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THE NATIONAL COMMISSION ON AIDS
WORKING GROUP ON FEDERAL, STATE AND LOCAL RESPONSIBILITIES

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VOLUME II

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APPEARANCES: January 5, 1990

Working Group Meeting on Federal, State and Local Government Roles

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(WHEREUPON, the following proceedings were duly had:)

MS. AHRENS: Good morning and welcome to this second day session of the Working Group of the National Commission on Aids. Pat Frank is, I must say, very skilled at this and she is going to facilitate the discussion, sort of give us a focus as to how we're going to approach the task that we've got and I'm going to turn it over to Pat and she is in charge.

MS. FRANK: Thank you so much Diane. What I'd like to do this morning is take about 15 minutes to do in this introduction 4 things: I would like to review the goals of the work we've had for day 1, for yesterday, for the testimony and questions; I'd like to define our goals for today; I would like to define our tasks and our time lines for today, we have such short precious time to work with each other, from about 8:30 o'clock to 1:30 o'clock; and I would like to define our process today in this first introductory session.

Our goals yesterday -- we had three goals and they were very simple ones. We wanted to know who is doing what, we wanted to establish priority policy per in service areas related to HIV disease for different levels of government, federal, state and municipal, and answer the question, who is doing what?

The second thing we're going to do is to delineate major problem areas related to federal, state, county, and municipal roles and responsibilities related to HIV disease. What isn't

working? That was our second question.

And the third thing we want to do is get views from the municipal, from the local, from the state and the federal levels about what would work better. What should federal and state and local roles and responsibilities be in specific areas? I think that we achieved those goals yesterday in our testimony and questions. And what we would like to do today is to pick up where we left off and basically to focus on goal three.

What we're going to do is summarize our day one findings related to those three goals and we're going to focus our work together on goal three. What should roles and responsibilities be in key areas of the federal, state, county and municipals, what would work better? And then we would like to get a consensus or a sense of the group in at least five areas of these key areas and then we would like to summarize and wind up our days work so that we have a very clear-cut path here together.

You heard me talk last night about respectful engagement. I believe very strongly in respectful engagement. I also believe very strongly in a collaborative problem solving mode in which we're here and I guess I learned something from the Stop AIDS Project in San Fransisco from sitting on the board. It's probably the most important lessons I've learned and that was: trust participants when you're working with a good group of people, that you trust people to be able to work with you to

define problems and define solutions. That's what we're about here today. We want to have a product and that product needs to be a report of public findings of the work group that will go to the commission at the end of this month. And so we need to be task oriented and we need to be product oriented and we need to be efficient and we also have someone who is trying to take all this down so one of the things in terms of process that I'm going to ask you to do is the first time you speak to identify yourself.

I'd like to take the next 15 minutes and summarize our findings from day one in terms of our themes and things that we heard on day one, and then I would like to from about -- for the next 15 minutes define areas in which roles and responsibilities are fairly clear and don't seem to pose problems in intergovernmental relations. And also define areas in which roles and responsibilities are not clear or where there are problems in intergovernmental relations. Then I would like us to define five priority areas and then I would like to take half an hour in those areas and really get down to the nitty-gritty in those areas. That's about it, that's what I have planned. I'm going to make it very simple. I want us to be -- some of the themes that we've talked about, I think we've had some wonderful themes from yesterday and I'm sorry that Anna (ph.) wasn't here because I want to start with his quote to guide us, well, it was really Thomas Jefferson's quote, "The care of human

life and happiness is the first and the only legitimate object of good government." James Smith said the second part of it, he said there was, "Great similarity between policy makers and physicians in terms of the care of the people." I would like that to be our guide in thinking about the roles of government and the levels of responsibility. My colleague, Tim Wolfred, said another thing that "Government shouldn't do for us but help us do for ourselves." That's the philosphy that I bring to you today which really reflects back what we have told each other about government. That was one of the themes. I think the two major themes were around words that were said -- I went through and I read the testimony and I went through my notes this morning at 3:00 o'clock. I got up and I was fresh and I went through and I said, "What were the words that recurred most often yesterday?" Two words, leadership, with or without the word moral attached to it, and partnership. Those were the words most often used yesterday. I think the other word that came up quite a lot was relationship. Those three words, leadership, partnership, and relationship. I think in defining individual roles and responsibilities it allows us to define relationships and then also to respectfully engage. I think that in functional relationships -- functional relationships are reinforcing, they're supportive, and they're enhancing. Nonfunctional relationships or dysfunctional relationships are adversarial, they're competitive, they're depictative, and

they're depleting and I think as we clarify individual roles and responsibilities we can also then include our intergovernmental, interjurisdictional relationships.

We discussed many relationships, federal to state, federal to county, federal to municipal, state to county, state to municipal, county to municipal, all these different relationships. And some of them sounded like they were very functional and some of them sounded like they were very dysfunctional. In terms of -- I think one of the major challenges that is posed by the AIDS epidemic is that it crosscuts so many different policy and programs in service areas: civil rights, public health, health care, social services, substance abuse, prevention, treatment. So here we are, we're trying to cut across all of these policy and program areas, cutting across all these levels of government. And we're also talking about not only the different levels of government but also the different roles of government. When I think about roles of government, I think that government plays a policy setting role. The tools in the tool chest of government are a policy setting role, a regulatory role, a planning role, a technical assistance capacity building role, a role of organizing services, delivering services, and financing services so that there are a whole lot of roles for government. That's basically what we're going to be talking about. We're going to be talking about the areas and then we're going to be talking

about the tools in the tool chest of government and try to get some clarity. I'm going to ask Maureen to help me. She said that she went to a Catholic school and had the best handwriting and that is why she was chosen for this task.

