of that at the June meeting. My impression is that at the June meeting a substantial portion of the time is going to be devoted to prevention issues rather than the whole range of issues in the final report.

So if somebody could just outline what the process is for having this comprehensive report put together, I would find that helpful.

DR. ROGERS: All right. Go ahead.

MS. DIAZ: I guess I have shared the same concern, Harlon, many times for the various reports or issues that we take up, not really being clear on the total process. This

reflects back to something you are talking about, us being able to support each other and support the work of this Commission with public audiences.

One of the greater criticisms that has been brought to my attention is exactly that, the process of inclusivity and the process of broadening our perspective to include diverse points of view with the consultative help, wonderful albeit, that we have had throughout consideration of various subjects.

I guess really the public, in many ways, are holding each one of us in our diverse and widely geographic representative areas to be able to defend that process. I would like to be able to say that the following subject was discussed by the Commission and this was the broad process of inclusion.

It is my opinion, and perhaps just mine, that perhaps that ought to reflect the best thinking of the staff. However, it also includes the best thinking of the people that are on the Commission in their various areas of interest and expertise, and also the input we can give as to best thinkers out there, and I think yesterday was a beautiful example of that kind of process, which is really the best

minds working on one selected subject.

But when we, in fact, are not told what the process is, or an issue or a subject is perhaps just looked at as a particular area or interest or expertise of one Commissioner which perhaps can provide all of the input, or guarded input, or carefully sought out input on a subject, it is very difficult for us to be able to stand and defend a credible process that has as its hallmark inclusivity of audiences around the nation.

The only other major criticism that I have heard of our work is that, because of time constraints, our process at the hearings less and less includes opportunity for public comment, public comment that is sought out in a careful manner and is really advertised or sold to the public as "this is your time to speak without any constraints before us." That has been an identifier or something that was sought out in some hearings. But throughout the country, as we go to discuss various subjects, time for public comment is minimal or tagged on at the very end at a time when maybe really there is no audience left and many of us are really packing our bags.

MR. ROWLAND: I do not know how it is going to be

written for it to do what I would like it to do, but I hope that this final report will speak with great authority. I think it is very important that this Commission is recognized as providing information to the Congress and the President; that it is recognized as being authoritative and very worthwhile, because the Congress still needs some direction about how to deal with this. It needs a great deal of direction, as does the administration, on how to deal with this issue.

Late last year in the situation that came up about the people working as food handlers and the fact that the National Restaurant Association and the Independent Federation of Small Business people got involved in this, I think they did more damage to the ability to deal with this problem. The fact that two national organizations got involved in that was fine, but not without a great deal of attention being focused on that.

Just this last week, at a meeting I attended over at Greenbrier, the United States Telephone Association had four or five members of Congress there. During the period when I was making a presentation, one of the members of Congress brought up the AIDS issue and food handlers. It was

not what we were there to discuss at all but he brought it up and he wanted me to explain why I had taken the position that I had.

So it is so important for this report -- and I do not know how you are going to do it -- to be authoritative, and hard-hitting, and respected and have it received well.

DR. ROGERS: That is very good. Harlon, I have not forgotten your question, nor yours, Eunice. I am going to try to come back to that in a minute in terms of what I think the process is. Diane?

MS. AHRENS: I am listening carefully to Roy because I think he is giving us some really good advice, and we are going to need Roy very much in the next several years in terms of whatever we do. If we were to stop right now in terms of the hearing process, I think we have enough terrific information to produce the kind of report that Roy wants us to produce.

I guess my concern at this point is how do we go about pulling all of this terrific information that we have together. That is going to be a full-time job for staff and I think it is almost going to be full-time for us if we do it right.

So I am very sympathetic to what Eunice is saying but we do have another year. We cannot, to me, continue to do both things and do either one of them well. We cannot continue to have a hearing process at each meeting and also deal with the very hard business, in my judgment, that we have to deal with to pull this report into shape, unless we simply turn it over to staff and say "you write it" and I think this Commission wants to have a lot of input -- not really input but I think we need to be the ones to cull out information that we are being given and say "this is what we want," just as we did yesterday in terms of the wonderful information we were given and we were able to come to terms with that and say that, "well, this is important; we're not so sure about this." How we format that, I think that is our job. I think that is why we were appointed. I think that is what the Congress expects and I think that is what we all want to do.

I guess I would like to go back to what Harlon said because I would like to get very clear and very specific on this and I think staff needs this from us. What are we going to do at each of the meetings that we have scheduled and when are we going to do it? That is the question and I guess I

would like some discussion on that. I think staff needs some direction as to what we want at these meetings.

We only really have three meetings left, as I read the schedule. We have May; we have June and July. We are going places and I guess I need to know when we are going to devote the time we need to get at the issues that we need to get to.

DR. ROGERS: Thank you. Let me try and respond as best I can and then others can add to this. First, in terms of the process, in my judgment, the process has been as follows: We have had several sessions in terms of where we have said what we would like as additional information; here are the major areas we would like to see covered when we craft that final report. Just these views I think illustrate the fact that we went through a rather democratic process, some feeling that we must have more input from different groups who are desperately clamoring to be heard; some who felt we have more information than we can deal with and we now must step back and try and digest it and put it together.

I think the staff, in terms of putting together, as they did for us a "here's where we will go; here's a working plan," tried to be responsive to something in between on that

-- here is where we will gain more information in areas of different Commissioners. I think they have been very responsive to what we have asked for, the information that different Commissioners have wanted to come in; and here is a draft outline; here are the areas you have said you would like to have covered in that report.

Now I think we are all feeling the enormity, Diane, and the pressures that Eunice has mentioned too, of how to get this done. We are going to be receiving materials crafted by outside people and crafted by staff in response to what we said we wanted in that report. I think simply in getting the first dose of this, many of you are wondering how we can possibly do this.

One suggestion that I might try out on you today is that each of us has special areas of interest and expertise, and again, in terms of trusting the process, we might say -- and Don suggested this to me this morning -- let's have one or two Commissioners be primary reviewers. They are the ones who are going to be responsible for the eight hours on that particular piece to say, "here's where it fits; here's where it does not." That does not absolve the rest of us from doing that work but different segments would be looked at by

different Commissioners, inputting back to staff, so that when we see the next draft we will have gone through that kind of thing.

But I think the process has been that we have told the staff what we would like in the final report; here are some of the groups we would still like to hear from. And we have had that work plan displayed for a number of months. Now, it seems to me, it is perfectly appropriate to say, "wow, wait a minute, maybe that is not what we should do." Though, bear in mind, the staff have done a lot of work on that particular bit and have launched a number of people to do different segments of this that are coming in to us.

MR. DALTON: David, I think you have just described the process to this point, at least as I have experienced it. What I am wondering though, assuming that we do not change anything in that process -- and I am not advocating changing it --

DR. ROGERS: And you may want to change it, and that is perfectly proper.

MR. DALTON: But even if we do not change anything, how does it all come together? I guess I do not really have a vision or understand how a comprehensive report emerges

from all this and at what point the Commission as a whole speaks to that, sees it. As I read the outline -- I believe this is a memo to the consultants -- I see the report going to the printer without any specifically designated time for the Commission to even read it as a whole. I know that cannot be true but I just do not know, just on a time-line basis, how we are going to do all the work that you and others are rightly calling upon us to do.

DR. ROGERS: Let's ask Maureen to move us through that.

MS. BYRNES: The way the plan stands right now according to the work plan and the time-line that we put together for ourselves and the consultants -- there are two things: One, to maintain the hearings which we had identified in January. So the May meeting in San Francisco would include hearings on the gay, lesbian bisexual community, as well as an opportunity to discuss issues around the Asian Pacific Islander communities, without a whole lot of time for work on the report. Most of the work on the report will be getting done by consultants and staff between now and just prior to the June meeting -- mostly hearings in San Francisco, individual consultants and staff writing drafts of the

report.

For the June meeting, which is scheduled for June 5, 6 and 7, in Denver, Colorado, the expectation is to have drafts of all of the chapters to you prior to arriving in Denver, with an opportunity to look at the issue of civil rights, which was scheduled for June, women's issues, scheduled for June and a whole day, with some of that day, looking at some issues of prevention. The bulk of that third added on day is designed for us to have time to ask what you liked; what you hated? What are your reactions to the drafts you have seen?

The two days in July, in Washington, D.C., the consultants and staff take that feedback -- the consultants will be at the June meeting, in Denver, for that day. Then they will rework those drafts, have them to you in plenty of time to read for the July meeting since all of July is designed to look at the report, get feedback again, and then, hopefully, to have a final draft to you by the end of July/first week in August, -- we have targeted August 3 for it to go to the printer -- to get it finalized by the beginning of August.

So between now and then -- May in San Francisco;

June, some issues and one whole day for the report; feedback; another draft which would be fairly complete in order to spend two whole days in July talking about it; rework that; submit a final draft, and we should be on track by August 3. That is how the plan stands right now. Karen, is that right? Have I missed anything?

MS. PORTER: I guess the only thing I would add is that the memo was to the consultants and it was about what we were expecting from them. So it does not really go over what we are expecting from the Commission.

I think the part that has not been emphasized enough is that none of the work can be done without the input of the Commission. Right now, the consultants feel as if they maybe did not get enough feedback from the Chicago meeting and want more. In part, lots of today is designed for that and it is really important when we have days out there that people really know that the work of putting forward recommendations and all of that is what we are looking for from the Commission. As much as people can take that seriously and be prepared to do that -- you know, it is just incredibly important.

DR. ROGERS: Harlon, let's be sure, is that enough

time? Does it satisfy people? Does it alarm you? Let's be sure. Diane, you look alarmed.

MS. AHRENS: I am alarmed.

DR. ROGERS: Okay. Let's get your input on how you think that could be better handled.

MS. AHRENS: In the description that we have just heard I do not hear the kind of time that I think is going to be necessary to deal with the various segments of this report. I hear a final time when everything will be in pretty firm draft form and we will then react to it at the July meeting. I hear that. I hear that there will be two days of that.

I do not hear where the time is between now and July for us to deal with the substance of the report, the substance of what the consultants are bringing in. We spent a full day yesterday on finance. It seems to me that the issues around prevention and a whole series of things here -- government structure and roles -- that is a biggie. Research, it seems to me that is a pretty large one. I am categorizing the kinds of things I wrote down in terms of what I think the final report should contain and I think communities affected is a very big one. Public health is

another big one. When are we going to deal with the substance in the sub-categories that will be in the report? I do not hear that. That is the concern I have.

DR. ROGERS: Okay. We might operate here as a group. Are your concerns sufficiently great so that you wish to say no, we should not try to collect more material before that final report; we should change what we have on our agenda to have more focused sessions on those particular pieces? There have been differences of opinion. Don?

DR. DES JARLAIS: The sense I am getting is that with the large amount of materials we need to process and review, we are not going to be able to do everything as a committee of fifteen.

DR. ROGERS: I agree.

DR. DES JARLAIS: There are so many things -- Diane's list could certainly be expanded without much trouble, and I get very, very worried if we do not really examine these issues in depth. But I do not see that we can have all fifteen examine all of these issues in depth. We may need to breakout some of these meetings into groups of three or four to tackle one specific section of the comprehensive report with two or three Commissioners and then have

a report back. There is an awful lot of trust that those two or three are going to do a good job but I do not think we are going to be able to have fifteen of us spend one day on each issue, as we did with finance and as we could do with public health and government structure. There are not that many days left.

DR. ROGERS: All right. Don?

MR. GOLDMAN: You attributed to me the idea of putting together primary reviewers. It was not my idea. I had dinner last night with Diane and Pat Franks and it was probably Pat's idea, actually, not mine.

You talked about the feeling that we have more information than we can deal with, on the one hand, and the fact that there are groups clamoring for attention, on the other hand, and those are not inconsistent with each other.

DR. ROGERS: Right.

MR. GOLDMAN: Clearly, there are expectations of communities affected that we need to deal with but, on the other hand, it seems to me that we do not have to deal with them by necessarily having full Commission hearings to the length, breadth and extent that groups might want to be heard. You can have it in smaller groups and perhaps have

representatives.

Don Des Jarlais and I had a conversation in the cab on the way to the airport in Chicago. I think Don referred to it as "changing tastes in Commission hearings and witnesses." "Changing tastes in witnesses" I think is what you referred to. As we go on and as we change our tastes in terms of what we feel is necessary is something that we have to cope with, and something that the audiences and the groups that we deal with also have to accept. I think now we are sort of in a transition of going from an information gathering mode into more of a consultative, bonding, togetherness, consensus building kind of mode within ourselves to put together something and I do not think that we necessarily have to be ashamed of saying to communities, "look, our needs are changing over time."

We have another year to go and that is the luxury that having another year gives us and perhaps we can put off some of the areas of concern and we can say to a group, "give us two or three people who can give us in an hour the essence of the problem that you want to deal with," and let's deal with it more extensively next year, or in a subcommittee or in some other way. At the present time we have to deal with

the more important issue of getting this report out.

Maybe that is the way to do it. Maybe you are going to insult some people by doing so. I suppose, no matter what you do, you are going to end up insulting people and making people feel bad. But I think that if you do your best effort and try to avoid it, then there are ways of accommodating both interests and still giving us the kind of time that is needed.

I like Don's idea of even at meetings perhaps breaking out into smaller groups to deal with some of the specific sections of the report. I think that would be a useful process.

DR. ROGERS: All right. Let me try to get some more input to get us out of this dilemma. Larry, then June.

MR. KESSLER: In my mind, I do not see any way out of doing what we need to do in May and June because those issues are so prominent and important to the report. If they were not in the report sufficiently, then we would probably have nothing but grief in our third year and we would be reacting to that rather than moving forward.

But the idea of smaller groups and even small groups that can be combined with a Commissioner, a staff

person and a consultant -- I think we are putting too much emphasis on the fifteen of us trying to do it all and scour every word and every comma. We would not have enough time in the next year to do it that way. We need to trust one another; we need to trust the staff and the consultants and come back with a fairly synthesized report that we can sign off on fairly quickly.

Where we might get some extra time is in, perhaps today, scheduling a tentative second meeting or something in July rather than short-changing ourselves on the front end now because if we do not get the data we need in San Francisco and Denver, that will be missing in July. But we do have a little bit more time in July and, even if we have to push the printing date back by one week, there is some flexibility there.

But I think delegation and trust will get us a little bit further than going into a panic about input on 300 pages or whatever it turns out to be.

DR. ROGERS: Thank you. June?

CHAIRMAN OSBORN: I have two comments. One is that Don, Jeff and I were involved in the six-month effort to put together the book Confronting AIDS, which meant that we were

really moving. The strategies that you described were part of the way that happened. In technical detail, that was considerably worse because it really needed to be referenced in a thoroughly careful and exhaustive manner, which we may not need to do here.

So I think what Larry just said about trusting the staff and having the primary writing done so that the conceptual adjustments and the turn of phrase is the kind of input that the Commission brings to it is a crucial bit of trust in order to let it work at all. So I think that element is important.

If we follow Don's suggestion of breaking out areas of responsibility, I would just superimpose that anybody who wanted to could have, in addition to their designated area of responsibility, as much input in the others as they cared to. I confess that in that Confronting AIDS study I ended up wanting to do a lot because I was very much into it. I had some time and I went over the last several drafts and was able to establish a good working relationship with the staff. I think that is how Jeff and I got to know each other, as a matter of fact. The staff were very happy to have that additional input. It is a time question, not whether people

trust each other.

So I think we have the process. The idea of scheduling a couple of days in July that could be cancelled, as needed, is a good one. An alternative would be if we did, in fact, establish smaller groups, those groups could schedule extra time as needed with staff that were particularly involved. There are a couple of those kinds of delegation strategies.

Turning to the other comment I wanted to make, when we talk about what we do as a Commission I think it is very easy to miss the fact that our very existence means a great deal to a great many people. I want to support what Eunice is saying. Not that I want great, long lines of more witnesses but I have the same reaction that I think the rest of you do, with one exception to some of the comments, that is, every time somebody gets a chance to say to us what they have been burning to say for a while, they tend to have surfaced because they cared so deeply. They say things with a great deal of passion that, in its own way, releases a safety valve in a community. As we go from community to community, we play a role that we are almost unaware of because much of the role is afterwards.

I had, as it happens, a detached experience of going to Milwaukee a couple of weeks ago. I assumed they had asked me because I am from Wisconsin. It turned out that they did not know that. I just ended up embodying the rest of you for the day somewhat inadvertently. But they, as a community, chose that as an opportunity to really crystalize. So there was a luncheon with 325 community movers and shakers in a city that had never faced this before and has one of the worst racial problems of any city in the country and they had come together in this context.

We do a lot that we are almost unaware of because we are so busy that we do not notice the dynamics that are going on. I think the staff do exhaustive work in advance to try to epitomize that effect. So I am concerned about trying to perturb or diminish what we have scheduled and I do not want it to go unspoken now because as we look toward our third year, I think we may be tired of hearing but the country is not tired of talking. I do not want to see us move away from a role in which, among other things, we continue to embody a caring part of the government that is hearing people as they suffer through these dreadful times. I think for us to forget that that is part of what we do would be too bad, and

it is part of what can, in the long-run, build the credibility and trust that Roy is talking about. If we are invisible because we are off somewhere working on manuscripts, the fact that the manuscript is well written does not do it. We have to do all of these different things. And as we say strongly over and over again what there is that needs saying, we begin to develop the kind of authority that then helps Congress and helps other people to do what is right instead of what is motivated by fear.

MS. AHRENS: What I am hearing is that it is very important that we continue on the kind of agenda that we have set. That being the case, I think that we have to adjust our schedules to do the kind of subgroup work that needs to be done on the report.

Two things: I think the input from this Commission to the consultants has to come prior to July. I think they need our reaction early on. I would suggest that staff take a look at San Francisco, for instance, if we are divided in such a way that we want to deal with the two things that pop out for me, prevention and governmental structure simply because Pat Frank is there and Phil Lear is in San Francisco -- maybe some of us should come in a day early and work on

those two.

But divide us up so that we get the input to consultants in May and June. I think July is too late to get input so that things are drafted in a way that we find acceptable. That would be my suggestion, that we plan to spend more time separate from the regularly scheduled meetings.

DR. ROGERS: Good. Harlon?

MR. DALTON: The other point, and maybe it is not necessary at this point because it sounds as if we are going to go ahead with the San Francisco and Denver meetings, but I wanted to echo Larry's sentiment and June's somewhat more softly stated sentiment that we ought to proceed with those hearings. I really think that audiences do not have to accept the Commission's change in taste; that we have heard enough. For every audience it is a new day.

I love June's phrase that we may be tired of hearing but the public isn't tired of talking. Personally, I am very tired of hearing and I may, indeed, resign from this Commission because I may have reached my fill. But I now understand why it is that people like Roy Rowland and Diane Ahrens and, for that matter, why the legislators sit up there

looking interested day after day, year after year. It is a terribly important public function and I think we cannot abrogate it.

Certainly in terms of these two hearings, they are so far entrained that if we were to abandon them or truncate them, Larry is quite right, we would be spending the next year essentially dealing with the consequences.

We have already gotten a sense of the fact that the public's perception of what we are doing is not the same as ours. They have not been with us in city after city. They have not heard the witnesses that we have heard. They have not had the same kind of cumulative understanding of what it is that we know, which is why people continue to come before us and, in some ways, we mix a little bit of AIDS 101 and a little bit of sensitivity, training etc., etc, because this is their shot and I think we just have to take it. We could certainly structure the hearings in a way that minimizes the pain to us but there is going to be some pain.

DR. ROGERS: Let me see if I can summarize what I think I have heard so far, just to check my instincts on this: That we should go ahead as planned with the May and June meetings because there are a lot of people depending on

that, and three or four of you have said that.

I think we have arrived at a consensus, perhaps best articulated by Don, that we have to change our style of operating, and I think many of you have said this. No longer, perhaps to the sorrow of some, can we deal with every issue meeting as a group of fifteen. We are going to have to spread ourselves out more appropriately to get the work done. That might include not only what we are going to do for this report, which I will come back to, but it may have to do with some of the hearings. We may have to appoint subgroups to be sure that we are hearing people. We are going to have to place our trust in other Commissioners to represent the full Commission well in that setting.

Third, for segments of the report, we should probably make some assignments to different groups of Commissioners so that they really will have done this carefully, thoughtfully, reviewed it in depth.

Four, that will probably need to be done before July. We are going to have to make those assignments swiftly. We will have to agree that X, Y or Z or two or three are going to be the initial or the most in depth reviewers of certain segments of this report, getting that

back to consultants so that they have that input before our July meeting.

Five, we should tentatively schedule an additional meeting for July which we might cancel if we find we can, but so that we do feel comfortable that we will have adequate time to put that input into this final document. June has reassured us that it can be done. I think those of us who have had to work on this kind of thing find it can be done but we will put that time in.

Finally, and this is an addition of my own, I think we should all recognize that we cannot put everything on this one camel. This is a two-year report. We are going to do the very best we can. It must, as Larry has indicated, address a number of issues and particularly be responsive to a number of the groups that have come before us so that they know that they have been heard and that we have articulated carefully what they have said to us.

But bear in mind that we do have another year. We will have to continue to pick up additional information. So do not feel that all is riding on this. If we push our golf game too hard, we will miss the ball. Let's do the very best we can and put everything we can into this one but recognize

that it is not the one and only shot that we have at it. That is where I am at the moment. Larry?

MR. KESSLER: I think the report also should frame it that way as well for the readers and for those people who are going to want to analyze our progress. That is, it should say that we have not stopped existing. We are still going to continue to work. In some ways, I think we are just beginning to hit our stride. Even though some of it seems repetitive, we have gotten better in setting up the meetings and designing them to cut out some of the repetition and to get to a different layer of concern, of insight and so on.

Being dean in the community of AIDS organizations movement, I can see a maturation --

DR. ROGERS: That means that you have been around a long time?

(Laughter)

MR. KESSLER: Yes. There is a maturation going on in the AIDS world, arena, industry, whatever you want to call it. That is simply because people have been around a while now and they are getting wiser. They are beginning to get down to the harder issues. It is not so rhetorical any more or panicky. Those who have sort of survived more than five,

six or seven years are beginning to frame it in a different way.

That is what I think we are getting to also. We have tried several models. We are beginning to feel more comfortable with models that are more productive. I am optimistic that in the third year we will not repeat some of the things that we have found boring, that we will actually have the key to unlock some of those new insights and, even with some of the groups that we talked to two years ago, we will hear things differently and we will be able to give them feedback differently as well.

So there is a future after this report, a future role for the Commission, as well as a future need too. In a sense, while we are listening, we are also a filter and a sounding board.

DR. ROGERS: Right.

DR. ROWLAND: I just want to make a comment or two. I want to express my appreciation to everyone on this Commission who has been so faithful in coming. I do not believe I have ever been involved with a panel before that has been so attentive and has attended so many of the meetings as you have done. I am the one who has been to the

fewest meetings of all and I regret that I have not been able to attend all of the meetings. But you have done a really fantastic job and I think the staff has really done an outstanding job too. They have all worked very hard.

What I hear this morning here is very satisfying to me, the comments that have been made here this morning and the way that you are going to proceed to deal with the issues, to compile the information that you have gotten in the report saying that this is what we have learned and these are the conclusions that we have reached about what needs to be done. So I just want to express my appreciation to everybody. I am very pleased with what I am hearing here this morning. In fact, I want to thank all of you very much.

DR. ROGERS: That is very nice. I think we should put up as our banner what Roy said, that the report should speak with great authority. We assure you that we will speak with probably more authority than we really believe we have.

(Laughter)

This group is eminently satisfactory in frustrating me on almost every agenda item I put before them but I think perhaps this has been the most important. I will try a couple of things on you:

One, I think a fair amount of it should be self-assignment but perhaps you will permit staff working with June or me to make assignments, if you do not yourselves, which has to do with the different sections coming along.

I am just going to review those for you. The big sections are an overview of HIV disease in the 1990's: Where are we? Where have we been? Where have we been going?

Section two, what has been the response of the federal government?

Section three, what are the tasks to be accomplished?

Section four, who can and who should be doing them?

Section five, how will we pay for the services? And I think we had quite good input into that yesterday.

Second, have each of you had a chance to read Don's memo?

(Several Commissioners respond affirmatively)

I will try a risky thing, would most of you largely buy onto what Don has to say there?

(Several Commissioners respond affirmatively)

Which I do not think is restrictive. I think he has given us a way of going at this but you can add any

comments or criticisms that you have. I liked it very much.

MS. AHRENS: I have a question. I do not understand the relationship of what you just told us in terms of the areas in the report and Don's three main areas of concern. I am confused about how all this fits together.

DR. ROGERS: I will pass around this draft outline. I was reading the major sections and you will see subsets that I think do address precisely the kinds of things that Don has talked about. Could we give that to each Commissioner?

MS. AHRENS: I also have a question about this response of the federal government section. I missed the last meeting. Maybe this was all done at the last meeting.

DR. ROGERS: No. No, it was not.

MS. AHRENS: I do not know where that came from but I guess I am wondering why that is in the report. It is past response.

DR. ROGERS: If you read the draft that Molly Coye put before us, I sense it is part of that. It is where are we with that? Where is it falling short?

MS. AHRENS: I thought you were talking about the response of the federal government document --

DR. ROGERS: Have you got before you now a draft outline of what was proposed?

MS. AHRENS: Okay.

DR. ROGERS: What I am suggesting is that each of you say, "okay, this is one section, two sections or three sections that I would really like to take a very careful look at." There may be several documents within a section. Isn't that true?

MS. BYRNES: And, Diane, after the January meeting, when we got feedback on what the outline should look like, staff sent this to Commissioners and asked for feedback at the Chicago meeting. We got none about the outline and had a sense from everyone that we were at least moving in the direction that the Commission wanted us to move in. But this was circulated after the January meeting when we talked about what the outline should look like and when Commissioners expressed a desire to see certain things in the outline. Then it was sent out with the materials prior to the Chicago meeting. It has not changed since the January meeting.

DR. ROGERS: My suggestion here, Diane, and this is not binding, is that each of you think about the areas are in which you have special interest and special expertise. I

would guess that each of you is going to want to see drafts in more than one of these sections, that you will take the responsibility for reviewing that with care and transmitting stuff back to staff.

MS. BYRNES: Karen also suggested a good point. We might not want to have everyone on section three but that you opt for prevention, or you opt for research or you opt for care. It seems to me we would welcome more focused input from you as a group on each of those issues. How we display them in the report, we can continue to talk about.

Do you understand what I am saying? If you sign up for section three, there are three very meaty sections in section three. It seems to me, you might want to ask to look at prevention as one issue, care as another issue and research as a third. Is that clear?

DR. KONIGSBERG: Section two, what has been the response of the federal government and section four, who can and should be accomplishing these tasks -- I understand, as everyone does here, why we have a special interest in what the response of the federal government has been. I think that is probably part of our statutory charge too, if I am not mistaken. But I think it is also important that we lay out

what we think the governmental response has been at all levels.

DR. ROGERS: Yes, I do too.

DR. KONIGSBERG: I think that we need to be frank about it. I have raised this question before in terms of what we think about the response of state government, good and bad, and local government, good and bad. We made site visits. I am just thinking out loud for a second -- this maybe gives us a clue about something we may want to do in the third year that not only would be slightly different in terms of information gathering about the state response, because I do not think we have done much of that, but it also might be something to get at the credibility gap between this Commission and state health officers. I am not taking sides on that issue. I could probably argue that one either way.

We have looked at the local level. We saw the local level under the auspices of the state in southeast Georgia, middle Georgia. We saw it in Seattle. I was not able to go but I am familiar with their system. It was seen in Palm Beach County, L.A. You know, some of these are good; some of these are bad; some are in between.

One of the things I will raise with Molly is that I

think there needs to be a good overview of our governmental system for dealing with health issues, public health issues and epidemics; how those integrate and how those do not integrate because it is unique in all the world. We just do not have an overall ministry of health in this country that kind of takes care of everything and I think it is very unclear.

Diane, I am going all the way back now, almost a year and a half ago to the meeting in St. Paul, and I think we need to go back to that report and take a careful look at it. So I guess what I am saying is that I think section two ought to be what is the response of government, (a) federal, (b) state and (c) local.

DR. ROGERS: And I think that is a good illustration of where we have gone since January. I would now modify this and I bet it will be modified. For example, I think section two and section four really need to be kind of coupled and we need to have federal, state and local. We heard that again yesterday and I think staff is already moving in that direction. After hearing this discussion, perhaps one of the things we are going to want, Maureen, is a new draft outline. I hope all of you heard that we got this in January, and I am

one of the sinners -- zero, not one response to staff who then, I would think, would operate on the assumption that we all thought this was great. I think we need a new one. I think there may be modifications that people may wish to make. Don?

MR. GOLDMAN: I am going to talk about two different issues with respect to the memo that I wrote. I think there are two separate points. The first one is the concept that I had of basically dividing the report into three sections, an executive summary, the main body and then perhaps a supplemental report of some kind which could deal with things and I think it is important that all of us know what section we are writing --

DR. ROGERS: Fine.

MR. GOLDMAN: -- in terms of dealing with the various issues from our perspective, as well as the consultants' perspective. You may want to say that what we ought to be doing is writing the main report with the ideas and we will figure out later which of those items go up to the executive summary and which or those items perhaps go down to the supplemental report, unless that determination can be made.

One of the examples I gave, not that it is not useful and worthwhile, but certainly that long history of the AIDS epidemic does not belong in the executive summary.

DR. ROGERS: Right.

MR. GOLDMAN: Maybe an abbreviated format belongs in the main report and maybe a lengthier one belongs elsewhere. That is my idea of how that could be structured if there is agreement on it. But we ought all to be writing at least at the same level. If we are going to be doing it, we ought to agree on that.

The second item is that I think, at least in response to Diane's question at least in terms of the areas of concern which dealt with one of the other questions that you asked, as I indicated in there, really this does, in fact, encompass it. Whether or not in the end we end up restructuring a little bit and moving things around, I do not think we are wedded to this draft outline in terms of chapter headings and order of presentation. But I think, if you look at all of the items, pretty much everything is somewhere in here. Then using the cut and paste feature of word processors, we can probably work it out. But I think this is at least comprehensive enough to work with, although I was one of

those -- I commented on the outline in April, having gotten it in January and that is my fault.

DR. ROGERS: Let me try this out on the group again because Don has asked an important question. My feeling, Don, is that what we are being asked to do is to say that we will take a careful look at these different parts of it. That distributes the load. That would be part probably of the main report though, as you have just said, as we examine it as a group we might say that that belongs in the supplement or a piece of it belongs in the executive report. But what we do as small groups or as individuals is work on what is going into the body of the main report.

I am absolutely convinced that all of us wish to have full input to that executive summary. That is a short one. That, it seems to me, we have to decide as we go through this process in July by saying that we will buy off on this or, "thank you, Diane, for your input on that one but here is the general skeleton of the main report and here are the things that we want in the executive summary." So that is a group issue, I think, to decide that particular part of it.

So my feeling is that what we are doing now is to

say that you will be responsible for these fuller sections of the main report, with the assurance that all of us will be adding our input to that executive summary.

MR. DALTON: Don, you just said "the sections that we will be writing." I do not know whether you meant that literally but --

DR. ROGERS: He does not mean that literally.

MR. DALTON: Actually, I want to make the point more positively. I think it is important that we not rewrite each section.

DR. ROGERS: Absolutely.

MR. DALTON: I think we need to guide the consultants and guide the staff, if for no other reason but simply the matter of the readability of the final report.

Similarly, although we would all want to have input into the executive summary, I think that needs to be written by one person.

DR. ROGERS: I do too.

MR. DALTON: I am guessing by our Chair, but by one person. The only other point I wanted to make is that I think we should not leave this morning's session without agreeing upon an outline. Yes, we all dropped the ball in

January. I heard you and I heard some other people suggesting some rearranging. I think we need to be clear to the staff and to the consultants because the order in which the consultants write their pieces will determine -- there is a need to avoid overlap. There is already overlap in the reports that we have from the consultants. So we need to have a sense of how things are going to flow before we leave here.

MR. ALLEN: I have a couple of questions. One, when we do finally come up with the sections, that we would put a level of interest, those that have the main reading -- I would like to see it all, of course, but I think we ought to make sure who is responsible and at what interest level. For example, one would be the primary readers; two, we would like to see this up front and have some input but not detailed; three, we would like to see just the copy.

DR. ROGERS: Everybody buy that?

(Several Commissioners nod affirmatively)

MR. ALLEN: Okay. The question that I have is who will be the final editor of this piece?

CHAIRMAN OSBORN: I will certainly volunteer to be one of them, Scott.

DR. ROGERS: And I will volunteer to be one of them.

MR. ALLEN: For consistency of the piece, I was wondering who is going to be the ultimate one.

DR. ROGERS: That is absolutely critical.

CHAIRMAN OSBORN: I must interject a very funny anecdote from the Confronting AIDS thing. At about that stage of things, Howard Temmin (phonetic), who is a vicious editor, had gone through every page and was up to about page 200-and something or other. He sort of gave up and he said, "before I quit, on page 245 somebody forgot to split an infinitive."

(Laughter)

DR. ROGERS: You are right, it has to have a flow to it. I love that one statement which pointed out that there have been some ringing reports that have really captured attention, and Roy has again said that it has to have that. June is an elegant writer and I will critique her writing and I think we can put it together as a cohesive piece. But it is going to be with full input from all of this group so that you all have ownership of that.

MR. ALLEN: I have one other suggestion, that is,

when something comes out, I think there needs to be a definite cut-off date when comment is done --

DR. ROGERS: I think I will ask staff to get that out to you.

MR. ALLEN: -- just so we know that something does not come in later saying, "by the way, I want this." It would be helpful to know up front.

DR. ROGERS: All right. We are arriving at the witching hour. Let me try a new outline out on you, and perhaps you should each write these down. Eunice, comment first?

MS. DIAZ: I have a comment on Scott Allen's idea. I think it is really important and in an underlying sort of way I think I heard June mention this too. I think each one of us knows, first of all, our time commitments, our areas of interest and expertise and how much time we can really devote without holding up this project. I like your idea of setting some very firm time dates.

Having participated with this august body in two major reports that had rewrites and rewrites of the rewrites, namely, the prison report and the psychosocial report, some of these taking almost as long as a year, I would plead for

sanity and respect for each other's work, and also with the idea of really moving things along, when it comes down to someone saying this does not have enough punch, or let's again rework the first page, or removal of writers or staff because we do not like their style etc., that we look at prudence and time constraints as something that really should underline our work.

But I think probably the thing that is most significant is what you said, which is really not so far from what Don is asking for in terms of primary review, secondary and tertiary interest. A number of us would like to be able to see a report even though we do not have the time to go through it --

DR. ROGERS: Absolutely.

MS. DIAZ: And I think that is very important. I would rather have that opportunity and privilege than you or the Chair assigning anything.

DR. ROGERS: Oh, yes.

MS. DIAZ: And our involvement in this should really come from within, not through assignments.

DR. ROGERS: Excuse me, if I used that word. It was inadvisable and your plea for sanity is very important. We

will all try and remain sane in this process.

MS. AHRENS: David, I want to understand an assumption, and I may be incorrect, you seem to be indicating that all this is going to be done by correspondence with the consultants and I would have a concern about that, if that is the case. You are not saying that?

DR. ROGERS: No, I am not. We have some more hearings. We have staff drafting things. We still have plenty of input to different parts of this. What I am going to try to do is to give you a broad-brush outline here of all kinds of processes to get to it, Diane. We must have a number of groups inputting to us and then getting our advice about how to proceed. It will be staff; it will be consultants; it will be stuff we have already done so far -- all of the above.

MS. BYRNES: In fact, Diane, we are finding that consultants are asking more and more to have smaller group meetings with Commissioners and with staff. Your suggestion about San Francisco was good. I think Pat Franks is going to talk about convening something in Washington to get some information and that would include, depending on schedules, your participation.

DR. ROGERS: Absolutely, and we should all feel free to say that we need to meet with those consultants or we want a piece of that action. I want to be as reassuring as I can that we are going to try and do it right.

Let me try a broad outline and do not argue with it.

(Laughter)

Because I think this, as Don has said, contains it but do not ask me to spell out every micro-piece of what we want in this report: One, an overview and societal issues. You have something in your packet on that now but I, for example, have said some of it needs a great deal more work.

Two, response of different levels of government -- who, and can, be providing the services. Charlie, I am trying to be responsive to all three, federal, state and local.

DR. ALLEN: Can you repeat that?

DR. ROGERS: Yes, response of different levels of government. It is kind of compressing our sections two and four together and then who and should be providing X services.

DR. KONIGSBERG: And for what?

DR. ROGERS: Don't ask me. Then I have four more: Care; prevention; research and finance. Under those broad

categories there will be different combinations of what you got in the outline. Harlon, I think that is as far as we can go. Is that satisfactory to you?

MR. DALTON: Yes, it is. This is just a minor question, should we put care, prevention, research and finance before what the response has been?

DR. ROGERS: Absolutely. I was not giving an order or priority here or how the thing would be put together.

MR. GOLDMAN: Are you collapsing what is in section six of this into section one?

MS. BYRNES: For now for the work.

MR. GOLDMAN: Okay. That is fine.

DR. ROGERS: And then I would ask each of you to get back to staff. I am going to use Scott's suggestion here. One is, yes, I will be responsible for looking at this with great care and I am the primary reviewer. Number two is desire input. Number three is I want to see it but you are not going to get a comment from me.

DR. KONIGSBERG: David, I have a question. Should we consider a section that says something about response of the private sector? Or would that be subsumed under care? I am not really sure --

DR. ROGERS: Let's say different levels of the government and the private sector. We will wrap all of that into the response.

CHAIRMAN OSBORN: It is better not to separate them.

DR. ROGERS: Let's not separate it.

DR. KONIGSBERG: Okay, that is good.

MS. PORTER: I just want to make this clear since I am the one who has to go back and put this outline together and get it back to you, if you looked at the "White Paper," I would suggest that section one and section six would be together.

DR. ROGERS: Yes, that is what we are saying.

MS. PORTER: Right. Then the next section would be section three, what are the tasks to be accomplished? I would suggest you leave it like that --

DR. ROGERS: Karen, don't screw me up now. I have agreement here. It is going to be overview, response, care, prevention, research and financing. I will work with you. I know what you have in the outline.

MS. PORTER: I am not saying anything that is different.

DR. ROGERS: I know. We are at the end of our time

and I want to get some agreement so that people do not feel that we have not settled it as we go out of here.

We will conduct the May and June meetings as agreed upon. I will ask staff to think about different subgroups to do some of the work even in the meetings that we have. We have agreed we have to have a new way of operating. We will see if that can extend to the meetings as well as putting together this final report. I will ask, Maureen, that you put before the group some additional days for a meeting in July.

MS. BYRNES: At that time, I would also run possible dates for the first or second week of September to begin to look at when we would release the report.

DR. ROGERS: Fine. And we have all tentatively bought on to something like Don has put together, which I do not think is restrictive. But read it over with care and give input to staff in terms of other things you want to add to that. I thought that was a very creative kind of memo that he put before us. Don?

MR. GOLDMAN: I have one more request, and that is of June. That is, since I think all of us agree and understand that the executive summary is a critical piece, and I

think we have all agreed that June is going to be largely responsible for its authorship, as I understand it, that we begin the process of getting drafts as soon as possible, even if there are large chunks of it that still need to be done, so that we can begin the process. I do not want to get into a squabble at the end over the language because that is the one that I think all of us are going to be very, very careful of each and every word that is in there.

DR. ROGERS: And I think there is going to have to be a back and forth there.

MR. GOLDMAN: I think if the process goes along on parallel tracks, with June developing the executive summary as we are going along, we can see how what we are doing in our own individual work groups, so to speak, might fit in and we will have a better perception. Likewise, as you see what is going on, you have a better idea as to how it works.

CHAIRMAN OSBORN: I think the idea is very good. I would slightly alter the process because I think if we have a very well developed outline of what should be in the executive summary, the exact wording is probably something that should be congruent with a fairly final report. So I would sort of modify a little bit what you said. I would not like to have

a draft of an executive summary that we start chewing on in May, and chewing some more on in June and July but, rather, as we go in any of this, small groups working together or whatever should pull out things which they feel should be highlighted in an executive summary and we could be working on what I call an expanding outline, the final language of which is where we may or may not be able to capture something and that could come in a last minute inspiration, which we would all certainly get to double-check. But I would make a little distinction between the language and the substance. The substance I completely agree with.

DR. ROGERS: June, I do not know quite how you write but would you be comfortable in starting that outline for the group? That is, here are four things that I think should be contained now?

CHAIRMAN OSBORN: I would have thought that what should be in the executive summary is the group process and the language is the part that I would probably put a unified spin on. So I think to do that would be a little bit preemptive of the process we just finished discussing. I would rather have that coming up from the groups in their discussions and then try and capture that with some language

that, with a little luck, can be memorable. As we said, if we can get one phrase that people remember, it would be nice.

DR. ROGERS: One other thought, would you be comfortable if the group began to input what they would very much like to see in the executive summary? Would you all feel comfortable in doing that in terms of feeding those directly to June so she could start that? Would each of you feel comfortable in doing that?

CHAIRMAN OSBORN: Let me suggest that that be fed directly to Karen who is overseeing all of this. Then Karen and I can be in frequent touch about how that is developing.

DR. ROGERS: You may or may not wish to do that. But, in essence, I am saying if you have things you feel intensely should be in there, write three sentences saying that here is something that you feel is critical to be in there, even before all the other work is done.

MS. DIAZ: Are you talking about the primary area or secondary area?

DR. ROGERS: Any that you feel passionately should be in there so that June right now begins to get the feeling of what the various members of the group want.

MR. GOLDMAN: Is there any format that you want the

responses in? Do the staff want to take a piece of paper and make up a form and pass it around so that there is some consistency?

MS. BYRNES: I think we need to figure out what it is you give us. I heard someone say that one is primary; two is direct input and three means sort of interested. I do not know what we are going to do with all of that. But I think we can get a sense of where you really want most of your time spent and give that back to you and share it with everyone so everyone knows who is doing what.

DR. ROGERS: If you are not able to accomplish that today, I will ask Maureen to send you those six headings with a column that will spell out what number one means, number two means and number three means so that you can get it back to staff.

MS. AHRENS: David, I think one thing that is important to know now is are we going to have recommendations in the executive summary and --

DR. ROGERS: Yes.

MS. AHRENS: -- to ask of the subtopics to look at their recommendations and select those that are key --

DR. ROGERS: Yes.

MS. AHRENS: -- and will go into the executive and those that will remain in the body?

DR. ROGERS: Yes.

MS. AHRENS: I think as we look at these with consultants, it is important to know that.

DR. ROGERS: Absolutely. Again, I thought Don handled that very nicely in his memo.

MR. GOLDMAN: Or the other way around, namely, those that can even go out of the main body and go down into the supplemental part. So it could go either way.

MS. AHRENS: If that is the case, I do not know how we write something until we know what the recommendations are going to be because the body of the executive summary has to be connected with the recommendations.

DR. ROGERS: I was simply suggesting that if you have something that you feel passionately about that you know right now should be in what June puts together in the final thing --

CHAIRMAN OSBORN: Or at any stage.

DR. ROGERS: Or at any stage, get it to her. I think we just want a continuous flow to Karen and to June in terms of things that we would want.

MS. BYRNES: To some degree, Diane, we were hoping, maybe not in a recommendation form, that some of those things would be brought out today, to bring the consultants or the authors of the chapters to ask what you really care about when it comes to care? What do you really care about when it comes to prevention? Those things need to be turned into recommendations to write too. But it is really what those individuals are looking for today. what are some specific things that you think must be included? Then the different groups can work out what the specific recommendations might be.

MS. AHRENS: And can we have more than one primary reviewer --

DR. ROGERS: Oh, absolutely. Take as many of those as you would like. My feeling is that a number of you are going to say that there are several of these in which you want a lot of input.

I think we have accomplished something here. Now I want to turn to June, who has two items that were burning issues for a number of you and I think she has some suggestions.

DR. KONIGSBERG: Just one quick question, will we

have a chance at any point fairly soon to try to get a notion of what we might want to do in the third year? Just big topics?

DR. ROGERS: I think that is an important point. I am not sure we are going to be able to accomplish it at this meeting but we definitely should. I think that should sort of be number one on the agenda for our next meeting.

CHAIRMAN OSBORN: Either that, or if you have some good thoughts, that is an issue on which I think some letter writing would be very helpful.

DR. KONIGSBERG: I will send a memo because I do have some ideas.

CHAIRMAN OSBORN: I think anybody who has good thoughts and strong feelings about how to proceed in the third year -- I am going to make a suggestion right now for the kickoff -- but I think that is something that we do want to have well in mind.

Let me just take a minute to tell you about a set of proposals that I have moved along a little bit because I think they meet a couple of concerns that were troubling people and, in some senses, causing some agitation that was not earned by intention.

The two issues I want to mention are a report about Puerto Rico and one of our small reports at some point highlighting issues that involve racial and ethnic minority components of the epidemic dynamic.

I confess, I was startled to discover that people thought we were not going to deal with the latter but, on the other hand, I suppose that part of my concern about how to go about it in my own mind had been how to do the former without tripping across a major principle that I think federal advisory groups have to maintain quite firmly, that is, that we do not come in like a deus ex machina and interject ourselves into local affairs and then leave. In the context of AIDS research it is referred to as parachute research. In the context of discussions of some of the local, regional issues as we go around as a Commission, a lot of people would like us to parachute in, comment on something that has actually been a tangled mess for years, and the chance of doing more harm than good is very considerable.

With that as a concern, I really was a little bit stymied in my own thinking. So I had some quiet discussions with people and came away reassured that we could, in fact, try and meet the expressed wish of many people to whom we

talked and who were involved in our Puerto Rican site visit for a special report of some sort.

If we are very careful and if we make it quite clear that this is exceptional because of the exceptional jurisdictional and other issues of Puerto Rico, we could avoid at least the worst side effect of having every single locality and group that we deal with want us to do likewise. That is a hazard. And I think you all have to recognize that we need to be clear in our own minds, if we proceed with a report on Puerto Rico and the issues in Puerto Rico, that we are running a bit of a risk, and one that I think we need to hold very firm on because I know that in other jurisdictions we can do a lot of harm.

I am assured that in the context of the Puerto Rican dynamics at present we can do more good than harm, and can try and avoid harm entirely with some very expert input from people.

Maureen and I talked about this and I have asked Eunice to work with Helen to try and put together what I would propose be almost like one of the working group reports. That is, not something that gets into a red, white and blue cover and goes out to the world but, rather, the

other format that we have sometimes used, a report that receives the Commission imprimatur, that is part of the Commission's body of work but is of special usefulness and interest to people in Puerto Rico and is created and crafted with that very much in mind. Eunice has indicated that that is something that she could take on and I think that would make a great deal of difference to how things go.

If and when that process is under way, then I think that somewhat eases the complexity, although it surely does not ease it much, of having a report on the issues of ethnic and racial concerns in the epidemic. For that I leaned on Harlon to see if he would be willing to work with me in a sort of collaboration to try and oversee a report somewhat more analogous to the smaller reports we have done, and then seek some help, perhaps asking someone like Raoul Magania (phonetic) to help us with Hispanic Latino issues. Raoul talked to us about special input concerning native Americans and probably finding a person from the Pacific Basin community who can help us with that, and have a report that I would propose be timed right after the comprehensive report, that is, maybe the first report of our third year.