MR. STOUT: I have a request. Since I'm not on the commission and have followed the activities from a distance, could we just have a real brief -- of what's going on with the rest of the commission? Are there other committees, what are they doing, just a little brief summary about that? I'd just be interested to know.

MS. FRANK: Diane?

MS. AHRENS: I don't think I'm really the one to really give you the update on that. If Maureen feels that she could do that?

MS BYRNES: At the November hearing of the full commission where we looked at a variety of issues related to health care and concerns about financing it became clear that not only was that a complex issue but there would be other issues that the commission would want to focus on that would take a good deal of time to do them well. So the Chairman, June Osborn, with the support of the entire commission thought it might be helpful to appoint at that point in time two small working groups. The first would be the group that Diane is chairing, the one that we're participating in in terms of responsibilities of federal, state, and local government. As

the commission looked at what was being considered and recommended in terms of health care changes in the system one of the issues that came up was who was responsible for what parts? So it was a piece of some of the findings from that full commission meeting in November that really initiated the concept of this small working group. In fact, in a letter to President Bush on December 5 that the commission put forward discussing the highlights of the testimony from the November hearing, the commission clearly stated that one of the things it would do would be to look at what the different responsibilities and roles in the various levels of government, as well as the private sector, is in responding to the crisis of the health care system. So this was clearly a follow-up to an issue that became clear to the commission needed to be addressed but perhaps could best be addressed in small group settings that then reports to the commission. The full commission will decide at its January meeting what to do next when they digest the findings of this report and they look at what the issues are. It might need some follow-up from there, it really will at that point in time be decided as to where we will go once this full working group has made its report to the full commission. There's another working group that is termed Social Human Issues. There won't be that variety of issues associated with the epidemic. I think at this point in time they're seriously considering looking at the issue of testing and narrowing that

topic down to look at particular areas within that broad topic of testing and they will report on their progress to date at the January meeting as well. They have not convened yet as a small working group. I also should say to those who may not have a copy of it, I did bring some extras of the letter to President Bush and I think that might help if you would like to take that back with you because it does clearly have a section in it about the follow-up of looking at the roles and responsibilities of government in the private sector.

DR. KONIGSBERG: We also talked about a group meeting on the public health system except we weren't sure whether to have this kind of group or just have a day of testimony so Jane has been working with me on that trying to come up with an agenda. I don't know that we've had a formal group.

MS. AHRENS: I'd also like to say that by census that as the commission continues to meet it will become obvious that there are other issues that are before working groups and so this is just an evolving process. We just happen to be the first, I think there will be many.

MS. FRANK: Does that help?

MR. STOUT: Yes, thank you.

MS. FRANK: Does this make sense what we're doing here today? Does it make sense to have a conference that is followed by discussions about leadership and I thought let's

not talk to much about leadership, but it's about leadership. And Diane said, "It's taking hold of an issue." It's taking hold of an issue, it's inspiring people, it's providing a vision, it's calling for the best in people to deal with the problem. It's a vision, a notion, letting people know what are the ramifications of action and inaction related to the problem. Where it's taking hold of the issue. Let's move things. I think what we need to do is to get up on the board if we were to summarize the policy program and service areas that we discussed yesterday, there were about ten of them, and the first one I'm going to give you -- this list here I think will be easier to work with, it's sort of a summary of the issues. The ten issues that came up were anti-discrimination of civil rights and under that education, employment, housing, and public accomodations as well as insurance. Discrimination, that was the first policy in the program or service area. The second one was public health insurance, Medicaid and Medicare, basically Medicaid. The third was health care for the uninsured. The fourth was private health insurance and health maintenance organizations.

MS. AHRENS: Pat, could I just ask for some clarification? With these issues, could you just tell me what you intend to do with these?

MS. FRANK: Yes, I will. That's why I'm putting them up there because I want your help in deciding what we're going to do with these issues. These were the issues --

when we reviewed the testimony, these were the issues of the federal, state and local responsibilites, these were the issues that came up. It's a summary of these issues.

MS. AHRENS: Either addressed or unaddressed?

MS. FRANK: Yeah. Issues that people raised. The fifth issue was patient care and here we talked about acute care, long term care, and drug treatments. The sixth issue was social support services and there was a long, long list under this issue. The seventh was housing. The eighth was HIV prevention/education information. The ninth was substance abuse prevention and treatment, and the tenth was planning, capacity building and technical support or technical assistance.

DR. KONIGSBERG: Pat, I want to ask you just as a point of clarification.

MS. FRANK: Sure, Charles.

DR. KONIGSBERG: These are policy issues that relate to the functions of government with respect to the AIDS issue in general?

MS. FRANK: Yes. These are policy programs and service in areas -- they are policy program in service areas that are related to HIV disease.

DR. KONIGSBERG: Let's see, you've got -- I've got a point I'm trying to make just to see if it's in there. You've got a prevention item?

MS. FRANK: Yeah.