What that would allow us to do would be to sort of

foreshadow the coming of that report throughout the comprehensive report where we would all want to make reference to these kinds of concerns because they are woven into everything and, yet, not feel that each section has to be written in great depth about that since it will be forthcoming.

The reason I do not propose doing it any sooner is that, if you think about it for a moment, if we have a Puerto Rican report that is coming through; if we have a drug report that is coming through; and we are already worried about the time available to get the comprehensive report done, it does not do justice to it to try and smoosh it too into the summer schedule.

In my own thinking about how we would proceed in the third year, it may also be a hallmark of a greater depth and complexity of issues that we may want to be taking on, having done somewhat descriptive work in the first and second year. So, in a way, it may be a signal to the world that we are going to be ambitious about what we accomplish in that year, either in revisiting old issues in considerably more depth and complexity or in taking on things that we did not think we could tackle before.

I have asked Karen and Patricia if they would help

back us up as Harlon and I take on that task, to have recourse to staff as we need it and also to have some additional input of people who have been closely involved in all of the hearings. We would obviously take advantage of other people's input as well as we proceed.

I hope that sounds okay to you. It is something that I have talked through with a number of people who thought that sounded like a good way to proceed. I think if we have that plan generally agreed on, we can alleviate some of the tension, particularly what I thought was some quite misplaced tension about whether or not we cared about some of these things.

Any comments or concerns? Eunice?

MS. DIAZ: Are you saying then that these two auxiliary reports, the one on Puerto Rico and the one on racial and ethnic minorities -- some of that content or bullets from that may surface into the report that we are now preparing?

CHAIRMAN OSBORN: Yes, as a matter of fact, it is almost a reverse process in the context of the racial and ethnic minority part. The bullets might show up in the comprehensive report with something coming later. For the

Puerto Rico report that could be discussed as we go. There are certainly some things about Puerto Rico that I think should surely be part of the comprehensive. I do not see any reason to tie the timing. It could be done exactly the same way. Or it could be that in terms of a sense or urgency you feel that you may want to go faster with the report that is useful in Puerto Rico. That is a bit of a separate issue but this does not mean that one extracts those issues from the comprehensive report. It just means that one can deal with them somewhat more telegraphically because there will be more coming.

If there is general agreement on that, let's break. Excuse us, all of the people who just came in. We are a little bit late but we will get to it pretty quickly. Larry, did you have something?

MR. KESSLER: I was just going to suggest that in June we set aside some time to talk about a communications strategy. If people, in the meantime, could start thinking about ways so we can support Tom, June and David in terms of how the report gets disseminated, what vehicles we use, what formats, what sites, whatever -- you know, I think the more creative we can be, the more contemporary and so on, the

better not only in terms of getting the message out and getting people to hear it but also in building a base so that people take us seriously in the third year.

My biggest fear is that we will put two years of hard work into a report that will be dead in 25 hours. We do not want that to happen. So I think we have to be a little bit more innovative, expressive and creative in terms of a delivery system, and it might be something more than a one-shot event. So if everybody could think about vehicles, formats and so on, we could devote maybe an hour in June at the meeting to strategize on that.

DR. ROGERS: Let me just respond because I think that is absolutely critical and there are a whole bunch of groups out there that can help us with this who know a great deal about it and that Tom could help recruit. We should spend a lot of time on how we get to our audiences. Absolutely.

We will break and we are going to rearrange things again. We have sort of had a more intimate Commission session. We will move that table back and bring other people up to the table.

(Brief recess)

CHAIRMAN OSBORN: Let me ask everyone to take their seats again, please. Molly, thank you for your patience again. Let me let you lead off the discussion. Everyone is eager to get a sense of where we stand with each of the consultant inputs and so forth and to react so, Commissioners, here is a good shot at that.

DR. COYE: Thank you very much. First of all, even though this is, just as an outline, much too long already for what we will finally write up for the report, I have to tell you that I have already gotten a lot of additional material, most recently from NACO. So there are even additional points and criticisms that are not on the papers in front of you.

But I see the task this morning as considering your own experience and what you know about the functioning of government, with an eye of selecting the themes and key points which you would like to see emphasized in the final report; really pointing out the ones that should not get cut, that are terribly important; where you see common themes that unify a number of different specific points, trying to characterize those with a particular slant the Commission would take on that issue; to point out areas where you have questions or disagree.

Much of the critique of the function of government stems from implied assumptions about how government should work. Some of those assumptions may not be shared with the Commission and it is important to point that out. Or there may be, in fact, factual errors in here. As a matter of fact, there are a couple of places where I incorrectly characterized the nature of government work on a very specific point. So I will be talking with lots of people in the agencies to make sure that I do not do that. But if you see errors, please point them out.

Point out things that you do not agree with or that you are not sure of and add additional themes or points that you are interested in seeing included.

I think that the next task after this discussion, working with the members of the Commission who expressed interest in this area, will be to write a narrative version which will only be able to incorporate, at a guess, something like a third of all of the material you have before you. That is why this job of paring it down and selecting the most important themes is so important now.

I want to talk for a second about what we mean by functions. Structures are pretty easy. That is sort of what

your budget is and what your administrative organization of the various levels of government is. I think that is fairly familiar to everyone.

By function, what we wanted to do is to focus attention not, for example, on the particular federal policy with regard to the promotion of particular prevention approaches, but how the federal, state and local government organize and work as machines to deliver the prevention message and to actually achieve prevention of transmission.

So the issue of whether federal, state or local branches do evaluate their prevention programs and whether they do disseminate, that is grounds for consideration. What I have tried to do is make an initial stab in saying whose responsibility that currently is considered to be. Please understand that the way I have listed responsibilities among federal, state and local is not my personal opinion of where they ought to be but my best guess of where it is currently assumed that the responsibility lies.

There is some quite strong disagreement in some of these areas. For example, on the issue of whose responsibility a surveillance system is, you get an entirely different answer asking federal, state and local government.

A lot of times the functions are identified by nobody wanting to do them, such as guarantied access to care. Unfortunately, local government winds up with that falling on their shoulders a lot of the time. Epidemiologic surveillance is one of the few areas where everybody steps forward and says that they have the primary role.

So I welcome your comments on the assignment of functions. If we can do a good enough job of that, I think it is a useful contribution for the final report to make a stab at defining these functions because, in part, that helps to identify not only ones which are not being done well or are being done well, but ones which no one is taking responsibility for right now, if the Commission thinks that someone should be.

I would point out before we start that the reason probably a half to two-thirds of the material addresses federal structures and functions is that I found it almost impossible to characterize state and local efforts, structures and functions simply because of the variety. I welcome help, as I have already gotten some from NACO, in trying to do that. But that is going to be one of the hardest things, to make state and local government not feel that the Commis-

sion ignored them but simply to understand that it is very difficult to make the kinds of explicit statements one can make about the federal government because there is only one federal government, at least we think so.

(Laughter)

The last point that I wanted to raise before we start is to point out that in the enormous array of needs that you have identified for addressing the HIV epidemic and all of the policies and programs and efforts and leadership needed, only some of those are probably things which government does do. Probably not all of them are things that government should do, although a lot of times there is an assumption that just because you have identified a need the government ought to step in and do it.

So a part of the consideration is not just which level a function should go to but is it an appropriate function of government. If it is not, why not? Sometimes there are functions that are appropriate functions for the government and government will not do. That is also an opportunity for the Commission to comment I think.

So with those initial comments on orientation, I think we have a very short time to talk about the entire

structure of government in the United States with regard to the HIV epidemic. So I would welcome your comments.

DR. KONIGSBERG: I have a number of comments. First of all, Molly, I really appreciate the effort that you put into this beginning. I think it is a good beginning and I share your frustration in trying to characterize state and particularly local health departments.

We have an interesting public health system in this nation that is hard to characterize. That may lead us to something. I am not sure where that will lead but right now, as the social workers say, we have to start with where we are, or something like that. I would agree.

You made a comment somewhere in the report that you wanted to do what I would characterize as kind of a governmental organization and function 101, and I think that would probably be a useful thing to do, although not perhaps in great detail.

I think it ought to include, not only what we characterize as state and local health departments of the public health system, but also public hospitals and other public entities that are involved with that governmental response.

I would encourage the report to use the IOM report on the future of public health as at least part of the framework, not necessarily the only framework. We did have testimony from Dick Remington, back in September, and it may be useful to look at the three major functions of assessment of policy, development and assurance and see how well we can characterize the response of state and local governments.

During the break you mentioned to me the wide variance in local health departments. Actually, it is true for state. In this nation local health departments vary from none at all to highly sophisticated, with every gradation in between. That is within states. It is a crazy patchwork of things. For some of us from the midwest, it is a particularly crazy patchwork. In some cases the states have strong control over locals. In other cases, in the midwest, perish the thought as far as the locals are concerned.

I think the legal basis for the role of government -- I know that can get kind of dry, but state health departments have the primacy for what is considered public health functions throughout each and every state, probably territories as well, on what they delegate to locals. Again, that is a patchwork and what is called an official state

health agency varies from state to state.

But I think when we start holding particularly state governments responsible, we need to look at what their functions are. Many times the statutory authority reflects communicable diseases as characterized in the 1920s and 1930s and 1940s and does not say anything about medical care and insurance. It does not say anything about chronic disease.

I, for one, think that probably most state health codes need to be updated. Lord knows, ours in Kansas does. And some states have done that. Maybe that would kind of help clarify the issue.

I think the report ought to be frank about the weaknesses as well as the strengths and I think this Commission did see some strengths in local government. I do not think we saw much on the state response. It kind of hit me this morning that that is an area we ought to look at, David and June, for the next year. I do not think we really looked at states. We heard testimony. Maybe we do not know how to look at a state. I know how to go to a local community, as we did in southeast Georgia, for example, or in Macon. I am not sure how you go to a state. But we ought to find a way so that this Commission has an understanding of what we

expect of state government.

CHAIRMAN OSBORN: That is an interesting idea. In particular, we might look at the unevenness issue, going into that a little bit deeper. I say that right now because it would make it easier to write this part of the report if we simply said that there is an unevenness without trying to detail it too much. But that is something that could take a little additional depth as to how very uneven, what the manifestations are and how it plays out for people. So that is an interesting suggestion.

DR. KONIGSBERG: Yes, I think that is good. I think I will stop at this point. I have some specifics but I am sure others will want to comment.

DR. ROGERS: Again, Molly, a very nice job. We appreciate all your labors. I like the sections you got. My concerns were that you might get down to telling people a little bit more than they really wanted to know. But I thought the sections that you had were quite appropriate. I like your introductory lead-in. I appreciate what you said this morning about structures, functions and budget. I think all of those could perhaps be done in a simple way. That budget piece particularly would show you who has the lion's

share and who does not.

In your sort of organization and inter-agency sector, I guess my own feeling is that one of the problems with AIDS is that it does not fit very neatly into anybody's template. It does not fit well in the academe. It does not fit well into the Public Health Service. It does not fit well into HSS.

One of the things I would like to see you perhaps do a little bit with is that part of our problem is that at the highest level we do not have any mechanism for getting cooperation between really different cabinet levels that need to be involved. For example, it "ain't" all Lou Sullivan's. It has housing. It has civil rights issues. It has Thornberg issues. It has Department of Defense issues. If we could think through some way so that these levels talk to each other or could coordinate their activities better, I think that might be a Commission contribution.

One of the things I think we could play with is should there be some over-arching body that is not too political that could, in essence, recruit or get the co-operation of those differing agencies, because it is not all health without the housing, without some of the legal

protections etc. That is where we keep falling down and those guys are not talking to each other.

I like what you have in terms of who has the responsibilities and it is clear you are going to try and pinpoint these for the epidemiologic surveillance -- where is it now? Where is it falling in the gaps for prevention, for services, for research? I think you are off to a good start on that. But I think you have to paint with a fairly broad brush. Some of my colleagues might disagree but I am afraid you may tell them more than they really want to know.

DR. COYE: Clearly, I am going to have to cut so much that I think it will perforce be more broad in the final version.

MS. AHRENS: I think it is an excellent start. Thank you very much for that, Molly.

First of all on the unevenness issue that Charles brought up, I think we hit this pretty hard in the first working group. If we go back and pick up some of that report, I think we articulated that pretty clearly. I think it is very important that we say that in the report.

I am always looking to make complicated things simple, which is probably a real weakness --

(Laughter)

-- but I think particularly policy-makers and maybe even the Congress can deal with things a little more easily if they are more comprehensive and maybe a little simpler.

Two things which I think are very essential to addressing AIDS in a governmental sense pop out at me from what you have constructed for us. The first thing is the disarray -- I should not use that word -- the lack of any central direction at the federal level. I think we need to address that, if we can agree on it, to give guidance to the Congress and the federal agencies that this is really essential and unless we begin to get some overall coordination. I think you said that we don't need a tsar and that is not what I mean either, but some central direction by somebody who says, "now, this is going to be the lead agency and everybody else listen to them; you're going to have to do these things."

I understand why it has not occurred at the federal level but it has occurred at a lot of local levels. Maybe because we are smaller, we do this at the local level in many instances. I suspect it is done at the state level. But that becomes a little bit more difficult.

I think that is one essential thing. We have to look at and make a recommendation on how we can put this together at the federal level.

The second thing that popped out at me has to do with how the states and locals are shored up. Some of them do not need it but most of them do. Who can come in and give the kind of technical -- and I mean in a broader sense -- technical support information to get the states and particularly the counties to get on with this and to do the necessary strategic planning that needs to be done.

I think that the feds and the states are pretty good at coming in and providing the sort of scientific technical kind of stuff because that is what they are comfortable with. That is, how you do surveillance, for example. I do not think they are very good at understanding motivation and motivation is what drives locals to do something. Unless we try to find ways to motivate the leadership, a broad cross-section of leadership in states where it is not happening, and especially in localities where it is not happening, I do not think it is going to happen. Unless the state comes in and says that they have to do it, they are not going to do it.

We are not very good at thinking in those terms. Feds are particularly not good at thinking in those terms, and I have to go back again to counties because I think they do not know we are out there. They think state. The republicans always think state because it is easier to deal with. It is easier to deal with 50 than 3000.

But in so many areas of this country it is not the states where the rubber hits the road; it is the counties and in some cases the cities. They think cities. I do not know why; it must be historical. But they do not think where the action really has to take place, where the leadership has to take place, where the money has to come out or the coordination has to take place.

So you get community-based organizations that are absolutely frustrated because these dumb county commissioners do not understand anything. They are not planning; they are not doing their job. So the community-based organizations are struggling out there to do something. They generally do not have the capacity to do it. They do not have the power to do it. And we need to put a thing together that encompasses the entire community's leadership in developing a plan and then a way to march in terms of implementation.

That is sort of my speech for the morning. But those two things very clearly speak to me, the need at the federal level; the need at the local level; and how we come at that.

DR. COYE: If I could just give two replies because I think that is very helpful and I would like to ask a little bit beyond that. On your first comment about the lack of central direction, I think one of the things I observed in trying to look at function across the federal level, as something I am familiar with from the state level and do not know so much about the county level or city level, is that most of the coordination is within the health agencies or between health agencies and private sector health providers rather than across government outside of health, into housing, justice or correction and other agencies.

So one of the points in here under the initial analysis of structure is the point you were getting at, David, about the failure to cross over those lines at the federal level. It certainly is a problem at the state level.

So one of the major themes that you are suggesting then is that because the HIV epidemic goes so much further than simply being a health problem, it cannot be addressed

functionally without structure and organization and work that cuts across outside of health into these other areas. And leadership and plans have to come from and go beyond the health agencies. Even if the result is to make the health agency the lead agency in many cases, you need an umbrella leadership of some kind. Is that a correct synthesis of the point?

DR. ROGERS: I hope so.

DR. COYE: Okay. Then the second thing is on technical assistance. I just wanted to give an example because I think this is sometimes hard for people who are not working in government structures to understand beyond just telling someone to do a cell count in their lab or something. If you think of the analysis that Karen presented yesterday and imagine that being boiled down into a spreadsheet as a format for state and local government to analyze the implications of making different decisions at a state and local level of investing resources, in other words, if they did a state only Medicaid program and put so much money into Medicaid, or they tacked on so much money onto Medicare and they put in their state epidemiology information and could look at what the consequences would be of resources allocation

decisions, and there were a team of people to come out and work with them on making those decisions, that is an example of the broader kind of capacity building and technical assistance that somehow I think we need to make real in this document.

The way it is right now is that usually technical assistance attached to a particular funding stream for how to apply for grants and how to comply with the requirements for reporting, which is a much more narrow version of technical assistance.

MS. DIAZ: Molly, I too appreciated the thoughtful way you have gone about outlining some priorities for this part of the report. I have three very brief comments.

I could not stress enough the need I see, and I think it is reflected here, for some coordinated agency efforts in technical assistance. You and I both served on the HRSA advisory group that has also advised that agency to look for some integrated way of delivering that assistance that makes sense to those governments that are really at the front line, whether they be state or local.

My second point is that I feel that within this part of the report we really need to see how the functions of

government can be tied into regular planning processes of government that are outside of HIV and that can complement what we need to do in the HIV epidemic. I am thinking of the goals of the year 2000, and any other kinds of things that the federal government or state governments may be doing to help plan for the people of Massachusetts or California where HIV is a component of that, so that we can look in totality at the health of the people and the response of the government and the function of the government within that arena.

My last comment is that I hope there will be highlighting that private or voluntary efforts enhance or provide role models for partnerships in addressing the AIDS epidemic, both at the local, state and federal level. We have some very good examples of where those things have worked so possibly highlighting that within the report in some way that it gives the individuals reading it the point of view that government alone many times cannot, whether at the federal, state or local level, fill the bill, and here are some very excellent ways in which gaps have been really narrowed by the joining of voluntary or private contribution.

DR. COYE: Let me just follow up with a question. The last two are especially helpful. The one about tying in

with other government planning processes is something I had not thought about. I think it is a very accurate point. The whole budget cycle process --

MS. DIAZ: Exactly.

DR. COYE: One of the issues is whether we would want to suggest that consolidated budgets for AIDS be developed, not only at the federal level but at the state and local level, so that you can look at cross-cutting investments in AIDS across different agencies.

On the third point about highlighting private and voluntary efforts as a government function, I can think of three things government can do. We have talked about technical assistance. For example, there is not enough for CBOs so that they can get their management into shape in some cases. Another is dissemination of successful models and fostering development by giving seed money for the development of CBOs --

MS. DIAZ: Exactly.

DR. COYE: If you think of any other functions, or if anyone else does, where government can be fostering private and voluntary work more, that would be very helpful as functional approaches we could be encouraging government

to do.

MS. DIAZ: My thought was along the lines where government has served as a catalyst to really bring this partnership about. I think we need to have the spirit of Ryan White and what that piece of legislation was enabling government and communities to do together on behalf of this epidemic. I was looking more at the catalyst type of function of government.

DR. COYE: Okay.

DR. KONIGSBERG: Leadership, leadership, leadership -- that keeps coming up. I have a theory that if leadership, and I will just say it for state and local health departments but it applies to anything, if leadership was good before AIDS, it was good with AIDS. If it was poor before AIDS, it was probably poor after AIDS.

There are a few little problems with that but I am just basing this on anecdotal type of observations, particularly in the State of Florida. Those variations that we talked about do not always apply to simply the size of the budget.

Now, how do we get at that? I think a good point was made about the more sophisticated types of technical

assistance that are needed which, by the way, does not only apply to AIDS. I will give one positive example of something the CDC is doing that has not been tied to the AIDS program. The CDC is working on trying to come up with a way to help state and local health departments with the strategic planning process, which would complement what is done with year 2000. Jim, I do not know if you are even necessarily aware of some the stuff some of those people are doing. It is a very interesting and new role for CDC, almost a shockingly new role and a very good one.

We need more of that type of help in leadership development -- that is assuming leaders are developed and not born but that is another whole issue -- the analytical type, the assessment type things and planning because most of what we get is still directed programmatically.

Capacity building is really a better word than technical assistance. Unfortunately, the rhetoric from the CDC director about capacity building for state and local health departments and the actuality has a long way to go. I do not mean to be critical but I am going to be a little bit like Diane, except that I am going to move away from the county level. I think many times the federal establishment

forgets about the poor backwater midwestern states, figuring that our statistics look good; we are all real healthy; we are probably growing a little too much corn and wheat and worry too much about cows. There really is a problem with that and this is not an AIDS issue, although the Ryan White Bill gives a little bit of a microcosm.

We need to even that out. For example, CDC needs to figure out a way to modify the EIS program to benefit all the states that need it and some localities rather than purely a teaching program. There is a major difference in philosophy between what I just said and what is done. And that is just one example. Yet, the planning is positive.

But I guess the word technical assistance is not the right one; it is capacity building for state and local health departments. I think there is a role for the federal government along the lines we have discussed.

Then there is a role for states. The ability in my state to assist local health departments in the same things is not very good either. It is something that we are working on. Again, it is not just how to counsel in a testing and counseling site but how to organize your community, for example, or do community assessments; how to do planning. If

we do not do a very good job of it, you can bet we are not translating that to the local level.

How do we get all that down? When you look at inadequate responses to AIDS, it just follows that if there was an inadequate response to a lot of other things, there is probably going to be a lousy response to AIDS. I think that is just common sense.

MR. DALTON: Two points: One, you have four major functions of government. I guess I was curious about education. Perhaps you are conceiving that as being part of prevention. But I at least want to raise the possibility that there might be some advantage to separating it out as a totally separate function, including educating the public to respond to this epidemic in a caring and compassionate way and to people who are infected in a compassionate and caring way. So that is just a thought. There are some important things that get lost if it gets folded into one of the other functions.

The other point I wanted to make actually comes from Patricia of our staff. She buttonholed me in the hall and she said it is sort of the buried lawyer in her. She pointed out that the judiciary is part of the government and

I do not think that as a Commission we have focused on the role of the judiciary. I am not quite sure where it would fit into our overall report. But here is certainly one place that the judiciary has performed a function in sorting out how we, as a society, respond to this epidemic. I have not kind of worked this out but we have all sort of forgotten the story of schools in this country because, in fact, the judiciary has done really quite a fine job on that issue.

But also the whole issue of individual rights of responsibilities, which we may not think of as a government function, but if you think about the tort law or criminal law and how we deal with the duties that one person owes to another with respect to sexuality in this country, for example, that is a role the judiciary has played. The rights of healthcare workers, obviously, is an area in which the judiciary has been asked to step in.

So just some sort of thought on that. I have no idea how it comes out in the wash but it is the third part of our tripartite system of government.

DR. COYE: I think that is very important because, frankly, I think I sort of slid over that and started thinking of Department of Justice in corrections. I was

thinking mostly of corrections rather than the legal role, the judicial role that you are talking about and I think that is an important function and it exists at all three levels too.

CHAIRMAN OSBORN: If I could point out, this is an area that is of sufficient importance so that that too might be part of something we think about for our third year's involvement. If that were done, then it too could be foreshadowed in the report without second guessing ourselves, if that is done carefully. I think it is a very important area that we have not actually gone after yet. Probably it would be quite timely in the third year to have some major commentary about that because earlier on the law was not quite as far developed to comment on as it will be by then and, by and large, there is a lot of positive stuff that can be said to counterbalance the correction issues.

MS. BYRNES: I wanted to comment on the idea of a consolidated budget. I was kidding Molly about this earlier and said that there is a reason why there isn't one. It is because the Senate Appropriations Committee said no way, no how for three years in a row.