DR. KONIGSBERG: Would that then include government functions with respect to some traditional public health measures?

MS. FRANK: Yes.

DR. KONIGSBERG: Okay. I wanted to be sure that we didn't leave that out as a function of --

MS. FRANK: No. That's prevention, education, information.

DR. KONIGSBERG: Because that is a function of state government in particular, and to a great extent local government as well.

MS. FRANK: Yeah. And of course to the CDC along with that.

DR. KONIGSBERG: Okay.

MS. BYRNES: Pat, would you review nine through the end again real quick, please?

MS. FRANK: Yes. Nine is substance abuse prevention and treatment, ten is planning capacity building and technical support, technical assistance. So this is what we talked about together yesterday in the morning and the afternoon. These were the issues and when we looked at areas in which -- I think we should add a couple, maybe we should add a couple to this. Let's add research as number eleven and drug and medical device regulation and blood and tissue supply protection. I think that was a pretty good summary.

MS. AHRENS: Pat, there is one that I remember Jim so clearly saying when we asked him the major problem in New York and he said, "Well, it isn't really money -- it is money but that's not the major problem. The major problem is human resources," and maybe that's covered when you talk about hospital/patient care?

MS. FRANK: Well, no. I think that would probably be covered under capacity building.

DR. ALLEN: I think that it is such a critical area, I think it ought to be either standing alone or put in a specific line in there, a sub-point as we have for some of the others.

MS. FRANK: Okay. Now, I have done my best so let's go for it. What do you want to add to this list? This is what I got summarized, let's go for adding to it. Human resources we want to add?

MS. AHRENS: I wonder if that really says it clearly enough?

MS. FRANK: Health care personnel power? What do we want to call this?

MS. ASHTON: The recruitment and retention of health care personnel.

MS. AHRENS: Well, that would make it specific. I like that.

MS. FRANK: Okay.

DR. ALLEN: Let's put training in there, recruitment training.

MS. ASHTON: Yeah.

MS. FRANK: What else is missing from this list that falls under a policy, a program, or a service issue related to HIV disease in the United States?

MS. ASHTON: What about surveillance?

MS. FRANK: We could break -- it's under prevention, education and information but let's break epidemiologic surveillance out. I have a sneaky reason for doing this.

DR. KONIGSBERG: Yeah. I don't know what your reason is but I agree with it, whatever it is. I think that some kind of priorities like public health control -- I think we tend to talk a lot about prevention in terms of peer education and I think that surveillance is a key issue and it's an important part of any epidemic whether it's infectious or not, it's a critical element of public health.

MS. ASHTON: It's critical in planning.

DR. KONIGSBERG: It's critical in planning. We don't know a lot about this epidemic yet. I mean, these fakey figures of a million and a million and a half, or two million.

MS. FRANK: Are there other major areas that federal, state, local, including county and municipal government

that are important relating to the HIV epidemic?

MR. BULGER: Pat, included in number five I would add primary care.

MS. FRANK: Primary care. Before acute care?

MR. BULGER: Before continuum of care beginning with a line right through primary home care for that matter depending on how specific you want to get.

MS. FRANK: Yeah, okay, let's do that. We're going to leave evidence of this on the wall for the Hotel Saint Paul, right?

MS. AHRENS: That's all right, they're redecorating.

MS. FRANK: Anything else that we think is missing?

DR. KONIGSBERG: Public health from the laboratory aspects and I'm not sure where that belongs. It probably goes under one of the categories, it's not strictly health care, it's partly --

MS. FRANK: What kind of category would that go in, Charles?

DR. KONIGSBERG: Well, I don't know. The state territorial lab directors are struggling with that issue too except they convinced me that that's a major issue and it doesn't belong strictly under the health care delivery, it would be somewhat under prevention, somewhat under epidemiologic and

surveillance. I'm not sure.

DR. ALLEN: We could broaden five and say patient care and associated support services.

DR. KONIGSBERG: Except that the laboratories are looking beyond, they got really tied in with the early intervention and the prevention and weaving the prevention into that, that's why Don Francis (ph.) was there.

DR. ALLEN: Well, certainly there is a component under capacity building, there is a component under the recruitment and the retention of training health care personnel, there is a component under quality assurance.

DR. KONIGSBERG: That's true.

DR. ALLEN: None of which are there.

DR. KONIGSBERG: Research too.

DR. ALLEN: Yeah. There probably ought to be a number sixteen, laboratories and recognizing it. We're now beginning to get into crosscutting areas there.

DR. KONIGSBERG: Yeah. So do we want to put that in there?

MS. FRANK: What would you like to do, I'm going to rely on you.

DR. KONIGSBERG: Well, I don't see there is any harm in putting it in there and being inclusive here. We can always collapse it later.

MS. AHRENS: We need another number.

MS. FRANK: I'd like to be always inclusive first and then --

DR. KONIGSBERG: You may want to reorganize and then it might take a different form later.

MS. FRANK: Well, more important, we're interested in the issues.

MR. KESSLER: I don't see partnership of nongovernment entities.

MS. FRANK: Public/private partnership?

DR. KONIGSBERG: I'd put private and nonprofit up there.

MS. FRANK: Is this in the same category of things?