I want to remind us that for at least since I can

remember, 1980, to consolidate meant to cut on the domestic side of the budget. Whenever you pulled things together for very good planning and policy reasons, it often did not result in just doing away with overlap; it meant an opportunity to see a big number that you could easily cut. There were reasons why I think many of the strong supporters, at least at the federal level, tried to keep that as not being one big number that looked as if we were spending a lot on AIDS compared to other disease, which they did not always calculate in terms of care, treatment and prevention numbers. They would often compare it to research.

I think the other concern I have is that many of us are trying, while we move in a way that helps us look at not overlapping, better coordination, clarity at the states and local, but at the federal level, again, even just in the last fiscal year cycle there was that sense of "why are you here for Ryan? Didn't I just give you 1.8 million dollars?" and no real understanding that there were very little care dollars in that number.

So I think we have a ways to go in educating at least federal policy-makers, and I suspect at the state and local level as well, about what all goes into that overall

number in terms of care, treatment, prevention, research, reimbursement -- that it is really pieces of a whole and not just one pot that dangles out there as though it were AIDS money compared to some other particular community or disease.

It may be the time to think about a consolidated budget and I hope we would be the group that could make clear what that means and why you would do it. We are going to watch very carefully that this does not provide a nice, happy opportunity for people to take an axe to some monies that maybe now need to be folded into all those different areas and functions that you outlined. But I would tread very, very carefully in this area.

DR. COYE: Yes. There are certainly some areas in the report that I would identify as ones where I am not sure I know all the implications of some of the things that people have discussed as potential solutions. Either now or at the June meeting, certainly, some of these things can and should be substantially revised.

MR. KESSLER: Along the lines of the issue of leadership and also consolidation, I think there is an area that we might develop. That would be the consortia model in terms of state, county, city and local CBOs working together

in partnership, either through a consortium model or through a contract model.

I know you have had experience with that in New Jersey and we have had it in other parts of the country. I think there are a lot of things there that we could highlight that are favorable, and some that maybe are not so favorable. But it is one way to talk about cost savings and to talk about deficiency, to avoid reinventing the wheel or even in terms of a quick response.

As we have gone around the country, this is of particular interest to CBOs and to minority agencies, agencies that are worried about the process vis-a-vis block grants and how they get out of the process rather than being included in the process. So whatever we can do to spin that might be very helpful.

DR. COYE: Yes.

MR. GOLDMAN: The one thing that at least I have observed in terms of how a community responds to AIDS and HIV disease within it I think is really dependent upon two factors, one of them being the issue of leadership and the other one being the question of planning.

I think leadership goes beyond the health depart-

ment. I think that is the important thing that somebody said before about health maybe being the lead agency involved but it goes beyond health issues. The same thing is to be said for leadership. Leadership of the local public health department is not necessarily sufficient to represent the community response. The issue has to go beyond that. I think we ought to say that that, in fact, is a necessity.

The other thing that I would suggest is that in terms of the strategic planning process at each level of government, which I think is important to be done, that that strategic planning include in addition specifically how that planning interacts with other government agencies and the private sector. The state plan has to deal with the issue of how it interacts, number one, at the federal level and, number two, how it interacts with whatever the local level is, whether it be local health departments or community health departments.

Likewise, at each level, each of the different plans that are developed ought to deal explicitly with that issue of interaction and how they plan to do it. And there ought to be some inclusion in that planning process so that, for example, if a state plan is going to include questions of

interaction with the feds, then somehow or other input of the feds ought to be part of the same plane. Typically that is not done. Everybody is out there in isolation developing their own little plans without really ever dealing with how they are interacting with each other.

By insisting on that process of communication, you can deal with some of the multiplicity of formats in which health is organized in the country. You do not have to deal with the issue of whether or not counties, state, locals or regions, districts, or whatever the case might be. The question is how they are interacting with each other and do their plans include representation of each other within that process.

DR. COYE: If I could ask you a question, I want to go back to what Larry had said before because I think it also ties into the planning thing a little bit. In the New York experience -- I do not know whether it was the State or the City that came up with the document that was so big -- one of the things that was difficult -- you know, I have had a lot of discussions with people at different agencies and the private sector trying to get this far, and one of the things that everybody kind of rolls their eyes about is planning. I

think that what Ryan White is trying to do is institutionalize in a number of cities what has worked in a couple of cases for developing consortia and developing the private-public partnership, and trying to bring people together to make plans, as well as to allocate resources and to actually run the services.

How would you describe the most effective way of planning in that regard, and how can we communicate that what we are talking about is not necessarily the kind of thing that makes everybody roll their eyes but, actually, is something that is a form of leadership that is very important? That is not a very articulate question --

MR. KESSLER: Yes, I think I know what you are after. One of the problems is that so often people come to the table as an afterthought. So they come as adversaries rather than having government initiate a process by which they throw out the net and say come to the table; let's work together; let's develop a plan and a process that is inclusive; that is comprehensive; that really takes into account the diversity of the community. So that is a leadership strategy and they have to be firm but also very open to understanding that probably in the early part of the

process there is going to be criticism; there is going to be doubt; mistrust and so on.

So, in a sense, there is technical assistance needed at that level as well for the conveners, the government, because it is so often defensive and this is a new role they are being asked to play as the convener and builder of a new kind of consensus.

In the states where it has worked it has been partly personalities, people who have been more open to change and thinking in inclusive terms. I do not know how to say that politely but that is part of the problem. If people have such tight ownership or if they do not value community input and do not value the diversity of the community, then they are going to have a problem at the outset and then it explodes. There is a series of explosions and sometimes it breaks down completely. So a Ryan White Bill itself will not solve that, unless somebody says to another neighboring state or city or county, "here's how it works."

There may be a role here for NACO and other organizations to help people get the language down, to get the strategies developed, to hold up models that have worked so that they can all learn from one another. It tends to be

geographic. It tends to be sometimes tied to the urgency. It depends on whether you are on the second, third, fourth or fifth wave of this epidemic and what is breathing down your back; how much groundwork has been laid in the last six, seven, eight or ten years.

So there are all of those factors. I do not think I have any one solution but it is probably a combination of everything that needs to be taken into account. But the goal of partnership is the one that we would probably uphold as a value and a principle that is worth achieving and worth struggling for and, in this case, the leadership that convenes it.

You know, there is the Seattle model where they designated agencies -- what is the term they use? -- lead organizations. But someone had to say this is how it is going to be and people fall in line, not necessarily that easily but somebody also has to say, "the buck stops here and as the primary agency responsible for good government and good services, we will make some decisions. Hopefully, you'll all play." Is that helpful?

DR. COYE: Yes. I think in the end what we want to do is have narrative that describes some of this as a

process. So it is very helpful.

MS. AHRENS: I wanted to add to what Larry was saying in terms of something very specific that came out of my state, and I think is the reason if we did anything well in this area that we did it.

It goes back to something that everybody in Minnesota talks about. It is called Springhill. About 1987 or 1987, a few people, including some foundation people, decided that this was coming at us and we ought to somehow pull together. So they set up a conference, two-three-day conferences by special invitation. They went out to a broad cross-section of leadership in the State of Minnesota. They went to school board members, to city council members, to mayors, to county commissioners, to people with AIDS, to foundation people, to community based organizations. We pulled together about 125 people in a conference setting. Very frankly, they were saturated for three days with this issue, with good speakers, inspiring speakers, in small groups. Every small group had a person with AIDS and a foundation person.

What came out of that conference type is what I call motivation. I do not know what else to call it. It set

people off so that they were motivated when they went back to their respective communities and were told, in a sense, what to do. And the state health department had a lot of input into this, of course. Every county in Minnesota has a strategic plan. Even the most sort of hostile elected officials in those communities came along because there were other forces out there in those communities that brought them along.

What that has done is not only to help us to deal with this issue but it has decreased the polarization that has occurred, or would have occurred, in many of the communities around this issue.

You can have the best health department in the world and if the local elected officials do not want to listen, they will not listen. It is that whole process of using what we know about people's psyche. We have to pay attention to that because that is what drives people to do something.

There are patterns out there, and it is not just in our state but in other states, where you bring people together and things can be accomplished that way. But there has to be some assistance to help some states and localities

to think this through.

MR. ALLEN: I just need some help understanding. We have the basic outline which we were talking about, care, prevention, research and financing, as main headings, and also governmental structures. How are we going to avoid redundancy?

DR. COYE: Well, this was always an open question, whether this should be kept in this kind of organization. For example, I would see under prevention talking about particular prevention strategies, such as use of condoms or use of the public media for messages etc., a lot of discussion about that, what things ought to be used and what things ought to be tried or recommended. Whereas, what we are talking about here is not just specific prevention strategies but, if you are spending public money on prevention, how should you organize it? What should the federal government be responsible for? What should the state level be responsible? What should the local level be responsible for? And are they doing a good job, not in terms of the particular method they select but are they helping each other; working with each other; making decisions on a timely basis? Those kind of things.

MR. ALLEN: That is good. Then I have a second concern. You mentioned somewhat the Care Act. Is it possible to look at some type of analysis on how the process has been going so far? I think there have been a lot of difficulties with that and some type of examination, not in detail -- I have some deep concerns and would like to see from the government responsibility and dissemination of this plan, monies and so forth -- I think it would be very helpful since we have this opportunity.

CHAIRMAN OSBORN: Scott, actually, I had jotted that down as a very important third year topic again. I think it is almost untimely to do it yet because a lot of the conferring is just either under way or finished and it is not happening yet. So if we can touch on it, I agree it would be good to touch on it but it may, again, be one of those things that we want to put on the menu for the upcoming year.

MR. ALLEN: I definitely agree. There needs to be a very detailed analysis in the third year but also at this time to at least touch upon it and to utilize what we know so far, because I think there are a great many people who are saying, "you've put together this report, where's the Care Act in all this?" And I think that is very much on the minds

of folks and the government could perhaps use some help in this process.

DR. COYE: I think there are some very important things already in the implementation of the Care Act that have arisen that would be things you might feel comfortable saying something about. I am also co-chair of a HRSA advisory council. So Eunice and I have been overseeing the implementation. Some of the material in here actually comes from that experience of watching the implementation. I know Pat and others have been doing technical assistance in it.

So maybe for the June meeting I could have a draft of a couple of paragraphs that point out some of the problems and successes that are emerging in the early stages of that and the need to track it closely. Since we are heading into a period of such level funding, the way that is implemented is going to be the single biggest new chunk of structure and function to look at for the next period of time. So I will make a stab at it but it will be, as June said, very preliminary.

MR. ALLEN: And also the inter-agency evaluation process. We are not talking only about the planning but, as implementation takes place, what is NACO doing to evaluate

the successes and so forth -- not necessarily just NACO. But I would like to see that.

DR. COYE: I do not know if it is appropriate to say it in a Commission document but, actually, one of the best ways to get agencies to work together is to steal people from each other. HRSA hired someone out of CDC, Steve Bowen, and I think that led to a lot of collaboration between the two agencies.

MS. BYRNES: I also wanted to add, in addition to what you have put in here and have a capacity to share with us about implementation, the pluses and the minuses thus far, that has been specifically one of the things that I had asked Holly to monitor for us. She was looking at implementation of the recommendations of the Presidential Commission, what, if anything, has happened since President Bush's speech, and what is happening with the Ryan White Bill. She may be able to share some of those things with us later this afternoon and she also has been working with Molly to make sure that some of that was included.

MR. GOLDMAN: I have two questions. What is the 80-20 rule?

DR. COYE: It basically says that 80 percent of

your problem is usually concentrated in 20 percent of the geographic area, the population, or whatever. It is sort of the Willy Sutton principle.

MR. GOLDMAN: Okay, fine. My second is just a point, and it is sort of self-evident I think but, at least in terms of a principle, I have found it useful to consciously think about it. That is, in terms of getting groups together, whether you are talking about communities or even smaller groups, generally speaking, you have success when the members of the group believe that getting together benefits all of them and when the group believes that failure to get together is the worst consequence. When you put those two together, the group, it seems to me, has a better chance of getting together.

The implications for that are that you ought to set up government structures in which those kinds of things, in fact, are true. That is, if they get their act together, then all of them benefit and, in fact, if they do not get it together, then there are adverse consequences. In that way you encourage people getting together.

DR. COYE: That has some very interesting implications for, for example, budgetary controls and issues like

that. It would be interesting to tease that out a little bit.

MR. KESSLER: In Boston we have had the phenomenon of having the city, the state and the local CBOs exchange staffs. I can think of 24 or 30 people who have moved between those 3 layers, and it does help tremendously in negotiations, in the contract process, in the planning process etc. Rather than see it as unfair competition, we see it as a collaborative way to keep the dialogue going. That horizontal movement, and vertical at times as well, has helped a lot in the Ryan White process. It has helped a lot in our approach to public policy issues in the state and in the city.

DR. COYE: In terms of capacity building for CBOs and development of leadership among the affected communities, that is something that is very important potentially. One of the things that really puzzled me is that I do not see a lot of good examples of development of leadership and professional training going out into the minority communities and into the other affected communities.

So if you posit that as a potential function of government, it is just not happening. There is not even anything going on to critique. And that is sort of like in-

service training if you hire people and develop them in the job or if you have exchange programs. It is one way of doing that. I had wanted to raise that as one of the areas of minority and affected community where I feel that there are not a lot of good models for me to draw on in order to propose what government function ought to be. I see the role of this chapter as critiquing what is currently going on, not making any recommendations. That would come more at the end of the document. But there is nothing going on to critique. It is a big concern to me.

MR. KESSLER: There is discussion, however, and I think that is encouraging. At the national level, some of the CBOs have begun to discuss sort of a lend-lease program with each other of sharing staffs to get a broader technical assistance base.

But even in Boston, we have assembled now six agencies, not all AIDS agencies but six human service agencies of relatively the same size. Their board chairs and their executive directors will be meeting in July to begin a process to design something along the lines of almost a Kellogg Foundation response, where we would collectively try to resolve some of the diversity issues because we are all in

the same boat.

Finding people to come in and then move up, develop their skills and so on is a problem, regardless of whether you are in AIDS or in housing or in child welfare. Part of it is due to the problem that we have in Boston because Boston is such a tight town and segmented in many, many ways. The other is fear on the part of many people of getting involved in human service agencies these days as the budgets get pulled out from underneath them and because they are viewed as high stress and low pay, whatever. We want to look at all those kinds of things and try to figure out a strategy for recruitment and retention and development so that people would then start notching up. But that will require an agreement that we will be able to share those staffs, that when someone moves, maybe not even within the same agency but a vertical move to another agency but with that zig-zag approach there would be more of a cooperative agreement rather than a threatening, competitive type thing.

But here I think there is a role for government as well to seed the kinds of institutes and seed model programs where it might benefit a lot of people. It is more than technical assistance; it is job training, development of

skills and really retaining human resources.

DR. COYE: Yes, it is our version of "a thousand points of light."

MR. KESSLER: Right, and we do not have an unlimited source for those thousand points.

MR. GOLDMAN: Larry, that kind of function that you are talking about has traditionally also been a function that has been assumed within the non-profit voluntary sector in terms of training programs. If you look at the leadership in communities in other health-related problems, you will find that that precise form of leadership training, conferences and things like that are done by the voluntary sector. It is what used to be done by NAN (phonetic) before NAN went under. I am not sure that it is necessarily fair to say that is strictly a government function to do. It is certainly not a government function that has traditionally been done in other arenas very much. I think it is a problem in terms of assigning it as primarily a government function. It has not really been done in other arenas and the government does not have a good track record or level of experience in having done it in other arenas.

I assume that somewhere out of these materials, at

least by the next draft of it, there will be included within it recommendations. I assume that in this exercise we are not merely identifying problems and leaving them hanging without having some recommendations to include in our report.

DR. COYE: Let me address that first and then go back to your first point. Definitely, this should lead to recommendations. But our thinking in the initial discussions with June, David and the staff of the Commission was that this was laying the groundwork. Then we would go through prevention, research and all these other pieces. Each of the other chapters would have their recommendations for what should be done in prevention, done in research etc. Then at the end we would come back and pull these pieces together and say, well, if you were to implement the recommendations in each of these specific chapters, taking into account what we said in the beginning about the current function of government in the face of this, this is what would have to change. So you would conclude with a series of recommendations which would say that in order to achieve and implement the recommendations under the content areas, we need a major technical assistance, capacity building. We need coordination and planning that goes beyond health agencies and cuts across

into the private sectors as well as into other government agencies. But those would be more resounding if they come after this whole series of things rather than having recommendations up front, before people have seen what the specifics are.

MR. GOLDMAN: Okay, but that does not mean that you have to wait until July and we have finished with those before we start --

DR. COYE: Oh, no, no. We can talk about the recommendations now.

The other thing I wanted to say about your suggestion is that, actually, there is a very good kind of model which I could use in this, which is that basically many states have their local Lung Association and the Thoracic Society which is the health provider professional association involved in evaluating state programs for TB control. CDC is in there. So you have federal and state. You have local cities that are affected. It is often organized by the private sector and sometimes under contract to the private, not for profit voluntary associations. So I think there is the Boston model, that kind of model and some very interesting models in that area.

DR. ROGERS: Just picking up on what Don and Larry had said, it is perhaps worth your knowing, although you perhaps already do, that I guess it is the National Leadership Coalition on AIDS and the National Community AIDS Partnership and so on that have had the same sense of urgency about the absence of leadership; the absence of trained personnel -- the sort of thing that Larry has done in Boston, developing a kind of training program to do just that. They are trying to do it across a number of community based organizations that are rather national in scope.

Don, perhaps one of government's functions might be to be attentive to that and to fund those kinds of efforts which are a little closer to the local scene in terms of training people for the kinds of roles that are increasingly important in terms of what we do with AIDS. That might get you off the hook, Don, in terms of the government not doing this, but these groups do and that they might be responsive, as they have to many of the things that have been community initiatives, but responsive to training programs that are an effort to fill that gap that we have there.

MR. KESSLER: I would say not only that but to join in partnership because the states and cities actually have

some of the employees who have great skills, but with additional skills and with encouragement could make a move, even if they were granted leaves to go to work within some of the CBOs for three or four years to help build up the infrastructures there, and then go back to government and not lose their seniority and not lose their benefits or their pension, things like that.

Recruiting fresh out in the community is difficult right now because of many problems -- homophobia, racism, tight economy, all of that. People are afraid to make moves. That leaves us with little to work with sometimes when we are trying to address the issues that the minority communities are so concerned about and you have white power structures in these non-profits, basically to-heavy with people who are not people of color.

There may be creative solutions here that government could be part of and that would be very helpful, and I am talking about all levels of government.

DR. COYE: If I can just add, I think this is a very good example of pointing out an area where government may not be the solution or all the solution. It may have to provide funds for private sector groups to do parts of this

and then work in partnership, as you are saying.

I think that the credibility of the proposal will be very good if we point out areas in which there is a real need to go beyond a solely government function.

MR. GOLDMAN: I agree with that. I did not want to suggest that government has no role in this process. In fact, in many other arenas, at least historically, there was a period of time when the epilepsy movement was in a rather extraordinary degree of disarray and, in fact, there was HRSA funding of various means of convening the actors in that arena so that they could get together and get their act together. There have been other arenas in which government functioning has, in fact, gotten people together to develop the capacity, to train the people up higher. The government function typically has not gone on in terms of the hands-on local things but almost building the capacity to build the capacity kind of arena. And I think the federal government certainly has a major function to play in that area.

CHAIRMAN OSBORN: I want to be sure people have had a good chance to communicate with Molly. This is obviously not the last round but it is an important round. It looks as if people are comfortable with where we are coming out on this

discussion. Obviously, the interchange need not always be with fifteen people around the table. So that too is another opportunity. But if everybody is content, this is the right time for us to break, I think, and come back in an hour and continue with what is a very fruitful discussion. Thank you.

DR. COYE: Thank you.

(Whereupon, at 12:00 noon, the Commission adjourned for lunch, to reconvene at 1:20 p.m.)

AFTERNOON SESSION

CHAIRMAN OSBORN: Why don't we get started, please? We are pleased to have Bob Fullilove with us to lead the discussion, and Karen Porter, and welcome again. Bob, why don't I turn the floor over to you and you can proceed as you will?

MR. FULLILOVE: We do not have a great deal of time. I only wanted to make three comments about the piece that I submitted.

Basically, what I did was try to take to heart some of the comments that I heard during the period of time that I gave testimony, and take into account as well some of the notes that all the consultants received right after you all started to think about what the configuration of this final report would look like.

I thought there were three basic points that this section -- and I am separating it from the actual pros that it contains -- had to hit. Everybody was clear about the notion that AIDS serves as a prison but they were worried about overusing that particular metaphor. So I wanted to stay away from that and present, instead, a worst case scenario that focused on what we see going on in New York.

As somebody who has just moved from San Francisco, a land of milk and honey, to New York, which has, unfortunately, become something of a toilette, one could not help but be struck by how differently the disease presents itself in the two cities despite the fact that the density of cases is just about the same.

The second thing is that I was very struck by Don Des Jarlais' comments that we really have to be clear with folk that, while AIDS may be a prison that shows us how much is wrong with society, we cannot let people get away from what we can do right now. I still think that that is really critical. In thinking about some of the things that have happened in the last two days, I still think that is a point that should not get lost. As we get into the intricacies and the mechanics of figuring out how to correct a really screwed up healthcare system in this country, we do not want people to feel that they have to wait until 1998 before they can do something, as Don pointed out, that we can do tomorrow if we really thought about it.

Finally, anybody who is in this work clearly has the sense that more and more we are thinking that this is a disease that happens to other people. I think it is important

that, at least philosophically, we try, in some reasonably powerful way, to point out that if one component of the body politic is ill, then all of us face some threat from illness. We are just not protected by where we live or by the amount of money we have or by the social status that we might enjoy.

I think that is particularly important because I think to the degree that the Commission is able to rally people around a flag, issue, if you will, or call to arms, it seems to me that that is something a section like this ought to try to do.

I also think, and I will end with this, that my recollection of something that Jeff Stryker said when the consultants all met is probably worth repeating, that a commission probably succeeds very well if six months after its report has been issued people still remember, for want of a better term, sound bites that emerged from what it was that all this deliberation produced. He cited the "nation at risk" piece that was done by the Department of Education where people continue to this day to point out the phrase that said that if a foreign nation had come in and imposed upon this country the system of education we have now, it would be considered an act of war. People still remember

that. If something that we do stays with people the way that did, then I think this Commission will have succeeded beyond what certainly my wildest expectations would have predicted. That is all. Now, help and guidance?

MS. PORTER: I just wanted to add that this is really very much a section in process. Both Bob and I are up here because we have sort of put the sections together, given the comments that we got from the Commission -- you know, the sense that we got globally, but particularly from Diane and from Harlon, in suggesting that perhaps we move what had been the societal section at the very end up front to clearly state some of these things and wed the two.

I think it is a little bit of a struggle to figure out how much of history to do. It is hard to know how much of it we are adding in, particularly since we have been given some restrictions on the pages for how long this section would be. So right now what you have in front of you is not anything like what the chapter will, in essence, look at.

I think there are a few things that we are right now trying to pull together. Some of it is the history. Some of it is an overview of where we are, where we have been and all of those sorts of things, then with the global

section that Bob is producing that really focuses in on some of the societal issues, and begins to express some of these things.

But I think the kind of help that we need is just to have everybody help us to understand that it is the introduction so it also sets the stage and the tone. One of the good things about this section that Bob wrote is that it really, I think, very nicely sets out a tone that we would like to uphold and carry through the entire report. Some of the guidance that we need is just on how you would like this chapter framed. How much of it do you want to be historical? How much of it do you want to be anticipatory of what is to come in the rest of the report? And how much of an overview epidemiologically or otherwise do you want? Those are the answers we have not had in order to give you the document that would look more finished at this point.