MR. BULGER: Maybe a question is necessary now. I see a list of functions here that various levels of government can and should be involved in. Is out intent now, once we have this list complete, to identify the roles and responsibilities of government entities in the private sector with respect to these?

MS. FRANK: Our charge is not private sector specifically, but we're basically going to go across these areas and then we're going to work at -- maybe the other thing we need to do is go back and look at the functions of government, the policy setting function, the planning function, those things. That was the matrix that I thought we might use to go and look

across the federal, state and local levels. Do we want to get those up as part of the matrix because we can change this.

Let's put down roles of government. And the first one is policy setting, planning, program development, program administration, organization of services, delivery of services, regulation, monitoring and evaluation, technical assistance and capacity building, and financing.

DR. KONIGSBERG: What about assessment?

MS. FRANK: What does that mean, Charles?

DR. KONIGSBERG: It means determing what the problem is, the extent of the problem. You theoretically do that before you do policy setting and planning. That's where --

MS. FRANK: It's part of policy setting and planning; isn't it?

DR. KONIGSBERG: Well, it's part of it but it precedes it and that gets -- it's part of what you do with surveillance and epidemiology and surveys and --

MS. FRANK: What would we call that?

DR. ALLEN: Planning?

DR. KONIGSBERG: Well, to me assessment is part of planning.

DR. KONIGSBERG: Well, the Institute of Medicine Report on the future of public health lists three very broad functions of public health which I think maybe are too broad for our purposes here. The first one is assessment, the

second one is policy development, the third one is assurance. If you look at the ones you listed, you've got policy development and assurance in there differently broken out but the assessment is what I don't see.

MS. FRANK: Okay. Do you want to put it in?

DR. KONIGSBERG: I would put it in as a category.

MS. ASHTON: There is one thing that bothers me about this list.

MS. FRANK: There are a lot of things that bother me about it. What is it, Sister?

MS. ASHTON: Well, it's not particularly unique to government. You could apply this to almost any organization.

MS. FRANK: Yeah, that's right.

DR. KONIGSBERG: That's true.

MS. ASHTON: So if we want to talk about what are the specific responsibilities of government in this area, it seems to me we need to be think a little more.

MS. FRANK: If we were to take this list which could apply to nonprofits or the private sector or institutions in general, what is it that government -- if these aren't really roles of government or institutions, public or private, what is the role of government then that's different? What's unique?

MS. ASHTON: It seems to me it's -- it has more to do with being sure that these are in place for whatever the needs are, that's why maybe assessment isn't important and then either reporting on those responsibilities that another organization can't do or because of the clientele that's involved it needs special attention. I don't know how to say this exactly, but it seems to me we're more filling in the gaps then assuring that things are in place, more than taking the inititive to put them in place if somebody else is capable.

MS. FRANK: Is that the role of government in the United States at this time, to do what the private sector can't do as a gap filling effort rather than a proactive? I think that's a --

MS. ASHTON: Well, I think it's more than that, but --

DR. KONIGSBERG: I would argue for a more proactive approach on the part of the government that gets at the assurances and it doesn't mean that we would do it all but that some group has got to take responsibility for identifying the problem and assessing the problem and bringing the people together. I think that's a legitimate role for government, and it's not to say that any level of government has the sole responsibility to do it, to do the hands on, but I think people look to government, particularly with a public health issue and that's what AIDS is, that's what HIV is, to identify it and to

follow through with the leadership. I think when we listened to some of the testimony yesterday the best examples of state and local response would lead one to the conclusion that government was taking a leadership role, was taking ownership. That might be another word we could throw in with your leadership definition.

MS. ASHTON: Well, perhaps what I'm saying is it depends on how you're using this role for government, if this is just general roles of government. That's what I'm talking about. If we're talking about it as it relates specifically to these AIDS issues then I think it might be appropriate and I would agree with what Charles is saying.

MS. FRANK: Right. If we take, for example, if we run patient care through that grid and we say, "Well, gee, the counties organize and deliver services, states also organize services, and everyone finances and contributes to the financing. That's what I want to do is run these things through the grid so that we can see how the different levels of government leveled out as it related to these functions. Does that make sense?

DR. ALLEN: There are several things on this list that really I think are unique or almost unique to government regardless whether we're talking about AIDS or some other type of problem. One of them, for example, would be surveillance. I would argue strongly that there is no private

organization, nonprofit organization, university setting or whatever they're doing in surveillance. They don't have the legal responsibility nor do they have the protections that are there for government.

DR. KONIGSBERG: That's right.

DR. ALLEN: Similarily, regulation is something that is almost uniquely a government function.

MS. FRANK: Okay.

DR. ALLEN: You can probably pick out other areas but those are two.

MS. FRANK: So then some of the government's roles come from statute and they're legal and some of them come from tradition?

DR. KONIGSBERG: Yeah. I don't think anybody is suggesting that most -- and I agree with Jim completely on what he said but I don't think anybody is suggesting on these others that these aren't shared responsibilities.

MS. FRANK: Right.

DR. KONIGSBERG: I mean, I think that in our system of health care in this country is already a shared responsiblity of public and private and that's been true for AIDS as well. I think that in terms of private responsiblity, the Robert Wood Johnson Foundation, for example, has been very influential in program development and in technical assistance and capacity building. I mean, as much as anything else the

foundations contribution to the community -- I mean, I left Florida when the health services project was building capacity. I mean, that put us so far ahead of just a whole lot of things it transcends the money. So there is that role -- Jim is right, there's some unique things that are strictly government that we need to identify.