DR. KONIGSBERG: This is really two different papers, which is a little bit confusing to me as to what we are doing. I know, on the one hand, that we want a dramatic opening statement. I would assume that. At the same time, picking up on Don's phrase of making the case and I think this is where you start making the case, putting on my public

health hat for a minute, part of making the case has to go to the epidemiology of it. How you weave that in with the rhetoric -- there is probably a way to do it.

I read all the papers and the most complete piece of epidemiology was in Karen Davis' paper. She had a team, which helps. But I suspect that most of that is there. What is not there is something that Jim Allen and others can get rather quickly. That is pretty easy to do, to characterize the epidemics because the numbers are pretty dramatic, including the stuff about the shift to minorities, to women, the shift more to middle American. That can be said without loading it up with tables and graphs.

We can put things in an annex or appendix -- I have never been sure what the difference is -- including the history. I actually found the history, the way you have laid it out, kind of interesting. Most of us who have dealt with AIDS for a number of years maybe sometimes fail to see the shifts that are going on. But that could be put in some sort of an appendix.

I think my main point is that to make the case we not only need the rhetoric and the human side but also the facts because a lot of people do not see the numbers. They

still say that this is a minor disease compared to heart disease in numbers and there is a way to characterize that to get at what that one million means and how that might grow, and make that case.

MS. AHRENS: This overview, whatever we are going to call it -- it seems to me that this is the one part of the report that has to have a lot of passion. To me, the most important thing about this part of the report is the passion that comes through the introduction or the overview.

I think there is a lot of passion in what Bob gave us. It is directed primarily at New York City. I guess my suggestion would be that we broaden that a little bit. I think we have gotten a lot of illustrative material that came through in testimony from Puerto Rico, from Los Angeles, from New York City. Maybe we can weave it into this so that it is not quite so New York centered.

I do not know if Charles is saying this but if he is, I agree with him --

(Laughter)

-- that is, that we weave also into this passion the epidemiology, the numbers, if you want to use numbers, or the

trends, if you want to use trends.

DR. KONIGSBERG: That is what I am saying.

MR. GOLDMAN: I agree with what was said earlier, with the other proviso that in terms of the overview I think we also have to talk about what this epidemic is likely to look like five and ten years from now, as best as we can. We have to talk about the future.

The future is where things are at, not where they are at today. The actions that we are going to take today, for example, in terms of issues of prevention, are really what is going to have impact many years from now. What is going to happen many years from now is probably going to happen in any event and we have to be prepared for that.

But, again, I think it is possible to be compassionate, be impassioned and use data at the same time. I do not think that they are mutually exclusive. I think we have to understand that in this particular case we are dealing with an audience that primarily, to a large extent, has to be awakened from an attitude of either complacency or not caring.

And this is the place in the beginning, where, hopefully, you are going to get them interested enough to

read the rest of it. If you lose them here because you are preaching to the converted and to an already convinced audience that HIV disease is the world's number one priority, then you are going to lose the majority of people who question that assumption. You have to really make a good case statement. You have to talk about the future and you have to remember that your audience, however you want to look at it, whether it be Congress or the President -- you know, Roy Rowland is not a typical member of Congress and the people who attend our meetings or whom we see in the AIDS affected communities or the public health system are not typical members of the public. Keeping that in mind, I think you have to do both of those things as well as possible. MR. FULLILOVE: Everybody has numbers. Each of the pieces goes into admirable depth in taking different slices and presenting in a quantitative form what the impact of the disease is going to be.

Just as somebody who is concerned with editorial issues, how do you paint a consistent picture? For example, should we all use the same data base and take different portion for it so that, for example, all of our numbers are consistent? That would help. I know in the tables that were

used yesterday the CDC estimates that are published every month are different from the ones that were used in the charts. I gather that the cases that had died were subtracted from the cases --

MR. GOLDMAN: I think in the data that were used yesterday the CDC assumes that its method of capturing AIDS only collects 70-90 percent of the cases. Therefore, they up the CDC numbers to reflect --

MR. FULLILOVE: No, they were down; they were way off.

CHAIRMAN OSBORN: They were taking out people who were dying.

MR. GOLDMAN: They were doing both things, they were adding to the CDC numbers the cases that CDC claims it does not capture and subtracting the ones that are dying.

MR. FULLILOVE: Good. I rest my case.

CHAIRMAN OSBORN: If I could make a suggestion, Bob, hearkening back again to the Institute of Medicine Report, one of the things involved a few people who were willing to read it all the way through at the end rather than trying to stay in sync throughout the writing process. I think that is something we would probably try to assign to a staff person

at the end.

Your point is exceptionally well taken and the numbers do have to line up. As a matter of fact, ultimately what the Institute of Medicine, National Academy report did was to decide to embrace the newly created Coolfont numbers because they were not identical but they were very close to the independent effort made by the epidemiology working group. It was decided that the Coolfont numbers would be more widely visible. So, rather than having to explain why it was 108,000 instead of 103,000, which is what people snag on all the time, they would do it that way. So I think probably we can do that as an editorial and polishing function, an important one.

There is one number that I use a lot and a phrase that I use a lot that you might like in terms of trying to capture the future and present at the same time, and that is, in the healthy people 2000 report the projected number of new AIDS diagnoses in that year is 98,000, projected by the U.S. Public Health Service in a thing called Healthy People. I usually add to that the simple phrase, "and those are people that got infected last week" and use it as a way into the prevention issue.

So I think a few numbers of that sort, especially given their source and so forth, can be used powerfully without dragging it all into a mire of numerical stuff.

DR. DES JARLAIS: One idea that I think is important that really has not gotten into this draft yet, and I certainly do not have the words yet for expressing it as articulately as it probably needs to be expressed, is that AIDS, as a stigmatized disease, as the epidemiology shifts to politically disempowered, otherwise stigmatized groups, has the potential for sort of reinforcing discrimination against those groups. That causes particular problems for leaders of those groups where, if they publicly identify AIDS as an issue for their group, it feeds into a lot of racial stereotypes about these are sort of bad people anyway and, as a nation, we need to address that problem of sort of reinforcing stigma and, until we do that as a nation, we should really expect to have tremendous problems doing effective prevention.

DR. ROGERS: That is a very nice statement, Don. Bob, I have a suggestion which, Karen, you have already made. I thought the societal issues part which you have written -- I wanted to preamble this by saying I want to be passionate

with Diane --

(Laughter)

I wrote down that I want to be passionate with Diane. I think the lead-in should be the sorts of things you have said in that part of it and perhaps the historical overview and the other kinds of things follow. That seems, to me, something that might capture. It ought to weave in the sort of thing that Don is saying too.

Some of you have seen the piece that I wrote recently for Africa. At the end of it I, in essence, said I am going to have to rethink one of the things that I have said for some time, which is one of the reasons for the sort of penurious reluctant response in American to AIDS, because it happened to have the misfortune of hitting two groups that were stigmatized, were disenfranchised, were disliked -- gays and drug users. But I had to rethink that because I had just been in Africa where it is an utter disaster, where I had to really recognize that this was a disease that was coming from doing what came naturally, that was perfectly acceptable, socially condoned behavior. It is a heterosexual disease and it is wiping them out. Yet, there are the same kinds of problems; the same kind of denial; the same kinds of dis-

crimination; the same kinds of fear. So I was going to have to think that through.

A couple of days ago I received a thoughtful note from somebody who said, "let me give you another thesis" -- and I just offer this up, which is that there is something about AIDS that comes so close to the value systems of many and, Don, I am just trying to build on what you were saying, that we also run the hazard of people taking this disease to make their own moral points. He pointed out that in Uganda it was being used, I guess, as a no-no for the use of condoms, for example. Or, in another area it was being used as a no-no on sexual promiscuity, and so on. People are using this disease to preach and to impose on people some sort of a value system. I am not saying this very well. I will share the letter with you, Bob. But it had another thoughtful spin to it in terms of what this disease is doing to us as a society and how people are misusing the disease against others.

MR. FULLILOVE: It certainly is happening in a lot of evangelical churches in this country.

DR. ROGERS: Yes. And we have always tried to find scapegoats for epidemics and disasters. You can take very

epidemic through recorded history and say that this group was scapegoated or that group was scapegoated. But I am not sure that each epidemic has been used as much to say that that proves my point in terms of how you must behave or what you have done wrong, or what-have-you. I think we have seen more of that in this one than in others.

DR. KONIGSBERG: Speaking of scapegoating, I read in a magazine last night that during the Black Death in the Middle Ages, in Europe, with the plague there was scapegoating of Jews who were accused of poisoning the water. So we have been around the Horn before.

A couple of things get at the New York orientation for the societal issues paper. Having been there, I keep a copy of Larry's picture of the armory in my middle drawer -- Larry, I cannot seem to take it anywhere else and I look at it occasionally. Southeast Georgia also sticks in my mind and also Puerto Rico, and there may be a way to kind of expand a little bit to kind of show the diversity a little bit without trying to do a travelogue of everywhere we have been, which I do not think is really necessary.

Now back to the tough stuff, this editorial business troubles me a good deal as to how that is going to

be done. The data need to be on a consistent basis. They need to be not repeated constantly but in one place where they can be found and repeated only where necessary. Also there needs to be close scrutiny of basic facts. I know we are not here to be editorial but some of the facts about Medicare being designed primarily for long-term care is not quite right and that is the kind of thing we need to kind of sort through.

I do not know, June and Maureen, what the plans are for overall editorial but that is going to be tough stuff and we will need somebody who is good with the data, on the one hand, and somebody else who is good with the syntax, the grammar and the spelling, on the other hand, unless Word Perfect and Grammatic IV will do all that for us, and somebody on the content itself. That strikes me as needing a team effort, as well as a single writer to get it all to sound the same.

CHAIRMAN OSBORN: On the content I completely agree with you. That has to be the kind of team requirement that we were talking about, plus interchange about it. Hearkening back yet again to Confronting AIDS, and the reason I keep doing that is because it was, if anything, a more complex task

because it was trying to take on everything from the social issues all the way over to the most avant garde immunology and virology. That is the point at which I and a couple of other people started reading every draft all the way through in one sitting if possible, because that is the only way that you can guard against either the over-redundancy of a certain number or the slight inconsistency of two.

We will probably need to find a couple of soundproof rooms to lock people like me in. I, for one, would plan to do that as the sort of final polish that either does or does not give somebody a chance to quarrel with little corners of a report when they are supposed to be paying attention to the big picture.

So I think your concerns are very well justified and "trust me" is an awfully worrisome response but in this instance I think there are enough of us who care about exactly that -- the staff is rather full of very good people at that and I, for one, plan to be doing quite a lot of too and I suspect David will and anybody else who wants to. I think we will all end up wanting to some quality control.

Your comment about Medicare is well taken as well. I think as we think about those potential hooks on people who

should be paying attention to what we are really trying to say, it will be important to accumulate our respective warnings. You can never do it really perfectly but you can come pretty close. Knowing that it is a hazard is the biggest part of the game I think. I do not know if that is enough of an answer --

DR. KONIGSBERG: It is.

CHAIRMAN OSBORN: -- but I think once we are comfortable that we are all attentive to that we can come back to it considerably later in the process if it is not working well. But I think that is where there is going to be a lot of the effort of a group of very well written and articulate people and the staff as well.

MS. BYRNES: And this is clearly no great insight and is probably how we all operate, but I am certainly someone who says that if we get the small things right they will trust you on the big ones. They will at least listen. But if we get the numbers wrong or we misstate something that can be checked out as being right or wrong, then we have lost them on the big policy recommendations. So I think we have to be particularly careful about stating what we are basing our recommendations on as being exactly right.

DR. KONIGSBERG: Yes, definitely.

DR. COYE: I do not know for sure if this is appropriate but I was a little bit concerned when you were talking about the exhortation that if anybody in society is sick, then we are sick; if anybody in the body politic is sick, then we are all sick. It seems to that one of the biggest challenges for the report is how to deal with leveling off of resources and the concentration of the epidemic among minorities, and how that interplay is working its way through society, how that is being worked out.

It may end with an exhortation that if any of us is affected, then all of us are affected. But it needs a lot more sense of being troubled looking at that and figuring out how society can pull itself out of the nosedive that it is in in terms of its response. We may preach to the converted. A lot of the people who are going to read this, probably four-fifths of the people are going to be people who think like we do, who think that we should improve our response. But what can we do besides exhortation that will sort of grab people who maybe have not thought that way and admit the fact that we have been getting worse rather than better in terms of responding to the concentration of the epidemic? And somehow

that also has to look at the spread in the rural areas and not just minorities but minorities in a different sense or maybe a looser sense.

Again, I am not being very articulate. This is not my section and I do not know the right approach to take. But I think that to bring anybody along with us on that, we would need to really spend some time making them understand that this is a really big problem that American society is dealing with right now in facing the epidemic.

MR. FULLILOVE: Yes, i would love more input on that point in particular because I certainly struggled with it. Remember, this is what the civil rights movement tried to do. It tried very hard in the 1960s to make people understand that democracy meant that everybody gets included and that it is a moral issue. I recall sitting around for years while we tried to figure out different ways to sort of present that. I see this as quite a similar kind of issue.

I am really looking for a hook, some way to present that and I am uncomfortable with exhortations as well. So I am certainly open to suggestions.

DR. COYE: I think the analogy that is very powerful is to point out that the 1990s are very different

from the 1960s because in the 1960s we thought that resources were limitless. We really thought that there was a lot out there; it was just a question of getting your piece of it. The whole world of the 1990s has the sense of limited resources and it is a very different context for those ideological struggles to be played out.

MR. FULLILOVE: Did anybody in the course of testimony talk about increasing racial polarization because that is happening in the midst of all of this, independent of AIDS? Those of us who work on college campuses are very worried about how all of a sudden, out of nowhere, it is beginning to look like the 1950s and 1960s again. You see, I think that part of this fuels it. So there is the notion again that if you raise the flag that there are diseased people in our midst, instead of getting people to unite and come together, instead, they will stigmatize, scapegoat and push off into reservations, if you will, those that are perceived to be -- I mean, I think this is the most difficult thing of all to do. I am convinced that I do not have the answer but the combined wisdom of those assembled would, I hope, help us think of a metaphor, an image, some way of dealing with this because I do think it is the most important

point we want to make.

DR. ROGERS: I have a way of dealing with this but perhaps I should check this with the rest of the Commission. This is a professional scientific opinion which varies from yours, Molly. I am absolutely persuaded that it is going to be slow and relentless that the African experience will be repeated here; that it is moving, albeit at a much slower rate, into our heterosexual community, into the teenagers. Part of my approach is to say that not only should we preach that this is all of us, it is, indeed, all of us and will increasingly be all of us.

I want to focus very carefully on the groups that have terrible burdens right now. But I personally believe that this is a disease of all of us. So I am reluctant to say that it is increasingly only a disease of these groups. I do not believe that and I think rural Georgia would be a case in point. As I see ratios moving from 13:1 males to females to almost 1:1, that, to me, shrieks of increasing heterosexual transmission. So some would accuse of trying to frighten the whole world about it, and I am because I think that the African experience is going to be slowly ours.

DR. COYE: Part of it may be how we cast the groups we see it being concentrated in. I agree with you that it is increasingly heterosexual and that there certainly is an increasing incidence in rural areas, outside the hardest hit cities etc. But I think that it will continue. I think, and I may be wrong, but my sense from the way I understand it now is that it is going to continue to be concentrated in racial minorities or ethnic minorities. Even when it goes out to rural Georgia, it tends to stay in a class and racial polarization.

CHAIRMAN OSBORN: I would argue with the word stay, Molly; tends to concentrate but not to stay.

DR. COYE: Okay.

CHAIRMAN OSBORN: I think these discussions tend to be carried on in five-year scenarios in something that is a major frame shift in human ecology and I think we need to avoid that. We really do want to talk about the human family at risk, at which point we care greatly about that part of the family that is in trouble now and that part of the family that is going to get increasingly in the way of trouble. All of the tendency to present epidemic statistics in terms of percentages is evil in my view because these are percentages

of a rapidly increasing denominator and, as such, as was said a number of times during Commission hearings, we should all care; we should all care about all of us but if we are going to be that silly about it, we can care about some of us and there is some of everybody already in something that is only ten years old.

So while I think your demographic comments are probably accurate for the next five to ten years, I like to focus rather sharply on adolescents because the thing that we have in common is a sense of our children's decision-making and what we teach them to be careful about. If we fool around for the next ten years without recognizing that sexuality is universal and this is a universal risk disease, we will have blunted all of the educational instruments that we currently have at hand that are reasonably sharp still in this country and no longer sharp at all in Africa because now there is a choice of any sexual partner. How do you use your head? How do you use the information that was initially fairly powerful in protecting you and yours from this dreadful thing? So while I think your comment is demographically very accurate, it is accurate in short term and I think that is what David is saying.

MR. DALTON: Bob, I think you are right to try to stay in focus on this because it is hard. I think I have heard several different approaches suggested. I just want to specify what I think they are and what I think at least some of the advantages and disadvantages are of each of them.

We started out talking about the exhortation -- you should care about other people because you should care about other people. That is terrific if you believe it. The downside is that it converts no one. But I think we need to say it because, in fact, I think it is the common morality of the people in this room and without it some of the other things that we, in fact, want take on a very funny -- you should pardon the expression -- coloration.

Something else that can be said is that if we do not care about these people who are predominantly infected, then there are lots of collateral consequences for you: They will get tuberculosis and they may breathe on you. They will be uninsured and you are going to have to pick up the cost. Your healthcare system will collapse. People will not want to go into internal medicine and you too will suffer. That is one kind of argument.

There is a lot of truth to it. The problem is that

it sounds amoral. It sounds as if we do not care for our people as people. It particularly sounds that way if you decouple it from the exhortation. So I have real trouble with sounding that theme in isolation.

Another argument is, well, you may not care about gay men; you may not care about African Americans and Latinos but this disease is rapidly becoming heterosexual -- a little bit of what David suggested. The problem I have with that is that, number one, I am not sure whether, in fact, that is going to be the course of the epidemic in this country.

Number two, yes, heterosexual but heterosexual blacks and Latinos. So if you stay with it long enough, you do not get out of the box of wondering whether or not people really care about people of color.

Thirdly, as the gay community has already discovered and were the first to make this argument, there were actually lots of people who, a few years back, were saying wait a second, it is coming into the heterosexual community. Among those were many gay men who sort of felt that we may not care about them; we care about ourselves. So let's pitch it that way.

There is a real downside to that. For one thing,

there is a potential self-denial involved among people who want society to care about them but pitch it in terms of the society's own interest.

We have seen the de-gaying of the epidemic, a subject about which I suspect we will hear a fair amount in San Francisco, I think to the disadvantage of the gay community and its members. So there are some problems, leaving aside whether it is, in fact, empirically the case that this disease is going to be increasingly heterosexual in whites, there are some problems with pressing that button.

There is some of everybody already. I think that is certainly worth saying, that is, there is rural AIDS, as Molly pointed out. Actually, the interesting point about southeast Georgia for me was that times are so tough that in their support groups you saw transfusion recipients and you saw white gay men and you saw elderly black women, everybody sort of coming together, in a way that we have not seen anywhere else in this country, really out of necessity.

So it is true that there is some of everybody already and we need to say that but not in a way that denies the real larger contours of this epidemic, which is to say that I think we have to bite Don Des Jarlais' bullet and

recognize that this disease always has been and will continue to be in the foreseeable future a disease that visits itself upon some of the most disadvantaged and despised in our society. And one of the consequences of that, as Don pointed out, is that for those groups to, in fact, embrace the disease is to risk stigma upon stigma and for us to even describe the epidemic in those terms is to invite that possible response. And we need to say that. We need to say that one of the real challenges for this country is to recognize that this is an epidemic that is quite disproportionately an epidemic of people of color and quite disproportionately an epidemic of gay men, of IV drug users, and we still need to figure out how to get off level funding and increase societal response along with the increase in the epidemic.

One final suggestion that has been made today, and it is yours, Bob, is the racial polarization, which is to say that one of the consequences of responding by adding stigma to stigma is that these different groups will withdraw from even attempting to become part of the mainstream.

I think there is some bite to that argument. First off, I think it is true and I think it sort of feeds larger

social currents. I think that even people who are not deep in their hearts committed to integration in society across class, race or sexual orientation are, nevertheless, quite afraid of Balkanization or afraid of Lebanization of the United States, if I dare use that phrase. So I do think that there is some mileage to be made from playing out the scenario of allowing stigma to pile on top of stigma.

MR. GOLDMAN: The point that Bob makes about racial polarization I think is a point that is certainly well made. Certainly the hearing we had in Baltimore demonstrated that at least there are substantial portions of communities that suggest that white leadership cannot speak to or for the black community and, on the other hand, as Don Des Jarlais said, black leadership is unwilling to own the epidemic and, therefore, there is no one left to speak to or for the black community.

That is a problem that I hope that you and June will deal with in your wonderful piece. I have no help to offer but I think that perhaps your piece can be shared with Bob's and that there can be some collaboration because, to a certain extent, I think that speaks to that issue and to each other.

MS. AHRENS: I heard some folks in the field of corrections the other day and they used a term which has a lot of meaning for me. That term is profound alienation. I do not know if that would be helpful to you and I am sure you have heard it. But it just seems to me that what we have here is an epidemic moving into those populations that are profoundly alienated.

It is that thing that Mary Edelman (phonetic) talks about so much. One of her favorite quotes is "hope is the best contraceptive." It means that with profound alienation there is a hopelessness. So what difference does it make? What difference does it make if we do drugs? And it becomes an economic issue and in my little community it is an economic issue; it is not a drug issue. It is an economic issue for a lot of inner city young people. So why should we change our behavior?

I think that is also playing out in a kind of blaming syndrome. It is easy for us to say if we are standing on the outside looking in, but it is almost an irrational kind of a lashing out at the institutions or the services or wherever there is an opportunity to lash out even though it does not make a whole lot of sense. But when

viewed from that kind of alienation, you begin to understand why it is necessary.

I guess we need something that kind of wraps it up. I love the saying that the only thing new in the world is the history that you do not know. But if we look at history, we do not have to look very far or back many centuries to know what happens when you have large groups of folk who are profoundly alienated.

CHAIRMAN OSBORN: Harvey, let me get you to comment. Then I am going to find out if Bob and Karen think that they are at a good spot to continue because quite a bit of the themes that we are onto now will follow through. We have prevention, care, research and response of the federal government to go before many of us start cutting and running for the airport. So I think we need to move on. I kind of regret it because this is such a good discussion. Harvey?

MR. MAKANDON: This conversation actually reminds me a bit of the discussion we had of David's point yesterday in terms of either we pay the cost now or we pay in the future, and the need to sort of show how the impact on one group really will affect the whole society is a case that needs to be made throughout the report.

But more specifically, looking at the discussion that you and Molly were having in terms of is it going to spread or not, I am struck that it kind of reminds me of the discussions we have with patients when we are looking at the cost effectiveness of a procedure in the population as opposed to an individual patient who comes into your office and says can I have a colonoscopy anyway?

DR. ROGERS: That patient is out of his mind.

(Laughter)

MR. MAKANDON: I know, but our lawyers like them because their law firms pay for them. But I think the real issue is one of separating where the disease is spreading from who is at risk. Even white, upper middle class teenagers are at risk for HIV infection. So I think it is easy to make the point of universal risk without necessarily getting into an argument of where the disease is actually spreading in huge numbers and that is really a way of continuing to keep that a very prominent discussion.

MS. DIAZ: Since you are asking for input on your section, I would just remind you that some mention of the devastation for both the Latino and the African American community of entire family nucleuses -- I have been working

in this field for ten years, as I am sure many of you have, and I have not seen that anywhere else. We heard a little bit about it in Puerto Rico. But if you work with these communities on a daily basis, such as you see in New York, what you see is a total, total understanding and hopelessness that is created by mother, father, son, daughter facing extinction. The feeling of that should be ever present before us, that in some communities the reality of total extinction by this disease is very, very real and there is no way that minimizing that or bringing us all into the brotherhood of the human family will take away that type of fear and real threat. Entire units are being wiped out and I would just like to say that.

MR. ALLEN: Bob, I wonder if you could just answer one question for me or articulate what is the value of a human life.

CHAIRMAN OSBORN: I think that is an excellent way to move on to the topic of prevention, as a matter of fact. Bob, do you have other input?

(Mr. Fullilove shakes his head negatively)

MR. GOLDMAN: June, just an off-the-cuff question, are there plans to simultaneously with the issuance of our

final report to issue at least a Spanish language version of the executive summary? Has any thought been given to that? Some of those have been done afterwards. With this report I think it ought to be done simultaneously.

MS. BYRNES: It is partly why it is important for us to finalize the report in enough time prior to the release date so that we not only market it in the way that I think Larry would like for us to talk about, but the appropriate translation, not just your basic give to somebody and in three days have it turned into another language --

MR. GOLDMAN: Right.

MS. BYRNES: We need enough time to do that. So let me say it is certainly something we should be thinking about doing. It has everything to do with how close to the release date we finalize the document. It is a good question.

CHAIRMAN OSBORN: Pat, let me turn the floor over to you now to proceed a little bit and then take questions, as we have been doing.

MS. FRANKS: Thank you so much. I want the Commissioners to know how proud I am to have been asked to be a consultant to the Commission. This first draft that you have, which is really an outline form, is a first attempt to

map out the terrain of HIV prevention and to identify major challenges and key issues.

In developing this draft, I have been fortunate enough to rely on my team of colleagues at the Center for AIDS Prevention Studies and the Institute for Health Policy Studies. They have been my work partners. I have used them to brainstorm with. I have used them to get literature searches going for me. So that is very wonderful. My other colleagues have been colleagues in state and local health departments and in community based organizations.

I guess there are two more things that I have drawn on, my own work in the past six years at the community level in helping to plan prevention, care and support programs. Lastly, I have in my office, sometimes much to my chagrin, all of the transcripts of the Commission's work in the last two years and all of the written testimony, which I ask staff to get ready for me. So I have that because I feel strongly that the final report needs to be anchored in what the Commission has seen and heard and what individual Commissioners have thought about.

Today, because we have such a short time, I would like the Commissioners help me do two things: To define the

process that you would like me to follow as a consultant. Here I have some suggestions about that process. I understand that the Commissioners do too.

There are two sides to the process. One is the internal review and consultation process and my links as a consultant to the Commissioners. On the other side, the external consultation process, and here are links to key participants in federal, state and local government, as well as affected populations and CBOs.

The second thing I would like you to help me do, as well as defining the process, as Molly did so well this morning, is to help me define themes and key issues. I will use the same instructions that she used so well this morning, and that is, to point out areas where you have questions or disagreements or where there are factual errors, and also to add additional key issues.

I will stop there and just ask for your reactions.

CHAIRMAN OSBORN: Reactions? David?

DR. ROGERS: Pat, I like very much what you started with here. It gave me hope about this area because it is a tough one and it is one of our most critical.

You may have this in and I may have missed it but

in the area of prevention and in the area of education all of us tend to get quite preachy. I would like to see you get in there also that we are, in part, frustrated because our science is so primitive in this area. We can get people to the moon. We can dissect the genome. We know how to go at the process of drug development. But our science is in a very primitive state in terms of how we meaningfully effect behavioral change.

I suggest that because we get kind of shrill oftentimes where we begin to sound as if we know how to do this and I think we should be clear about the fact that we do not. We know what needs to be done to prevent this epidemic from spreading but how to impart the behavioral change to others -- we still do not have all the tools we need and I think it might diffuse some of it if you can get a little of that theme into it.

MS. FRANKS: That is a great suggestion. Thanks. Other thoughts? Other reactions?

DR. KONIGSBERG: I have not had a chance to go through this draft that thoroughly but it is certainly well written and is readable. I want to take a little more time to study it because I will be putting down an interest in

following this one.

In looking at section three, strategies in HIV prevention and education, and then there is public health strategy, and then (a)-(g), and then clinical strategy and health professionals and it goes on through, one other way to consider looking at it which might give a different kind of organization of those would be in terms of primary and secondary prevention. In fact, one could consider even dropping the phrase public health strategy. I think I have seen an earlier draft of this and have commented to the effect of this.

If part of our point is that there are multiple points of entry for care and there are also multiple points of entry for prevention, and the prevention and the care have a lot of interface, or they should, whereas, in the past with other disease maybe they have not -- I think what I am saying right now is my colleagues in the American College of Preventive Medicine, who are into clinical preventive medicine and I actually on occasion say the same thing. One of the things we are talking about is marriage of preventive medicine and clinical medicine. I think Public Health has also moved into much of a clinical mode. Early intervention

is a good example but there were earlier examples. And I again hearken to the old TB days. Let's not set up these separate systems of care.

I am not sure how we do that, Pat. But I would be glad to try to assist and it may turn out that that is not the right way to do it. But if we focus on preventing new infections as a primary prevention strategy and then preventing progression to symptomatic disease as secondary prevention and that also offers opportunities for primary prevention -- there may be another way to craft this that better gets at it. I would have to work on this in order to be more articulate about it and it may turn out that this is fine, I do not know.

MS. FRANKS: Thank you.

MR. GOLDMAN: I think you have done a marvelous job with this outline, which I had a chance to briefly look at last night after a fine dinner.

MS. FRANKS: That is why I took you to dinner, Don.

MR. GOLDMAN: And I think you have laid out all of the areas. It is really an extraordinarily comprehensive piece. There are a few areas, however, where I think what needs to be done is to hone in on what needs to be said

within it and what does not. I think there are a few perspectives that I would suggest need to be emphasized within it.

The first one is that while what David said is true, that we do not know an awful lot about many aspects of behavioral science and behavior change, and there is a whole lot of research to be done, we also know the consequences of not doing anything about it and we do not await providing what care we can provide until we find a perfect cure. We do not do that in medicine in anything else and we ought not to do it in dealing with issues of prevention or education or areas of behavior change.

That leads to my second point, namely, that we ought not to be measuring the success or failure of attempts at prevention and attempts at behavior change by its failures. We, instead, ought to be measuring it by successes. Given that kind of process that we are talking about, there are bound to be as many, if not more, failures than successes but that is no reason to abandon the efforts.

MS. FRANKS: I think that is very good, Don. That is very true.

MR. GOLDMAN: That is the message that has to be

given. The point you are making here is consistent with the point I have always found to be true, particularly when you are dealing with areas of sexual behaviors, that the idea of knowing somebody's HIV status is some kind of magical thing that is going to change their behavior. Instead, behavior changes come about through constant, repetitive, repeated and repeated and repetitive and repeated --

(Laughter)

-- kind of education and counseling and single shots do not work, except for one-dose vaccines.

The other item that I suppose all of us agree on is that in order to communicate with people, you have to communicate in a language that they understand and the context of the value system that they accept.

In a sense, I would caution you about the following: That is, how you communicate in a language that the Congress understands given the value system of the Congress, which is our audience that we are trying to educate and achieve behavior change in to a certain extent -- so just as we talk to Congress, to others and to health professionals, we need to allow people to do educational materials within their own communities and in language that their own communities

understand but, please, remember that we are communicating with another community --

MS. FRANKS: That is right.

MR. GOLDMAN: -- and we have to be as respectful of their value system as we want them to be respectful of the value system of others.

MS. FRANKS: Good point.

MR. GOLDMAN: And it is difficult but it is something to keep in mind.

MS. FRANKS: Thank you very much.

MS. DIAZ: This is an area that particularly interests me and I scanned it briefly. But I wanted to support what Don Goldman just said, that perhaps the area that talks about language and cultural barriers really needs to be strengthened in terms of the understanding and the prioritization by heavily impacted communities about the seriousness of this epidemic, and I do not see it there but perhaps it is couched in a different way that I am not picking up.

The fact is that many of the individuals dealing with issues of prevention and education, or recipients of campaigns or efforts of education and prevention are also

struggling with day to day survival issues and the education or the message is one that may not take the same priority it has for the person, agency or groups delivering the urgency of this message.

Pat, of all the areas that this Commission has really heard eloquent testimony on and seen first-hand examples, probably in the area of prevention and education we have had people testify about successful and not so successful strategies in reaching certain groups and communities. I would hope that this would be an enriched area, with some narrative of some vivid examples and illustrations of reaching the hard to reach many times or those populations that we have had an opportunity to visit first-hand and seen some beautiful work being done which can lead the way.

MS. FRANKS: That is great, pulling that stuff in and widening that out.

MS. DIAZ: Yes. I think if you ask any of us what stands out in our mind --

MS. FRANKS: I am going to.

MS. DIAZ: -- it is just rich with testimony over a year as far as good prevention and education models and perhaps some are struggling along with trying to look at

barriers and obstacles, just as your report outlines, but a rich narrative will enhance this.

MS. FRANKS: Great. Thank you.

CHAIRMAN OSBORN: Let me suggest that we be quite brief. We are beginning to run behind schedule. Don Des Jarlais?

DR. DES JARLAIS: I also looked at this with great interest and I expect to follow up on it. I have a few comments, one with respect to what David was saying earlier about the primitive state of behavioral science. I think either we need to be very careful when we say that or maybe we should not even say it at all. I speak as a behavioral scientist with vested interests in it --

DR. ROGERS: They are fairly primitive, aren't they?

(Laughter)

MS. FRANKS: Don't take that seriously, Don.

DR. DES JARLAIS: No, I really think that in terms of our knowledge base, if we acted on our present knowledge base, generated over the last six years of studying AIDS, we could reduce the rate of new HIV infections by at least half in this country. It is not a matter of ignorance. We have studies showing that drug users who are homeless use clean

needles less and use condoms less than drug users who have homes or have a regular place to live. That is good scientific knowledge and we could act on it but we basically have chosen pretty much not to act on it. So it is not a lack of our scientific knowledge that is fueling the lack of behavioral changes as much as a lack of a national commitment to do something about it.

The second point is that I would almost want to take education out of the title because I think that is very, very misleading.

MS. FRANKS: Yes, I kind of do not like it being in the title myself.

DR. DES JARLAIS: It is not that the country does not know about AIDS and it is not that if you give them three facts that you are going to get behavior change. The country knows that smoking cigarettes causes lung cancer. The country knows that eating fatty foods causes heart disease. We do not need to sort of educate ourselves about that. We need to have careful and detailed plans and programs for behavior change but it is not a matter of conveying basic AIDS 101 and how the virus is transmitted.

The third point is somewhat specific to the drug

use parts of the chapter. There is a reasonable discussion of syringe exchanges but a strategy that is not really touched on much at all is simply over-the-counter sales and decriminalization of possession of sterile injection equipment. It is a strategy that would basically cost no money at all, that almost the entire rest of the developed world has implemented because of AIDS and I think that really needs to be addressed in this chapter.

MS. FRANKS: Thanks.

DR. ROGERS: Your own opening statement in part proves my point. I do not think I am in that much disagreement.

DR. DES JARLAIS: Yes, I agree.

DR. ROGERS: But I think we want to be very careful not to be too preachy. Your statement was exactly that, that if those dumb SOBs really would accept what I already know, then we would not have half the cases of AIDS. And I do not think that gets us very far. That is why I am trying to diffuse it a bit and I would still say that we know what should be done but it is still awfully hard to effect behavior change. You mentioned smoking and other things. We have a tough time with that and I just simply want to get

that in there. It "ain't" easy.

DR. DES JARLAIS: Yes. There is confusion in the behavior change area, saying that if we cannot change it, it is because of a lack of scientific understanding. You would not apply that to geology. You would not say that because we cannot prevent an earthquake we do not know anything about earthquakes. We would simply say that it is going to take massive amounts of resources to change these tectonic plates so that we do not have earthquakes. It may take large amounts of resources, not on the same level as an earthquake, to change the diet of the United States, for example, and it is not that we do not understand how people change their diet; it is just that it is really a bit resource problem for heart disease and for nicotine; less of a problem for AIDS.

CHAIRMAN OSBORN: I am losing the battle of the clock here. Pat, Molly, Diane, Larry, and then a break.

MR. CHAULK: Just briefly, to the extent that we care, we want to make sure that our financing section at least talks as comfortably as it can about some of this. We do not want to get into a spreadsheet about all these different things we want to pay for but I did not see anything in there about financing. I do not want this to

stand out as things that need to be done without our addressing that.

MS. FRANKS: You are right, Pat. There is no cost effectiveness --

MR. CHAULK: Yes, but in terms of the CBOs and things like that which will be doing some of this, and how coordinate that, I want to make sure that we help you with that.

MS. FRANKS: Good. Thanks.

DR. COYE: This does not have in it a lot of the stuff that I have in my section about the structure and organization. In your obstacles to progress there are no structural --

MS. FRANKS: Because I knew you were going to do that, Molly.

DR. COYE: But the issue is are you worried as a Commission that people may just read the chapters they care about? In other words, some people are just going to read the chapter on prevention. I know you are in a hurry but is there any guidance you want to give us for work tomorrow on how to deal with that?

CHAIRMAN OSBORN: My own instinct is that we are a

little early in the game to worry about redundancy. That, again, is an editorial thing to come at the end. I think it probably is a wise guide to have a chapter be free standing. It may not need to be free standing in every particular detail and that probably comes out to an issue of length, style, the spin that a certain thing is getting at the end. So I would not worry about it. If it happens to be doubly represented, that surely will be something that will pop right out once one starts reading through the whole set of chapters stapled together and sees how they come together.

DR. ROGERS: Some will read the executive summary, like you read the abstract part of the New England Journal and then bite on the ones that you want --

DR. COYE: I read every article.

(Laughter)

The concern is that we have areas where there is duplication. So I take it from what you are saying that it will be better to make sure all of these points are covered to some extent in each chapter, with cross references, and then worry later about taking stuff out.

MS. AHRENS: Very quickly, Pat has given us a very comprehensive document. I know one of the things you are

going to be asking us for is how do we make this just a bit more concise.

As I read it through, some of it is very basic kind of stuff and I am wondering whether we can make some assumptions in terms of our readers and either leave some of the very basic stuff out or gear it at a little higher level which would make some of that drop away. It is just a question in terms of looking at who our audience is. Even the Congress people who read this report, most of them will stop after the executive summary and there may be some who will want to read further, but those who do would have a little higher understanding I think.

There are just a couple of things that I want to mention that I really like in the report. It is more use of language but I think your emphasis, starting pretty much on page eight when you talk about the emphasis on communities -- I think that is just a wonderful concept. Keep that and strengthen the community concept.

Then on page eleven you talk about the sort of motivational aspects of getting communities to respond. I think that is awfully important, not so much for Congress but as this goes out to the land, I think that is very important.

I guess what I am looking at, and this would be part of the interaction between you and the Commission members, is to kind of cull out the essence of what we are doing here, the most important issues in prevention and strategies and make that a part --

MS. FRANKS: To work together.

MS. AHRENS: Yes.

MS. FRANKS: Other comments?

MR. KESSLER: There are three things, I guess, that I am interested in seeing in the final draft: Some mention of the generational gap that happens and seems to be happening between young people and older people in the same populations, particularly younger gay men versus older gay men, and the differences in how they view this epidemic vis-a-vis their older counterparts. I think the same thing will happen in the future too among people of color, as the epidemic settles and the generations begin to shift, as to what is logical for them or applicable to them.

The other is the issue of relapse. There are some data now, both from Seattle, in Washington, and soon from Boston. It is striking and controversial, particularly the sections around what happens to people who take the test and

are found negative, as well as those who are found positive. As soon as the embargo is lifted on our report, I will see that you and the rest of the Commissioners get it. The Seattle and San Francisco studies are already available.

The third is the linkage between care and prevention issues. So often when we talk about prevention we forget the HIV patient in terms of educating him/her about prevention and spread. Unfortunately, the survey we just finished showed that somebody missed the boat. Whether it is peer pressure or peer support, you know, we have found that in the last six months a third of the community responding to the questionnaire -- it was a sizeable study of over 1200 people -- a third had unsafe sex in the last six months. Among the HIV patients who were surveyed, again, one-third had unprotected sex. Of those, one-third had unprotected sex with the opposite sex. So it is not simply a straight -- excuse the pun -- cut across gay straight lines. We do have people who see themselves as bisexual, or unsettled in their sexuality, still experimenting or whatever. If they happen to be positive, it is another way of the virus being spread. It is tough. We cannot sit on the information either but it goes into the hopper when we talk about behavioral change and

just how difficult it is to get sustained behavior and consistency across the pike and across populations.

CHAIRMAN OSBORN: I think I am going to try and accomplish a couple of things rather efficiently now. First of all, David has a 4:30 plane. I think we should make sure that we are essentially done with major business in time for David to catch his plane, which means that we have a lot of work to do.

I would like to point out that if you make your points very succinctly, you are talking to people to whom you can talk some more. So it does not all have to be done right now, as long as the item is brought up so you know to continue the discussion. So that may help us to move along.

Secondly, let me suggest that over the break we do two things -- and the break will be no more than 15 minutes because otherwise we simply cannot do what we need to do -- first of all, let me point out that Don Des Jarlais' recommendations were passed out yesterday. It is a single page that looks like this. So during the break I would like you all to have read that so that you can respond with any comments that you have and so that we do not have to take up very much time at all with discussion, unless there are major

points that arise.

Maureen has one other thing that will also be break stuff.

MS. BYRNES: Actually, I have two other quick things. I wanted to mention to everyone that Pat will probably be organizing an opportunity, similar to what Jeff did with members of the research community. Toward the end of May we will probably be convening a meeting at the Commission office to bring together a couple of different people around the issues of prevention. One of those people at least will report on the topics, concerns, issues that were arrived at at that meeting.

Let me go through this a little bit more slowly but not belabor it. We were trying to figure out what would be the best way to get some information, in addition to what we talked about today, to Pat and to you and not monopolize a lot of the time during the June hearing. So this will be at the Commission office. Any Commissioners who would like to participate will be welcome. We will let you know what the date is. Then there will be a presentation during the June meeting to highlight some of the findings and recommendations from that group. I wanted to be sure that you are all aware

of that.

Along those lines, during the break I am going to pass out a sheet that will allow you to select which of the sections within the report you would like to be a primary reviewer for, or number two or number three that we talked about this morning. If there are any questions, I will stay in the room so that we can get these filled out and staff will know when we meet with the consultants tomorrow who has a particular interest in what area and who would just like to be kept in the loop basically on all the other issues. Please put your name on them. I think the form is self-explanatory except that there is no place to indicate who you are. Thanks.

MS. FRANKS: Thanks you.

CHAIRMAN OSBORN: Fifteen minutes and back we come.

(Brief recess)

CHAIRMAN OSBORN: I am going to turn things around just a little bit, if you do not mind. I would like to get any reactions that people have had to the set of recommendations that Don Des Jarlais has put before us so that we can be sure and do that before the stragglers start straggling. David?

DR. ROGERS: I thought those were elegantly crafted and punchy. Let me read the big question to us: Do we want to recommend that the federal government develop integrated policy in this area or do we want to recommend that our recommendation be that policy? In reading your recommendations, my reaction is that our recommendations should be that policy. That would be my vote.

CHAIRMAN OSBORN: Does anybody have any problem with that? I happen to strongly concur.

MR. GOLDMAN: All those in favor?

CHAIRMAN OSBORN: All those in favor, say aye.

(Show of hands)

Do you have any problem with the statement that says that our policy should be the policy?

DR. KONIGSBERG: Who wrote it?

DR. ROGERS: Don Des Jarlais.

DR. KONIGSBERG: No, I do not have any problem with it.

CHAIRMAN OSBORN: Carte blanche is what that is called. Any problems with points 1-5? So we are happy with that.

Let me remind you to fill out the grid with number

one if you want to be a primary reviewer; number two if you would like to have some input, although at a less involved level; and number three if you have some interest but you do not want to be interactive on the topic. Make sure that your name is on them so that it is not an anonymous survey of interest, and that it then comes forward to Maureen or gets handed to one of the staff who will bring it to Maureen, whichever is easier.

Harvey, thank you for your patience and welcome, and we will turn it over to you now.

MR. MAKANDON: Thank you. I also would like to thank the Commission for this opportunity to work with you on this very important project. Harlon suggested that I start off with a joke but I do not know any and June advised that we be brief.

What I have tried to do is go beyond the outline that I submitted and today I wanted to sketch some ideas which drew initially on documents provided by the Commission, including Scott Allen's recent subcommittee report. I also tried to listen and write some things down that I heard either explicitly or implicitly from the statements that were made yesterday in the context of the financing discussion.

So I will go through a number of items and then really ask you for your input to see what you think I have left out or what comments you think I should pursue in more detail or less detail.

First, I guess, was that the Commission supports a model of care which offers comprehensive services designed to minimize in-hospital care. The elements would include prevention on an individual level; early intervention; primary care throughout the spectrum of HIV disease, including access to investigational new drugs and continuity of care during hospitalization; and long-term care.

Looked at solely with respect to delivery of traditional healthcare services, I think that this is probably somewhat broader in scope than our traditional view of what healthcare services offer. It is also broader in that there must be explicit recognition of the full range of health professional involvement, including physicians, nurses, mental health professionals and dentists.

I think it is also broader in that the model of care we are looking at includes additional programs which go beyond what are traditionally included as medical care services. This would include supervised housing, as well as

coordination of care with a multitude of health services and educational programs offered by community based organizations.

Having said that and outlined this model, I think the disparity between where we are and where we want to go presents us with a number of challenges. What I wanted to do now is run through a number of areas where I think there are some significant challenges for us to deal with and some barriers to making some of these changes.

The specific areas where I think there are challenges that we need to face are in integration of early intervention with primary care efforts; looking at ways to facilitate access to clinical trials; coordination or integration of treatment for drug use with primary care services; acceptance of the broader mission by primary care providers; coordination of primary care with both in-hospital and community based case management programs; and, finally, systems of care for specific populations, such as prisoners, migrate health workers and programs offered by the Indian Health Service.

I think some of the questions we need to look at are, first, the issue we discussed yesterday, whether the financing mechanisms are possible for us to begin to make

some of these changes and how can we look, not just at a long-term strategy for universal healthcare, but immediate strategies which would facilitate the development of an appropriate primary care system?

Second, how should structures be developed to the extent that they are new? On this point, I guess I am thinking specifically of asking for some guidance from you with respect to your thoughts regarding segregated AIDS facilities or integrated AIDS care programs. I think there are data which suggest we should go in both directions. There are some data on quality of care which suggest that separate AIDS facilities provide better care. There is also a document, produced by a group in New York, looking at some of the serious potential problems by developing specific AIDS hospitals. I think the issues raised in those two arguments kind of run throughout out discussion about the kinds of health services we are talking about and what we want to develop, particularly when we are talking about new services.

Then a third area which I want to ask about is sort of what do we need to do in order to develop an appropriate response among health professionals and what kinds of stimuli do we need to put in place in order to do this? I think

there are attitudinal issues that we need to deal with, as well as issues around knowledge and skills.

When I talk about attitudinal issues, I am talking in part about attitudes towards people with HIV infection -- gay men, the poor, IV drug users, clearly, stigmatized populations that have been avoided by healthcare professionals in a variety of different settings. That is probably compounded by the concomitant diagnosis of HIV infection.