MS. FRANK: What are some of the other elements other than the ones that Jim has already identified, that are unique, and I would say essential roles of government? Not only unique but essential roles of government?

MS. AHRENS: Pat, I think I'm going to go back to what Commissioner Ashton was -- what I think was trying to say, and I'm not sure how to say it but I'm uncomfortable with this too because -- and maybe it takes an introductory statement when we get into this. But the role of government is to assure that whatever we're looking at -- and it's AIDS at this point -- that services are provided in a sense to all the people. Now, that's not the role of private industry. I mean, government has to serve the people and that's what the Declaration of Independence, I think, says and maybe you get at that by some kind of general statement as you put this report together, but I think there is some assumptions here that we have to make where we are different from anyone else, any other institution.

MS. FRANK: I guess I'm trying to understand

if there are other differences between the public sector and the private sector in the United States?

MR. JONES: It seems to me that the more disenfranchised a particular group of people are their expectations of the government or the private sector are there, and I don't think perhaps the government responds as well as the private sector responds to the needs that are going to be there. And so some of that has to be taken into consideration that even we who get assembled are going to present different -- we're just going to come with different expectations based on, perhaps, how needy we are at that particular moment or it could be the degree of the crisis existing how much we call upon the government.

MS. FRANK: Related to government, related to the role of government, yes.

MR. JONES: And then eventually as we help them, and I think as Tim said, the way to help those groups is to empower them to take care of themselves and then they will begin to pull away from the government and try to do this for themselves. Part of the government role is going to have to empower individuals to take care of themselves, to do for themselves. And if we fail to do that, if the government gets into a position of saying, "You must rely upon me," without providing that training and technical assistance to become empowered, then the government has set itself up to forever

remain impassed.

MR. BULGER: My understanding, and it may be limited, of what we're trying to do in this first phase is basically to develop a matrix where you have these functional areas from assessment right on through to monitoring evaluations, go over the top, across the top, and then what we call the service area, we want to identify what levels of government are responsible for what functional areas?

MS. FRANK: Yes.

MR. BULGER: It would seem to me that everything I've just heard in the last ten minutes is consistently what we want to do because if you begin with an assessment process or a planning process whether they're emerged or separate, that process should identify, assess the needs, and if it's done right it should identify who is going to address the needs.

MS. FRANK: Right.

MR. BULGER: And then you step through the rest of the horizontal line. After that there's financing or monitoring evaluations, et cetera.

MS. FRANK: That's right. Are there other thoughts about that?

MR. STOUT: I agree with that. I think we need to proceed and decide what needs to be done and then get on with who does it and how you do it. Now, at our particular

local level we've finally come down to the fact that we see what the problem is and then we look at the resources that are out there and we don't have a set pattern for solving a problem. In fact, our response to this crisis in our community involves both the public sector and the private sector. We help the Department of State and Relief, we have a very strong hospice, we've put county money into hospice which is a private nonprofit organization and they help deal with the problem. So I think that's how we're going to finally solve the problem amidst all these resources but the government is going to have to take the final responsibility for seeing that it's done, not necessarily for doing it but seeing that it's done. I want to say one more thing about the difference between the government structures and economy structures. The government is about 40 or 50 years behind in management theory, that's the problem right there.

MS. FRANK: It's true.

MR. STOUT: At least 40 or 50.

MS. AHRENS: Don't get Herb started on that.

MS. FRANK: Yeah, I was going to say that. No, I wasn't going to say that. Lori?

MS. PALMER: Is it your desire that we proceed forward then on the 16 things?

MS. FRANK: No, certainly not. My desire next is that we go through -- I think what I want very much is to have us agree on a sort of analytic framework. We need to

have an analytic framework to make use of what we've learned. I guess I'm trying to test this more to see if this makes sense except early in the morning in my hotel room. So I'm trying to get you to work with me on that. Then I want us to go through these 16 -- I'm going to go through and say, "These are the ones in which I think responsibilities are fairly clear from testimony yesterday and intergovernmental relationships do not pose a major problem." We're going to cut those out. Then we're going to go through the problem areas and we're going to choose 5 that are the most important to people in this room and that's why we're here today, is to choose major priority areas, and that's my understanding. Only it can't be 20, who's going to listen to us if we do 20. We really need to narrow it down to 5 things. So that's where we're going. Please ask me -- this is a -- you know, I don't want to make it feel like a civics class. I see us all getting really uncomfortable and saying, "Oh, God. Why are we talking about government?" I think we have to because I think the role of government at all levels has changed immensely since the early 1970's and it's still in the process of shifting and I think we need to go back and remind ourselves maybe that the world has changed.

MS. PALMER: And I would like to affirm what you just said and suggest that we go ahead and for purposes of the clock that we agree on working with this list.

MS. FRANK: Okay.

MS. PALMER: We need to proceed now to identify those that you think there is fairly good clarification roles already in place.

MS. FRANK: Okay.

MS. PALMER: This is helpful, the roles of government, because I know in looking down this list of 16 and as you analyzed them further, it's real clear to me that I can hone in even more clearly on what aspects of those we in city government --

MS. FRANK: Yes. There is a need.

MS. PALMER: -- need to do more of and what the federal government needs to do more of. So I'm pleased with where we are --

MS. FRANK: Thank you so much.

MS. PALMER: -- but I would like us to move on a step.

MS. FRANK: Is anyone else pleased with where we are or burdened by it?

MR. WOLFRED: I agree with Lori.

MS. FRANK: Does it seem like it's going to work for us?

MR. WOLFRED: Yes.

MS. FRANK: Good. Let's go for it. I think the areas of which there seem to be fairly clear responsibilities and not major problems would be research. It

is fairly clear that the primary role -- that the federal government plays a primary role -- that the federal government plays a primary goal, not an exclusive role, but primary role in biomedical, clinical, epidemiological, behavioral and other social sciences, health services research, and health policy research and analysis. Crosscutting those areas, that the government, the federal government plays that major role.

Now, I come from the state of California and I can say that that isn't always true because our legislature is putting out $10-$15 million dollars into research at the state level. Some people think that money might be better spent in services so that it's not an exclusive but I would say that research is one area that cities and counties are not fighting the federal government to conduct research. States do not normally set up many NIH's. We're fairly comfortable with having the federal government support and do intramural research as well as its own research. The second area I think that --

DR. KONIGSBERG: Pat, please, before you leave that.

MS. FRANK: Yes?

DR. KONIGSBERG: I think it's fairly clear but I don't think it's 100 percent clear because I know in Florida that there were competing interests for the state dollar, much like California only a little bit smaller scale. We need to bear in mind that a lot of how government carries out

its research is through public and private universities and occasionally it might be through a very sophisticated state health department so when we talk about the government role that it's not all just done on how it falls in NIH.

MS. FRANK: Or CDC.

DR. KONIGSBERG: Or CDC. So if you had someone here from a state sponsored medical school, public medical school --

MS. FRANK: We do.

DR. KONIGSBERG: Okay. Then somebody might say, "Well, this is potentially a responsibility," but there again, the funding is primarily --

MS. FRANK: It's a primary responsibility.

DR. KONIGSBERG: I mean, I don't, for example, as a state health official I'm not going to take a research component through what I hope would be eventually a good planned out Kansas State AIDS plan. I might make reference to it but I don't see that as being part of our agenda. Although we might, you know, carry out something that is real wide but it wouldn't be the kind of research we're talking about. So it's clear but it's not -- you know, it's a little bit direct.

MS. FRANK: Okay. Secondary, what I think is clear is drug and medical device regulation although again there's a trend to set up many FDA's in some states. It's

fairly clear that the federal government has a regulatory role. The Food and Drug Administration regulates drugs and medical devices. And it's clear too that the FDA takes a leadership role although a partnership role in blood and tissue supply protection in terms of establishing regulations and finalizing them; so that's the third area. I think it's fairly clearcut whose responsibility it is even though there are partnerships. The activity seems clear, the regulatory authority is clear.

MR. STOUT: Pat, I agree with that. In our recommendations we make those recommendations and we go one step further and we say improvement of the testing in the approval process used on the federal government for drugs to obtain a more timely release and alternative therapies and elimination of inappropriate therapies. Jim counseled me a little bit on the statement I made yesterday and gave us some additional information on that which was very helpful concerning rural dwelling. I think the goal, however, is one that needs to be put into your report and I think it needs to be discussed with the federal authorities so that we're all cognizant of the importance of putting the appropriate attention on this process in this particular epidemic. I just think it's very important that that be done.

MS. FRANK: Mm-hmm.

MR. STOUT: I don't know how to do it but I'm sure that you do and I'm sure that Jim can help us with that.

MS. FRANK: Set a goal in which there are unclear responsibilities that there may be an appropriate level of effort or a better effort.

MR. STOUT: Well, I mean it's legislation that makes it clear what needs to be done.

DR. KONIGSBERG: I don't mean to keep playing devils advocate here. The way that regulation is described up there, that's clear it's a federal role. If you were to broaden -- taking the role of government to broaden the category's regulation, and think more broadly than what's up there, you might come into regulation of health care facilities, nursing homes, hospitals, hotels.

MS. FRANK: Well, we are going to use regulation to do just that as we go into other areas.

DR. KONIGSBERG: Okay.

MS. FRANK: Yeah, this is one area though.

DR. KONIGSBERG: Okay.

MS. FRANK: I believe -- Jim, when he addressed this area really as a priority for the federal government had called the evaluation research. Actually, it was the way he described it and I heard him talk about vaccines and therapeutic agents.

DR. KONIGSBERG: Well, this is clearly a federal responsibility, I think.

MS. FRANK: Right. So we agree that that is

basically a federal responsibility. I think one thing we want to avoid is to call ourselves back to the charge and the charge is to clarify, to bring clarity and agreement about federal, state, and the local responsibilities. We're not suppose to be giving grades on how well those responsibilities are being carried out, but to define -- our first step is to define those responsibilities. One other area I think that there is fairly clear -- epidemiologic surveillance has clearly defined federal, state, and local responsibilities in my mind related to HIV disease. The CDC -- it's very clear to me what the CDC does in relation to epidemiologic surveillance.