But I am also talking about attitudes towards patient care. I think AIDS has raised the issue around patients really looking for a more patient-centered approach to care. Belinda Mason actually wrote a forward for a primary care book that I am editing in which she used the term that the patient should be the pilot and that the healthcare provider should work with the pilot in providing a system of care. I think that really puts in focus a different view of healthcare that people with HIV infection have raised, which has been raised by other groups. Women in the 1970s, in terms of the women's health movement, raised many of the same issues. But, clearly, this has taken on a great deal of interest now and I think it is something we need to think about in terms of how we begin to make some of those

changes in the healthcare system.

Aside from attitudes, there are real issues in terms of how we help health professionals gain the knowledge and skills that are necessary to provide care for people with HIV infection. I think no other disease has challenged our ability to develop educational mechanisms as quickly. I am not aware of any situation where there has been such dramatic change in technical skills and changes in clinical care which providers need to keep up with on a regular basis. So we need to think about how we disseminate state of the art information; how it should be synthesized; and also how we disseminate information on the minute to minute changes in clinical trials and new drug development, which not only primary care providers need but other providers.

Again, this issue I think is are we talking about educating a group of primary care physicians, or are we talking about developing new groups of healthcare providers who would provide care specifically for people with AIDS and HIV infection?

So having laid out that range of issues, I really want to ask you now what the things are which you think are the most important. What should we focus on as we develop

the report? I would like to suggest that this is also another area where we might want to get a group together to talk in more detail at some point in the next month.

DR. DES JARLAIS: I just wanted to comment on the issue of segregated versus integrated care, since I am looking at that in terms of my own medical center. I think AIDS hospitals are probably a bad idea for a large variety of reasons. The only way I can see AIDS hospitals being viable is if somehow AIDS care were reimbursed so well that the hospitals would naturally spring up and survive by themselves, and I do not see that as a problem we need to worry about.

The level within a medical center within a hospital -- I think there is probably movement towards the idea that you do both: That you may have a separate AIDS ward with highly motivated and very competent staff but, given the number of AIDS cases, you will probably also have AIDS patients scattered throughout the rest of the hospital. Many of those people with HIV infection will not need the level of care that you would care on a dedicated unit. So, rather than having us try to say do it this way only, I think probably the field is going to move towards doing, within a single hospital, both, having a separate unit for the people in

really dire straits and then having other HIV-positive patients scattered throughout.

DR. KONIGSBERG: A couple of things, the paper is short, Harvey, but, in my opinion, you have the right ideas and the right concepts to build on. I think you are correct in pointing out that attitudes, at least with physicians, although I am sure it applies to other healthcare providers, is going to be the most critical.

I think one of the more awkward things I get into in the type of work I am in right now -- and I am running the risk of becoming, as David would say, a bit preachy about it which is a real danger with my clinical colleagues, as you can well appreciate -- is that I am starting to really push physicians about the need to be prepared to take care of these patients all across the spectrum. I think I may have commented about that yesterday.

It was interesting to watch in Nebraska last week the panel of practicing physicians from key regions of the state, a low incidence state, as to why they thought it was important to sit in front of about 100 second year medical students who really were not all that interested in AIDS -- I mean, you can read their faces and tell that. We had a

pathologist from western Nebraska who had a blood bank and she had become the resident expert on AIDS. There was nobody out there who knew anything. There was a family physician who had seen patients who had come home -- when the elephants come home to die -- that was his phrase. Then there was an internist who had seen a few patients, who had an interesting viewpoint. He said that one of the reasons, besides the fact that he just opted to take care of these people, is that if you learn how to take care of AIDS patients real well, you will practice good medicine for everybody. That made pretty good sense to me on a real practical level. The students were listening to that one in particular.

But how to craft a recommendation on what to do about getting physicians to accept this disease in their practice in a way that is compassionate and competent at the same time is tough. I think there is a widespread feeling that the ETCs have not done it. I do not know what the solution is but somehow I think we need to really address that, yet, in a way that does not get the AMA complaining that we are trying to tell them what to do.

MS. DIAZ: Harvey, one thing that I think might provide an interesting backdrop is that we had some initial

testimony to this Commission on the value of looking at the hemophilia model and levels of care. I would pull out that testimony because, to me, that was very thought provoking. Being from a primary care background, I had looked just at that particular way as probably the ideal way of delivering a spectrum of HIV services. A number of people suggested to us that it might be a very good model to look at it.

I am just saying that we should not put all our eggs in whether or not this ought to be specialized versus non-specialized or segregated versus non-segregated. I think there is merit in looking at the total needs of the patient population or client population throughout the entire spectrum of the illness that might call for a combination of those kinds of models of care.

The other point, which I did not hear you articulate as well as I have heard you articulate before, is to increase the access points for entry into the HIV care system, whether that be through family planning clinics or existing structures that are there, like community health centers, migrant health centers, neighborhood health clinics, maternal clinics -- all these types of existing services where people are already going. This is particularly important with populations that

have no alternative sources of care and depend on those access points.

My last point is that you talked about perhaps motivators and perks that we might hold out to increasing the manpower pool that is available to provide these services. This Commission has heard a lot of lucid testimony as to the obstacles and barriers to further participation and involvement. I think your section definitely should pull from that. We heard a presentation by the president of the Hispanic Physicians Association, from New York, that outlined very well why it was beyond reimbursement issues but a whole array of issues as to why a greater pool of physicians or professionals from our minority communities are not involved. That certainly would provide some good backdrop.

MR. MAKANDON: Thanks.

MR. DALTON: Harvey, yesterday when we were discussing financing you reminded us that it was important to think about the model of care that was implicit. Today, in talking about care you talk about financing. I do not know if it is appropriate for one consultant to talk to another but I hope you and Karen, in fact, do talk to one another because you are inextricably linked.

The reason I wanted to talk at the moment is that you referred to native Americans and the Indian Health Service and it reminded me that yesterday, in talking about financing, we did not separately treat financing issues with respect to native Americans, which are quite different, or with respect to Puerto Rico, which is quite different given the Medicaid cap. So this is not so much to you but, staff, please communicate to Karen Davis that it is absolutely important for us to separately treat financial assistance that are different.

MR. MAKANDON: It was intended that we were all going to work together after this. I actually think Molly's section on government structure goes into this issue.

MS. BYRNES: Harlon, I was at a meeting recently where someone used that as a perfect example of where a universal access system was not working, was responding very inadequately. Everyone was covered but no one was getting it.

MR. GOLDMAN: Let me put on another hat that I sometimes wear, and that is of a person with a chronic disease and from a patient perspective for a moment. One of the things that I have learned, not only for myself but for colleagues and friends, and not only those with hemophilia

but those with other diseases, is that the last thing in the world a person with a chronic disease wants to be is the only patient with that disease treated by a given physician.

(Laughter)

And the consequence of that is that I think the structure of comprehensive care that we are talking about may end up being structured differently depending upon the concentration of cases and incidence of cases in a given community. You may be talking about one model of care in New York City or San Francisco and you may be talking about another model for Nebraska or Iowa.

You ought not to make an assumption that the same kind of model is necessarily going to be appropriate for both communities. I think the way to get around the issue of segregated versus integrated centers for AIDS is to call them something else and you called them centers of excellence. I think everyone agrees that there is, in fact, a need.

It is just a question of what the numbers are because you need a certain minimum number of patients within a given community and a neighborhood in New York City might generate enough patients to have such a center, or at least a borough. In other parts of the country you might need a

multi-state region in order to accumulate the same number. But the fact of the matter is that you need an accumulation of patients to put together a center of excellence where you have the kinds of facilities where multi-disciplinary care can economically provide it.

Multi-disciplinary care is essential in treating any kind of chronic disease, I would submit, but particularly one like AIDS and HIV infection which to a certain extent, like hemophilia, is one that is particularly multi-disciplinary in that it cuts across systemic lines. That is, a person with AIDS or HIV infection may need the care not only of an infectious disease specialist but a neurologist, and a dermatologist, a surgeon and a hematologist -- all sorts of different kinds of specialties at different points and at different times during his/her care.

I like another analogy better than the one that Belinda used of the patient being the pilot. I would suggest that what is really essential is a team approach where the patient should be viewed as a full member of that team. A team approach is essential. Just to give you an example, a physician or the infectious disease specialists suggests that it would be nice to have the patient come in periodically for

aerosolized pentamidine. The patient says, "wait a minute, I can't take time off from work" and what you need to do is a negotiating process to deal with that. Is there some other place to get the aerosolized pentamidine? The social worker or the person looking at that person's healthcare financing system may say that in this case bactrium would be appropriate but maybe bactrium administered at home would not be covered under the insurance program but aerosolized pentamidine would be. There has to be a kind of negotiation of what makes the best sense for that system given his/her employment setting; his/her healthcare financing abilities and his/her medical needs. And that can only be done in a way in which people are communicating with each other in a team setting.

The last point that I would make, which in part deals with the economics, is that one of the advantages of having an approach in which multiple people are involved in care is that, it seems to me, care ought to be provided by the less skilled professional available under the circumstances. What I mean by that is that if a patient wakes up in the morning with a slight cough and is concerned and worried whether this is or is not pneumocystis and calls, he/she ought not necessarily have to speak with the consulting

infectious disease doctor at that point in time and ought to have some interface and be able to speak to a nurse perhaps or someone who can say, "look, what's your temperature?" or do some diagnostic kind of work, or semi-diagnostic, and at least have some triage mechanism so that you do not end up having the chief of the service responding to every call. It is not that calls are not important but I think there are more efficient ways of structuring the care so that it can be more cost efficient, thereby, using the same dollars to provide more care to more people.

DR. ROGERS: Harvey, I like very much the way you come at this. I like what you gave us and I like even more what you said to us. I think you are right on target.

MR. MAKANDON: Thank you.

DR. ROGERS: I have a couple of comments. I would buy completely on what Don Des Jarlais said and I would couple it with what Don said. You are going to need different kinds of systems for different parts of the country. There is no question about the fact that you have to have it both ways, and no question about quality of care which needs a special unit but you are not going to put all your AIDS patients there.

I would suggest, just to build on what Don was saying about the team approach, and I do not wish to push this too far but the designated centers in New York have just changed the care of AIDS patients remarkably. Instead of it being dreary and oppressive, believe it or not, it is a rather joyful setting. The reason is that there is a team. And this is what I would add to what Don had, it is not only physicians; it is nurses, occupational therapists. It is social service people. It is lawyers. It is a full service bank where people share in a nice democratic way that is wonderful for doctors too. So when somebody asks who saw Harvey Makandon today, the social service worker may say, "I did" and here is what he needed. And it is not always the doctor. And it is perfectly clear to everybody that different professionals have different things to contribute to his care in ways that have been enormously popular for patients.

I think it gets around some of the burnout phenomena because they support one another. It does what Don says. It puts care at a less expensive level often. I think it is a wonderful model for all kinds of chronic relapsing disease problems. You might want to use just a little testimony from what goes on in one of those centers.

MR. MAKANDON: That is a good idea.

MS. AHRENS: I was concerned lest we come down on one side or the other in this issue of integrated or single approach. I do not think we are ready to do that. It may be that we need to spend more time thinking about this next year but, certainly, if it is going to be in the report, I think that it has to be based on the variations in the country and the approaches based on those variations.

I think that the group that is working with you from the Commission -- you have to pay a lot of attention to that. I am concerned about what we put in the report about that lest it be taken too seriously.

MR. MAKANDON: Actually, I had hoped that no one would come down too heavily on either side because I think there are advantages and disadvantages to both, and there are very different systems that are necessary in different regions of the country. So this discussion has been very helpful.

DR. ROGERS: Diane, there has been an enormous amount of thought on this and it really can be both ways. If you are 10-plus sick and in a high incidence area, it is perfectly clear you do 20 times better if you have a highly

experienced unit that deals with it. But to make a segregated hospital or to leperize it is probably not a good idea. I think we can state that you need expertise and you need dedicated people under certain circumstances but also that all physicians really have to make some commitment to taking care of people with HIV infection.

MS. AHRENS: That is not to say that in areas such as Des Moines, Iowa, you cannot have a hospital that is the designated hospital with a unit that is specialized in treating HIV patients. It seems to me that in an area like that that is the only way you are going to do it and have the kind of specialized people that you need because the numbers are not there.

CHAIRMAN OSBORN: If I can interject, I think what I am hearing is that nothing will be excluded and it may even be that the wisest thing to do, partially by example and partially by caveat, is to be careful that the hazards of each approach are well brought out. So if the right situation is in the wrong place it does not work, and so forth.

So I think in Des Moines, Iowa, that could work as long as it does not suddenly precipitate a stampede phenomenon, as has happened in some areas that considered them-

selves to be out of the range of this epidemic. But I am sure that will be part of any discussion of the various strategies. From what Harvey is saying, the impression is that they would mostly be delineated as a set of options.

MR. MAKANDON: Right, and, for example, the presence of a designated center in a city like that may well enable people working in family planning clinics and community health centers to do more early intervention and basic primary care because they can develop a relationship with the designated center, to either get backup when they need it or refer patients when they get too sick.

MS. AHRENS: And it is already being happening without it being designated.

MR. MAKANDON: Right.

DR. KONIGSBERG: Harvey, I think you hit on a point that I want to try and explain. Nobody can see this [Dr. Konigsberg holds up a piece of paper] but this is the time-line from risk factors to infection to the acute phase, to all that in between, to declining immunity, over to end stage HIV disease with 10-24 years out.

Here is what I want the primary care physician to do: I want that primary care physician, first of all, to be

aware of his/her role in prevention, the pre-infection. Second of all, be able to make a diagnosis of infection early on and to manage the early stages.

This is the primary care circle. This is the specialist when it gets over to opportunistic infections. The primary care physician in liberal Kansas is not going to take care of Pneumocystis pneumonia and all that other business, most likely -- well, maybe out there they have to because they are so isolated. So there is a need for specialized care and there is an overlap.

But if we have 3000-4000 infected people estimated in my state, we cannot depend on infectious disease specialists or centers to take care of all these people. We are missing a lot of prevention opportunities.

So I would really plead that we define a role for the primary care physician, and that is a different issue from whether we have centers. I agree, Don, if I had full-blown AIDS, I would want to go to a center where they take care of a lot of it. But I would also want my primary care physician to be alert to either help me from becoming infected or diagnose me early and participate in the early intervention.

MR. MAKANDON: Although I think you should not sell primary care physicians short in terms of their ability to learn. That is the way all of us learned how to do this. If you start at the beginning and you follow someone through the course of their illness, you feel better the second time.

DR. KONIGSBERG: My concern is that most primary care physicians in the State of Kansas do not even know this. That worries me. We have to do something about that.

CHAIRMAN OSBORN: Let me point out that we have relatively little time and we still want to talk about research and response of the federal government. So these points are important but make them concisely and give Harvey guidance in a telegraphic way.

MR. GOLDMAN: I do not know whether we want to deal with it or not but my experience is, in terms of dealing with overlap that Charlie was talking about in the transition from the primary care physician to specialized care, that the local medical politics ends up being the largest barrier to those kinds of things happening. I have no idea how to deal with it but it is often a major, major problem.

DR. KONIGSBERG: I think it is individual physicians. There may be an absence of leadership in terms of the

organized medical establishment but there are no barriers, at least not in my state. Whether there is leadership is another question.

MR. GOLDMAN: I am talking about medical politics. I am not talking about politic politics.

DR. KONIGSBERG: I am talking about medical politics too.

MR. GOLDMAN: I am talking about issues of who controls the patient, and who gets the reimbursement, and who defines the care, and things of that nature.

DR. KONIGSBERG: I think it is just lack of leadership.

MR. GOLDMAN: Okay.

CHAIRMAN OSBORN: I am glad we got that fixed so quickly. Other comments that need Harvey's immediate attention? I think we are all quite happy with the direction of things and are grateful to you for a really good start.

MR. MAKANDON: Thank you.

MR. ALLEN: While we are waiting for Jeff, may I comment? I know Irwin has been such a dedicated member of this in his attendance and participation, I know your wife is in the hospital. Could we get a brief report on how she is

doing?

MR. PERNICK: Thank you very much. She is feeling better. But I do not know what that means because the doctor refuses to give me a prognosis, which is typical of doctors, right?

MR. ALLEN: No.

MR. PERNICK: No? Well, she is on a ventilator.

MR. ALLEN: You are in our thoughts and we appreciate your being here.

CHAIRMAN OSBORN: Jeff?

MR. STRYKER: Hello. It is late in the day and I promised Scott that I would stay awake at least for my own presentation --

(Laughter)

-- but I think I can do that for at least five minutes. So that is all the talking that I will do at you and then we can sort of go over other materials a little and talk about process as much as about substance.

What you have in front of you is labeled research. I think we should be clear that we are talking strictly about clinical trials and clinical research and there are a lot of other areas, both in the biomedical realm, in vaccines in

particular, and there is also behavioral and health services research. So we should be clear about just how much we are biting off here.

I would like just a couple of minutes to sort of frame what I have been trying to do. I think the area of clinical trials is one where we can see some real fundamental changes as a result of AIDS in terms of our understanding about the research enterprise and how it is perceived by a lot of participants and players.

Certainly, that is seen in people's view of research as therapy as an entitlement almost. Changes in drug regulations, changes in statistical trial designs, the increasing roles of patients and advocates in the process and exacerbation of tensions, what is often called in medical ethics the double agent problem, the tensions that occur when an individual physician is both a clinician in the service of an individual patient and a scientist in the service of a greater search for knowledge.

My main interest in this has been from a long-standing interest in human subjects research and the ethics of human experimentation. One way to think of this kind of fundamental change is to think back to the late 1970s, when I

started following this, through the eyes of what was then called the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. The key words there are "protection from." Research was viewed as something that we protected vulnerable subject populations from.

If you look at the charge to that commission and their series of voluminous reports, they were around a series of vulnerable populations -- children, fetuses, the mentally disabled and, of course, prisoners, something that we have already spoken to, or around controversial procedures like psychosurgery.

Today we have a different view of research I think. It is not just in AIDS. I think a number of patient groups have taken a leaf out of ACT-UP's book, if you will, and we are now seeing a different look at women as research subjects. Certainly, there are new questions about breast cancer trials and just in the past few weeks we have seen that Alzheimer disease patients are willing to sort of look at ACT-UP patient advocate strategies in getting drugs into the marketplace.

What I have tried to do in the research for this is

to keep my eye on the ball with one fundamental question, what is keeping getting drugs from the lab bench into patients who need them? That is a sort of broad-spectrum question. We can look at a number of potential shortages of funds or drug candidates or research ideas or trained professionals or facilities.

I think one thing there has not been a shortage of is advice. That has come from a lot of different quarters, from the Institute of Medicine, from the ACT-UP treatment and data committee, from the Lasagna committee, from FDA advisory groups, from the Commission itself in its report number three.

So I think what we might want to think about today and in subsequent discussions of this is how the Commission plays into that, what kind of use it should make of advice that is already out there; whether it wants to underscore or emphasize the work of other groups; whether there are some areas of this that ought to be left alone because there are groups that are constituted to look in greater detail at certain aspects of this.

I guess the other main question is what kind of audiences we are going to have specifically for this portion

of the report. Certainly, the federal scientific establishment is one key audience and we have already heard from them after our last report. But, clearly, a congressional commission ought to be interested in where federal dollars are flowing and the kind of impact they are having, whether we are getting the most bang for our buck out of the clinical research efforts at NIH and with the whole ACTG system etc. Of course, that involves the question of scientific management.

But there are other audiences and areas of concern as well. We talked about some of them yesterday. They are all pharmaceutical companies. Although that, interestingly, turns out to be a government question in some ways as well because, clearly, one of the functions of government is to pick up the slack and to do research that private for-profit companies are not in a position to. Certainly, there is a keen interest in federal regulatory policy around drug development.

I think another set of players that the Commission want to address their recommendations to are certainly health insurers, both public and private third-party payers who are at one end of the spectrum of the question of how to get

drugs into patients who need them and, clearly, how to pay for them and at what stage insurers should consider reimbursing experimental therapeutics.

I think the key audience that we always need to keep in mind -- and I am sorry Belinda is not here but certainly there are others with personal interest, and we have heard from Belinda through David -- are the patients. When you think about AIDS treatment drugs from a patient perspective, you think perhaps about a bewildering array of choices.

It has been unusual in the AIDS era that persons with AIDS have come to physicians offices armed with the latest Lancet, New England Journal of Medicine, GMHC Newsletter -- a very educated patient population in a lot of regards. I am always impressed by the efforts people go to become educated on this and the sophistication of a lot of the patient population because these are incredibly complex scientific and sometimes even moral questions, the question of whether to lie to get into a trial; whether to cooperate in a buyer's club that is buying drugs out of the country and importing them legally or illegally.

But, clearly, we ought to keep in mind throughout

the whole process the end users here and what we are talking about when we talk about the types of drugs involved, their toxicity, the side effects, the problems with doing drugs in different combinations, what it means to a patient if a drug is a tablet or if it is something that has to be administered IV in hospital, or a nebulizer at home or hospital setting. How much the drugs cost came out yesterday in the discussion of the orphan drug situation.

So these are things that we need to keep clearly in mind and also to keep in mind the brief history of AIDS drug research. Already the history of AIDS drug research is littered with some failures, some drugs that did not work and, in some instances, may have killed people with AIDS faster than the disease process itself might have. So we are in an area that is fraught with a lot of complexities.

And I wish I were a team from Hopkins, but I am only me. I am not a statistician, lawyer, pharmacokineticist -- any of the types of specialties to understand this issue. But like other consultants, I have tried to call on the people in the field who do understand many more aspects of this than I do. Our first foray into that process was a meeting we held in the office of the Commission on April 8,

and invited a number of members of the federal research establishments and the people on the front line of the ACTG to talk to us.

We would like to do a similar process in San Francisco and we will get back a little bit to what that will look like and whom that will include, especially after you have designated with your check marks who is interested in what.

I have also tried to go to a lot of patient meetings and I think I will go to one more patient meeting in San Francisco and I think I will take a trip to New York so I can talk to a bunch of people one-on-one. I think it is important, especially in this area where there are a lot of heartfelt feelings of people involved to talk to people in settings where they can really share with you their deep, heartfelt feelings, not always in a sort of hearing/testimony kind of setting. So we will be trying to do that as well. I welcome your input at every level.

To get back to where we are now, the materials you have include a little outline, a narrative that is very descriptive of some of the history of these questions, and then some minutes of our April 8 meeting, and a summary of

some of the recommendations that came out of the most recent advisory committee report, the IOM report on the NIH scientific establishment, and then a sort of point-counterpoint of testimony of Dr. Faucci and Jim Eigo with two different perspectives on how we are doing in this. So that is all I have to say.

CHAIRMAN OSBORN: As I understand it, now you go to sleep and we ask questions?

MR. STRYKER: Yes.

MS. DIAZ: You did not mention this but I am sure you know that most of the groups that have discussed research related to HIV are very cognizant of the fact that a real challenge is to involve more communities of color within research related to AIDS is very much before us. It is something that is being worked on by different institutes and investigative teams but, yet, we are a long way from that desired goal, particularly with the demographics as they present themselves right now in this epidemic. I would urge that your section at least speak to this. If we do not feel that we have enough documentation from the different people who have testified about their challenges in getting into drug trials and being included within this process, at least

the experience that is coming up before the various bodies that are considering this be recorded within the research section.

DR. DES JARLAIS: I think it is also important to realize that among communities of color there is an expectation that they will probably face discrimination and racism in AIDS research, clearly in the behavioral research but I think also in the ACTGs. They do not come in with the idea what the researchers have good faith. They come in with the idea that they will be discriminated against; that sort of the institutional problems that they have had with the healthcare system as a whole will also exist in people doing AIDS drug development. So we are not starting out with the situation of good faith on all sides. We are starting out with an expectation among many people of color that they are going to face the same discrimination and racism issues that they face when they go to the emergency room. The same sort of thing will happen when they go into the ACTU.