It's very clear to me what states do. We can look at a list of states and see what state statutes are related to reporting, what the procedures are for case finding but we know what epidemiologic studies -- the family studies that CDC is taking on. So it's very -- I may be because I'm not sitting in Charles's seat in Kansas, I may be more clear because I'm further away, but to me it's very clear. Maybe because these relationships existed in the past whether it was measles or polio or something, so that when HIV came along there was a way for the federal and the state and local government to come into partnership that was easy because of the existing chanels already existing.

DR. KONIGSBERG: I think that's by and large true. I think we really need to be sure that we understand,

though, that -- and I think you've already alluded to it that surveillance and disease reporting is basically legally state functions and every state has that primary responsibility. Now, they may delegate certain responsiblities to local government through a local health department, but I think in every instance it stems primarily from the state and Jim can comment more intelligently than I can but the CDC's role is different in lacking the same kind of statutory authority that a state would have. But I agree, those relationships were there in place in a kind of a natural grouping.

DR. ALLEN: As a matter of fact, you're absolutely right. The disease reporting responsibility is a state function.

DR. KONIGSBERG: Right.

DR. ALLEN: CDC can't require any level of government to report in any -- except the International Quarantine for Diseases -- and all of our ability to carry out national surveillance rests totally on our superb working relationship with the state, mostly with the state and in some instances with local health officials and also then with our ability to provide financial support.

DR. KONIGSBERG: I agree with that characterization.

MS. FRANK: Do we have any problem then in saying that these are areas of which federal, state and local

responsibilities are fairly clear and not considering them as other problem areas or areas in which there is no clarity and agreement?

DR. KONIGSBERG: I could agree that they're clear if we were giving grades.

MS. FRANK: No grades.

DR. KONIGSBERG: But no grades in this session.

MR. STOUT: You mean we're not going to do that at all?

MS. PALMER: We're going to do it but we're going to start with counties.

MS. FRANK: We're going to start with Texas -- no, no. I think that is not our primary role. We're going to do it -- in talking about functional and dysfunctional relationships we're going to do it, but we're not going to do it -- we'd be here for several years doing that and I want to go home. It's warmer there. What I would like to do next, then, if we're agreed to strike these off our master list as things that we will not consider, then what I want us to do in the next fifteen minutes -- it's now about ten to ten o'clock, is to get this list down to five things.

DR. KONIGSBERG: Pat, I'm sorry. There's one thing I would like to make clear for the record.

MS. FRANK: Right.

DR. KONIGSBERG: My understanding is we're striking these from the list because the function of this group today is to look at these intergovernmental relationships and we're not striking these from the National Commission on AIDS because these need to be looked at --

MS. FRANK: Oh, not at all, not at all.

MS. BYRNES: I would love to see them clearly defined at some point in time.

DR. KONIGSBERG: Yes, but I think as far as the intergovernmental relationships they are clear. I'm sorry, I just felt the need to go on the record for that.

MS. FRANKS: Exactly, Charles. I understand that. These functions are not being eliminated.

DR. KONIGSBERG: Okay. I just think we need to be really clear about that as to what we are and aren't doing here.

MS. FRANK: Okay. What I would really like to do is have people speak passionately about -- we have struck some of these from our list. This is just what we're going to consider today. It doesn't have to be the final work of the commission but our work here today.

MS. AHRENS: Could I say something. It just strikes me that number one, anti-discrimination is a trial level issue as well.

MS. FRANK: Absolutely.

MS. AHRENS: And it seems to be just as -- let's see, what was the other one -- epidemiology and surveillance, and could in that sense be struck because it is federal, it is state, and it is local.

MS. FRANK: Well, that's not the criteria for striking them. I think it's very unclear what the responsibilities and relationships have been related to discrimination and the HIV epidemic. I think it's extremely clear what epidemiologic surveillance has been. I think this has been a major problem area and one that people mentioned again and again in their testimony as a major problem area in where government isn't reinforcing, supporting, and enhancing various levels of government.

MS. AHRENS: But we're not giving grades. We're just saying this is --

MS. FRANK: I'm saying that's an that doesn't work.

DR. ALLEN: Part of the difficulty I think here is that the responsibilities at the governmental level for anti-discrimination may be very clear -- certainly at the federal level we don't have all the pieces in place although I certainly hope that by the middle of this year we will have. What makes it difficult, however, with discrimination as one of the speakers yesterday pointed out, is that having the mechanism in place doesn't prevent discrimination. All it does is to give

you the authority to handle through a long drawn-out process somebody who is guilty of discrimination.

MS. FRANK: Right.

DR. ALLEN: And I think the difficulty is that until we can work with the population at every level -- and this doesn't absorp the government, but if somebody is identified as being HIV positive, until you can get somebody from standing up and walking away from that person you haven't solved the problem of discrimination. And yet, allowing somebody to stand up and walk away, to turn their back, isn't illegal in the sense that you haven't denied them services but that person has been discriminated against, he's been picked out. Until we can resolve that -- and that I don't think the government in itself can solve. It has to be part of the education and part of the moral reinforcement and the cultural morals.

MS. FRANK: Yes, that's true.

MS. AHRENS: I agree.

MS. FRANK: What about talking about minimal statute, talking about laws rather than human behavior? Do laws exist and/or are the localities, states, and federal government clear on their roles related to anti-discrimination and civil rights and HIV disease or is there a great confusion and inadequate protection of human beings?