MR. STRYKER: We had a little discussion in our meeting with Fred Valentine, from New York, and with Wynne Graves, from here in D.C., about that whole set of issues and trying to tease out what the differential impacts of poverty

and the lack of access to this system in general is, and this kind of disaffection with researchers in general. That is something that harkens back to Mark Smith's testimony in Boston about the shadow of the Tuskegee syphilis study and other similar efforts overall by medical research in general.

MR. GOLDMAN: Just three points. I just want you to note the staff study group that we had with respect to the hemophilia community. That is another community that has problems with access to drug therapies which are based on a twofold basis, one of which has to do with the issues of co-morbidities that affect persons with hemophilia, but also with respect to geographic issues. The fact of the matter is that I do not think you mentioned terms of lack of access the problems that people out there in the midwest and in the rural communities, in terms of where they get access to drug trials and what they do. I think it is something that we ought to deal with in some way.

The last point that I would make is that I think we ought to say something about the fact that certainly I will be the first to be highly critical of much of what is done at and by the FDA. On the other hand, looking at its budget, staffing and leadership turnover or lack of leadership that

has historically existed, it is a wonder almost that it has gotten as far as it has. I do not mean that to be necessarily critical but the fact is that its funding is horrendous and it has a terribly important mission connected with the approval of new drugs and its role in the research process. From my perspective, it is clearly one of the more under-funded arenas in the health community.

MR. STRYKER: Yes, I think if we have any fingers to point, we want to be sensitive about where we are pointing them. I think those are some of Dr. Faucci's concerns in response to report number three. They wanted it to be clearly understood that NIH is not a healthcare delivery agency and to the extent that the problems are around accruing people to trials involve their getting into the system in the first place or paying for concomitant conventional care at the same time that they are getting experimental therapies, we ought to look to HCFA, to private insurers and to other places.

By the same token, I think the FDA has some problems but I was very sympathetic when Ellen Cooper left and she was quoted in JAMA as saying that she is sort of sick of being the whipping boy for the failure of other key

players to evolve possible candidate drugs. Clearly, we ought to recognize that FDA is sort of in a passive regulatory role and their responsibility is not to go out and find the drugs and sit around with the test tubes and the patients. They are to look at the data and see whether they are safe and efficacious under the standards set up. As you say, they have not really been given the staff to do that.

In terms of the geography issue, I mention it in this little narrative just in passing in terms of all the equity issues. If you conceive of research as therapy that people are entitled to, we ought not to have barriers in terms of age, race, ethnicity or certainly geography in getting people onto trials. Those are not sort of morally or scientifically relevant criteria.

We did mention in report number three, in terms of a little story of one of the women who testified about her travels, starting out in Florida, to get her child onto a trial that went through Duke and all the way up to Washington. Certainly, one way of looking at the system to see whether it is working is to see whether people are able to get onto trials and get trial drugs in ways that are not incredibly burdensome in terms of expense or travel.

The question of co-morbidities, the problems of doing research in hemophiliac populations especially, I just had a chance to quickly look at one of the largest briefing books in history, the one that you provided for your meeting a couple of days after this one on clinical trials. There was a nice little abstract about some of these issues and about how to coordinate research in that population. It is something that I hope to remember to put in. But if you keep reminding me, that would be a good idea.

MR. GOLDMAN: I am afraid I will.

MR. MAKANDON: I appreciated your including comments about the need to communicate information from the clinical trials to practicing physicians. I think that is an important link that does not get made.

The other point I wanted to make has to do with parallel track, which I do think has evolved for a number of reasons but one is to provide access to treatment for people who do not get onto formal clinical trials. I think it has been done without much consideration for what it means for both patients and also the physicians who do that.

I would actually urge the Commission to look at the two books that come when you want to begin to become an

investigator for ddC and enter patients on ddC and to follow your patients on ddI, which at least has a national investigators review board so that you do not have to go before each hospital's human subjects committee. Literally, the materials are totally different, require different information, different data and there is no consistency between the two. So if you are a physician who wants to enter patients on the parallel track, you literally need to do totally different things for different drugs.

That is a problem now that there are only two drugs on parallel drugs. If the number of drugs on parallel track expands, it is going to be totally impossible to keep track of your patients, what drugs they are on and who requires what data. I think one thing this Commission needs to do is recommend that there be a uniform system of monitoring patients and keeping track of data, and also beginning to do investigations on the parallel track because there are absolutely no guidelines at this point for any of that. I will be happy to send the books.

MR. STRYKER: When we were organizing this at the last meeting, we were encouraged to have people bring the books with them so that we could see what it is like to enroll

patients.

MR. MAKANDON: I think everyone in this room should see them. It is unbelievable. It would be good for everybody to just see it because it is an enormous process just to enter your first patient. Obviously, after you have done it a little bit it gets easier. But the systems are completely incompatible and there is no way they could be computerized at this point.

MR. STRYKER: I think your first point was also important because I think it is clear that that is one issue that has not been entirely resolved, the question of releasing information from promising trials to doctors and patients, either through or aside from the peer review journal process. Clearly, there is potential with the HRSA training/education centers which are taking an awful lot of money, or some other mechanisms to get information out more quickly and having one audience for the report being journal editors and scientific writers who are concerned about -- in AIDS it has been with AZT, with pentamidine, with corticosteroids and a number of the sort of celebrated examples of too long lags in getting information out.

MS. BYRNES: One of my observations from the

meeting we had in the office, and even talking about it again and highlighting it as being a problem -- it really struck me that they still do not get it. So that clearly needs to be included in our research section about dissemination of information to practicing physicians.

MR. PERNICK: Jeff properly mentioned the other areas of research which he was not responsible for. We have to somehow make reference to that, and if it is going to be an area of next year's interest of the Commission, that should be so noted in the report as well because people are going to be interested.

DR. DES JARLAIS: In an area that overlaps with other areas of research in access to healthcare, I think it would be worth noting in this chapter that there is a black market in AZT and ddI and ddC, separate from the parallel track, that is going on certainly in large cities. We ought to be sort of at least monitoring that much more so than we are because you see all sorts of interesting combinations of drugs being taken at the same time. To pretend that medications for AIDS are given out and taken only within an approved physician-patient relationship is missing an important part of the whole treatment of AIDS for many

people.

MR. STRYKER: And it seems that there is an interesting overlap of behavioral research with the literature on compliance. There are a lot of concerns about how people view research and whether they really take the drugs that are prescribed. I think that is a point very well taken.

CHAIRMAN OSBORN: Jeff, thanks very much. Holly?

MS. BYRNES: I mentioned to Holly that I would formally introduce her to you. If I have not done this already, it is a little bit late. I will also indicate a little bit about how it is that Holly got the assignment she did. Holly is a presidential management interne with the Centers for Disease Control. I came as a renegade PMI to Washington, D.C. and left the Justice Department very quickly. Holly has chosen to stay in her PHS assignment, which was much preferable to mine back then.

It was in response to Don Goldman's request that we really take a look at what, if any, implementation or ability to measure any implementation of the things that President Bush said in his March 29th speech could be summarized, highlighted and at least put in one place for the Commission to look at to see if there is some way in which we could,

either in summary fashion or evaluation fashion, comment on what, if anything, had happened since the President spoke on March 29th. Because it is in the statute and Eunice, among others, strongly encouraged us to monitor if we could the implementation of the recommendations of the presidential commission on the HIV Epidemic and that in some way we might also want to at least acknowledge that or include it in the report, I asked Holly, as part of her temporary assignment with the Commission -- she will be with us through the end of May -- to put together some discussion about those two issues, as well as to be the point person on summarizing some anecdotes around the implementation of the Ryan White Care Bill.

So to some degree, I do that by way of introduction of how Holly is assisting us; how it is that she came by her assignments and I think, in addition to any comments she may have about the materials Holly submitted, it would be helpful to Holly, myself and I think Molly Coye to know how you might like us to use this information in the report.

MS. TAYLOR: I will just say one thing about why you are probably wondering about why there is a separation between Molly's and my part at the beginning. That was

because we sort of had an understanding that mine would look at the federal response, apart from the public health response, and that Molly's would focus on the public health response. Since then the two have sort of clouded in the middle in terms of what Molly was relating this morning. So keep that in mind too. We will probably blend them together. Does anyone have any comments?

DR. KONIGSBERG: I think the operative word maybe is merge and integrate, hopefully, not cloud.

MS. TAYLOR: I was not advocating clouding. I meant that there is a clouding now that we would like to clear up.

DR. KONIGSBERG: Yes. The reports are very different and it would be up to your working together and your editorial groups to get this together. This report is a good report. It spent a lot of time bashing Reagan and Bush, perhaps for good reason. Do we want to take that tone or not? I am just asking the question. But it was a repeated kind of thing throughout.

CHAIRMAN OSBORN: Let me make a comment about that. I think probably we cannot really decide that well until very close to the end of the time that we write this report. I

think if President Bush remains silent -- that was March 29 of 1990 and we are into April of 1991 now and the only thing he has said since then was to do a little ACT-UP bashing in The New York Times last week, which is a pretty trivial bit of attention to pay to something as big as this.

So I think if that keeps going we may want to call for a little more constructive participation. I think you were talking very appropriately about leadership and we do need it. But I would suggest that we not debate that right now because what happens in the next little while would seriously influence the way the debate went.

Now that the war is no longer clouding everybody's borders, or seems not to be, the chance of getting domestic issues back into the gun sights is at least there. I think the next few months will be very critical to how I, at least, would approach that. Right now, every time I give a speech I quote his March 29th speech at considerable length and say "right on" and that sort of thing. So let's put that one on hold right now.

MS. BYRNES: And, again, the assignment was to go back and look at the federal response. The only two presidents since the epidemic have essentially been Reagan and

Bush and it probably there is lots of room to criticize but I think tone is important, and I think that is partly what you are raising as something we need to listen to carefully.

DR. KONIGSBERG: That is exactly what I am raising.

MS. TAYLOR: Do you have suggestions? When you say tone, I can certainly understand why. I am just wondering how you would put it differently, or how you would soften it, or what areas do you feel are too strong?

DR. KONIGSBERG: Yes, it is hard to sit here and try to actually rewrite the language. I think it is asking for what it is we want, and it starts with the leadership question, June. And I think you are absolutely correct, the leadership has to come from the very top. That means the President. It probably does not do a lot of good to say much about what went on during the Reagan administration. The leadership was not there. We can perhaps take note of that and then move on and say to President Bush, "this is what we want you to do." That gets into the tone rather than saying you have not done it. If we tell him what we want him to do, it implies that he has not done what he apparently said in that speech over a year ago.

MS. AHRENS: I think we have to ask the question in

this report what will move us to achieve our goals. I think in dealing with what has passed, we may feel very negative about it but to articulate that, would that move us ahead or is it simply going to turn off one-third of the Congress?

So by subsuming or consuming the issue of the federal government's role in terms of what Molly is going to be doing I think will move us ahead in what needs to be done. I do think, however, we need something, and it probably should be perhaps in the appendix, because we were asked to monitor what occurred in the presidential commission. By the way we do that -- if I were reading that, it is going to be pretty negative because I do not think a whole lot has happened. Somehow, I think that needs to be a part of the total report. Maybe it should be in the appendix but it should be there some place.

MS. FRANKS: I would use a score card approach rather than a narrative approach in showing what the implementation of the recommendations of the presidential commission has been.

I think one way to get around what we might describe as negative, Holly, is factual -- you know, just factual. It is not a judgment. This is sort of what

happened. Things like score cards -- you know, you do not have to attach President Bush's name or President Reagan's name. You can always say "the administration." There are ways to not be judgmental about what has happened. But I think you have done a tremendous job and I think it is a very important exercise to go through to be true to history and not forget what has happened because a lot of things that are not so good have happened. So then it becomes just what Diane said -- how can we further the cause, fully recognizing the history?

MR. GOLDMAN: I agree with Pat. I think that you can say that the fire truck drove by the fire three times without stopping and let the reader come to the conclusion that the driver was stupid, without having to say that the driver is stupid.

MS. FRANKS: Right. You do not even have to say who was driving.

MR. GOLDMAN: And you do not necessarily have to say who was driving. That is correct. You can essentially lead the reader to that conclusion, if you wish, rather than coming out and saying it. That is all for now.

MR. PERNICK: There are, obviously, a couple of

grey points about this otherwise well done paper and I really commend you but I wish you had talked to me earlier. You should not personalize the issue. President Bush may or may not have made a policy statement. In this case he did, and that remains the federal government's policy statement. He is not expected to say something every day. The fact that his wife has made a big point of going out and visiting patients with AIDS or people with AIDS and making various statements about the children who are affected, that in itself is something that does not belong in here but I suspect that at least some of us should feel that it is reflective of the man's personal attitude. That is why you have to depersonalize the issue.

If we want to criticize the administration, that is a separate issue. Sure, he is in charge of the administration but, let's face it, a lot of us write the policy papers and decide the policy issues and make the recommendations to the President and while he can say, "no, I want to focus ten billion dollars on AIDS" instead of whatever the figure is, and he has not done it, I do not think that is criticism of him in as much as he is being squeezed on all the other budgetary needs as well. That is all I will say for the

moment.

DR. DES JARLAIS: In terms of changing people's behavior, it is very important to reinforce their good behavior. I think that is a very, very important thing to keep in the tone and in the overall report.

I think it is appropriate to personalize things when a leader of an administration sets his own standards for what should be done. We should feel quite free really to both reinforce a number of the things that Bush has said, that Sullivan has said and other spokespeople for the administration and Congress have said, and then simply push for consistency between policies and actual implementation of them. The one place where it is worth personalizing is where people have said "this is really what we should be doing."

MS. FRANKS: That is a good point.

MR. DALTON: Yes, I am all for reinforcing good things people have done. The question, of course, is how much good has been done, for example, with respect to the presidential commission's recommendations.

In any event, I think this conversation is really about the use that we make of Holly's document. I take it, it is something about which there is probably little disagree-

ment.

MS. BYRNES: And to some degree again, I have to say in all fairness, the assignment was not to go back and say the good things that we can stand on. I thought we were asked to sort of go back and measure how much had been done in terms of the recommendations and in terms of the President's speech. And I thought Holly hit it right on the head. I think there are questions about what we choose to do now that we have talked about it again.

MR. PERNICK: I do not have any problem with that. I think it is very important, since this Commission is looked on almost as a successor to the presidential commission, that we see what the presidential commission came out with, what recommendations, and we then look at what implementation everybody involved has put into following the recommendations of the presidential commission.

What I am saying is that we should not go out and say, well, the President said this on March 5th and he has not done it yet. That would be self-defeating and that would get us a black eye. Really it would probably serve to create an issue that the press would love to jump on, that is, contention between the Commission and the administration on

this issue, where you have three administration members as Commission members.

CHAIRMAN OSBORN: I think we have reached the end of the line and I think that is probably just as well because I think people are getting a little tired. Diane?

MS. AHRENS: I do think though that the score card approach in the appending relating to the presidential commission is perhaps one that we would want to move on.

MS. BYRNES: Holly, is this okay?

MS. TAYLOR: Yes.

MS. BYRNES: Holly is not the first person to try to look at the implementation of the presidential commission recommendations. Nicole Ryan in the office has been working on that. Karen Porter has worked with Nicole. Janice worked with them. Holly came in with a lot of experience. It is very difficult to do a score card or even make some statements about what, in fact, has happened to even a number of the 597 recommendations.

It was on my advice that I encouraged Holly to write about why that process was even so hard; that we needed to look at why we cannot make sense of information that is collected.

DR. DES JARLAIS: In part, that is the fault of the presidential commission. They did not write recommendations that were realistic in many cases and in many cases they did not write recommendations that you could follow up in any rational way. I think it is important that we avoid that trap also. Holly has made a real good effort to try to track those things and it makes you realize that part of the problem really goes back to the way that commission made recommendations, and we need to try to avoid having those same problems in our recommendations.

MR. KESSLER: They made some dumb recommendations too actually among the 597, which people do not always remember, given that they had such a wonderful theme of no discrimination and stuff.

DR. KONIGSBERG: Maureen, you have done an excellent job of making me feel very guilty. This was not an attempt at Holly bashing as opposed to Bush bashing or Reagan bashing. So since I started it, I will try to make it clear that the issue was not content. The issue was tone and I do stand by that one.

MR. DALTON: Apropos the question of the difficulty of tracking what happened with the recommendations, I suspect

that Don is right that in part it is a function of the particular recommendations that were made by the presidential commission. But I take it that the difficulty that we have had is also in part a function of the fact that if you are an agency and you have not followed through on a recommendation, it is much easier to, in effect, stonewall in your response than it is to simply come out and say that we have not done squat and we never will do squat.

I think we need to give some attention to whether there is some way to create a mechanism by which we can get feedback on what happens with our recommendations.

CHAIRMAN OSBORN: As a matter of fact, Irwin, I am disagree with you just a little bit. We have not even gotten a letter back since our first set of recommendations. I believe that should have happened.

MR. PERNICK: Just on a procedural matter, I cannot even begin to suggest where all the recommendations are on how to handles these particular reports. I mean, obviously someone in the White House, perhaps the Domestic Policy Council of maybe even the President himself, just decided not to respond and not to recommend that the President respond,

and that is a failure. But I do not know how to handle that, except that we do have people in three agencies -- two represented here -- that probably should get their commission members to pay some attention to it at least at that level, you know, when we issue a report or when the Commissioners issue a report and write to the White House and say, "hey, it's about time you got the President to say something about this damn report."

CHAIRMAN OSBORN: In point of fact, we have done all of that with considerable energy and no return in the recent past. So while I agree with your general tone, tenor and the way one deals at this level and does not personalize because it is not the way things happen, I think there may come a point before this comprehensive report where we need to say something about that sort of thing.

I am glad that you are aware of the opportunity to be a non-voting member because back when we were doing, for instance, the immigration thing, that is how we handled that. We said something that was very much not administration policy and I was asked maybe five or six times in a press conference whether Secretary Sullivan agrees with this and I said that Secretary Sullivan is not a voting member of the

Commission. And they asked another time and we went through that several times. Finally, I said that if they were asking me if the non-voting members voted, the answer was no. That took care of it.

I would continue to do that. If we do not get a little more responsiveness by the time this comprehensive report comes out, I think it would be derelict of us not to say so. Given the very strong personalized statement the President made on March 29, 1990, the fact that following about two weeks nothing else has happened in a dreadful epidemic -- I think this Commission has to retain the right to say so in reasonably unusual language because this is a reasonably unusual circumstances, and a disastrous one for many people who could have stood for some leadership. I think we have to make that an issue as we go forward.

As I now say sometimes when I am feeling particularly tired, the Commission has been extended. You are looking at a genuine point of light because, in point of fact, we are all doing this and if we are shouting into a vacuum tube, that is just not sensible. We could all go home and do our jobs better. So I have some strong feelings about this.

While I take your point, I think we must as voting

members of the Commission retain the stance that we may need to say something that is a little louder than usual.

MR. GOLDMAN: Two comments. First of all, none of us has fallen in love so much with the limousines that this Commission provides that we worry about what we say. I think all of us would prefer to say the truth and let the chips fall where they may. Once upon a time, I once thought about the question if the President chooses to reinstate or continue this Commission whether or not that is indicative that we have not spoken loudly enough or strongly enough and whether or not that would be a failure for being continued. I guess I have been dissuaded from that perspective but certainly nothing is going to persuade me from the proposition that I am not going to temper what I urge the Committee to say with the idea that we ought to stay on for another day or continue the dialogue for a long period of time. The truth is more important than that.

The other point that I would make with respect to the president's report, I think there is a good deal of truth to the problems being presented by the nature of the questions themselves. The fact that we were charged to follow up on the presidential report in terms of our legislative mandate

does not mean that we have to follow up on 529 of 592. We can be selective. There are some that are measurable and --

MS. TAYLOR: It is 113.

MR. GOLDMAN: But there is some set that we can come to some conclusion on, it would seem to me.

MS. TAYLOR: The thing is that we have information on 113 and there has been follow up on a set of 113 with the agencies. But the response we get is unevaluable. It is no change or we are sort of doing something that is sort of related. You cannot evaluate them -- you can by saying that there is no change, and that is it.

MS. BYRNES: Don, I have argued that we could limit it to two. We have the Americans with Disabilities Act; we do not have treatment on demand.

MR. KESSLER: Just a point of information that tomorrow is the unofficial tenth anniversary of the beginning of this epidemic. That is, the first case went in ten years tomorrow. I am sure that the President intends to address that on television tomorrow night --

(Laughter)

However, if he forgets or does not, we can get him on the official date, June 5th, when the CDC report came out.

So be hopeful.

MR. PERNICK: The points that Holly made are very well put into a report as an addendum to our report, stuck right in the report saying, "hey, listen, three years ago the commission that preceded us came out with some 500 recommendations and we have only found evidence that 160 or so have been implemented to any extent, not even to the full extent. We just want to make sure that you, the President, Congress and the world knows about this." That is all. Let the President get angry at that; that is fine.

MR. DALTON: I just wanted to recognize something that is implicit in what everyone has been saying, which is that being able to say "I didn't have a vote" is not -- I do not want to put it in terms of protection -- the role of the three secretaries on this Commission I think is a complicated and difficult one. Simply being non-voting members does not mean that if we are perceived as Bush bashing their lives continue happily along. So I think we ought to at least recognize that. I do not know that that changes anything ultimately but I at least want to reflect, Irwin, that I understand that that is a problem.

CHAIRMAN OSBORN: Let me point out to the Commission

that our second report, to which we have not yet received a response, called for a cabinet level coordinating structure to help with the incredible difficulties of this epidemic. It was issued more than a year ago. We have not yet received a letter acknowledging its submission. We continue to discuss as if somebody were listening and I think we really must take this fairly seriously, otherwise we should be doing better things with our time.

I am sorry to be so strongly spoken from the Chair but I do not think this is a trivial issue. I think our continuation can serve as a deadly layer of oil on very troubled waters, about to boil, if we are not strong spoken about what needs saying. I really feel very strongly about that, as you can tell.

I think Irwin's comments about how one discourses with people at different levels of government are very well taken and reflect deep experience. I think, however, you also know that we are not bad at that. When I interjected at the beginning, I was trying to say let's decide what tone we take when we see where we stand. There is no sense in writing language that is angry now and having things go great. There is no sense in writing happy language now on the assumption

things will go great and end up so frustrated that we are overly angry when we get there. But I do think we have to be aware of the fact that we are being stonewalled, if you will -- pardon the expression. We have to get past that point.

We have to beat our heads against the wall to get a letter of reappointment as opposed to a silent continuation through the OMB budget. That is improper. We have twelve people who are totally volunteer members. We have been spending X, Y and Z days a month working hard to try and make things go.

The earliest question that stopped me when I was a fifth grader and I had a teacher who was being a little sadistic, actually, was "if the tree falls in the forest and there is nobody there to hear it, did the tree fall?" I cannot tell you how many times that has come back to me in the last couple of months. The trees are falling and we have to make sure somebody hears. And we cannot decide now how to say that but we must keep open the right to say it because that is our primary job. If we do that, we can screw up a lot of the rest of this. If we do not do that, a beautiful report is not going to help.

MR. DALTON: I am hardly going to take issue with

you, June. I am delighted to hear you say that. My comments recognizing the dilemma of cabinet secretaries and their representatives was hardly meant to suggest that we should not speak forthrightly and passionately.

I think you remarks, however, say something about who our audience is. I have felt for sometime that we have inappropriately focused on the President and, more broadly, the administration as our audience. I have long since concluded that nobody is listening. I continue to harbor hope that Congress or at least some members of Congress may be listening. I know damn well that the AIDS community out there is listening.

MS. BYRNES: I think we are adjourned.

(Whereupon, at 4:30 p.m., the Commission adjourned.)