MR. ORTIZ: Well, inadequacies there are and

that exists at the local level. That's exactly why -- that's why my organization is on the committee right now because we have instructors in the city of Philadelphia that are not adequate enough to begin addressing the issues.

MS. FRANK: When there is no effort or inadequate efforts so that the function isn't being carried out, the problem isn't getting solved. In my view, you can't -- shouldn't cross it off the list.

MS. AHRENS: We're not crossing it off anything.

MS. ASHTON: What we are saying is there is clarity here.

MS. AHRENS: I guess what I'm saying if you needed clarity that this is a tri-level responsibility.

MR. ORTIZ: I think it's a tri-level responsibility. I think the best way to resolve this would be in some sort of national civil rights legislation, but absent the will of the federal government at this moment to move along that direction I think it behooves the local and the city and the states to begin putting into place their own mechanisms against discrimination. I agree there is a tri-party type situation here but I don't see at the federal level that we have yet the willingness, political willingness to begin this.

MS. AHRENS: But again, we are not giving grades, we are not saying that this is being done right. We're

just saying -- I guess I'm saying that it's clear to me that this is a tri-level responsibility and for that reason I could put it in a category of surveillance. Now, surveillance may not be well done in Alabama or Minnesota or wherever, but that's not to say that we're not clear as to the fact that this is a responsibility.

MS. FRANK: Sister?

MS. ASHTON: I'm inclined to say that this should be one of our problem areas because the big question that seems to pop up all the time is where does the legal responsibility lay? Is it in the federal government, is it in the state government? It's not the implementation or the way we carry it out that's the problem. I mean, we obviously all have responsibility to see that we protect that particular issue, but that's what we're about it seems to me, is saying, does the major responsibility for this in terms of what it's possible for government to do, rest with the federal government or the state or local government and I think just this discussion shows that it's unclear.

MR. JONES: I also think in terms of lack of clarity it is that when issues around the subject pertaining to persons with AIDS and persons who are HIV infected it is not clear whether HIV positive or AIDS are covered so there is, I think, a lack of clarity there. So if we're not sure, we constantly have to review that so that's why I think I'm not

quite comfortable putting it there and saying that the responsibilities are clear. They are clear in certain categories, but I think we're finding ourselves having to go back to legislative and back to statutes to make sure that HIV positive and PWA are covered under those issues.

MS. PALMER: May I project?

MS. FRANK: Yes, please.

MS. PALMER: In principle I agree with what Diane is saying. I think that that is a shared responsibility and should be for any area of discrimination whether they're social or political issues, but as long as there is not consensus or comfort in the group to assign it to a category right now then we probably ought to leave it out.

MS. FRANK: Let's leave it out, that's great.

MS. AHRENS: One things clear, we don't agree about it.

MS. FRANK: I agree. I think that's what we'll do about all the issues because you know, we're here working together and it's agreement among this group, not some abstract thing that I'm seeking and let's keep anti-discrimination off. What about public health insurance, Medicaid and Medicare? What are people's -- this appeared to be a problem that was raised by several speakers in terms of Medicaid as a kind of a -- of course as we know it's a shared federal and state responsibility.

MS. AHRENS: I'd like to say I think we've got to keep -- I think two and three as well as four might even be grouped together under another title and we certainly should address it, but I think it's of sufficient importance that one of the things that I would like to see us discuss is recommending, the entire commission, that a special working group be established just to deal in depth with the full issue of finances.

MS. FRANK: Public and private health insurance?

MS. AHRENS: Well, financing the health care system. I mean, I think of it as a very broad deep issue of which AIDS is just one aspect, but I sort of would like to see us go after this in a separate session. We don't have time to get into that.

MS. FRANK: Okay. So we've called this health care financing and then underneath we would have public health insurance, private health insurance, and care of the uninsured?

MS. AHRENS: Right.

MS. FRANK: Those three categories, I think.

MR. BULGER: I think it's more than health care, I think it's human services financing because you get into a number of social services.

MS. FRANK: Well, we've got those on the

list.

MR. BULGER: But if you're going to deal with a subcommittee to deal with financing issues I think it should be on that list.

MS. FRANK: We'll call it health and social services financing?

DR. ALLEN: That should be under number six really then.

MS. FRANK: I guess one of the problems, Doctor, if we knock them out with financing, what happens to organization, delivery?

DR. ALLEN: Well, that's why you've got number five there, the patient care, it's in separate compliance.

MS. FRANK: I do and I have it there for a reason because who's responsible for organizing patient care services, for delivering them? It's not only the financing aspect. You can't -- so if we want to deal with financing of anything, I'm happy to have it as a category but as Jim says, let's make it complete.

DR. KONIGSBERG: Yeah, I think it ought --

MS. FRANK: You know, if we're dealing with financing, it's not just health care here.

DR. KONIGSBERG: I think we ought to try to group the social services and health issues. I think that's

appropriate.

MS. FRANK: What's the virtue of that, Charles?

DR. KONIGSBERG: Well, the virtue is that that's -- you just can't deal with the health and isolate the social services.

MS. FRANK: But the funding streams are entirely different.

MS. AHRENS: I have a concern about that.

DR. KONIGSBERG: Well, that's true until -- it depends on how far you want to reach up into your state or federal government. If you reach far enough the funding streams go to the same place.

MS. FRANK: Well, yes, but the way localities receive funding from the federal government. You know, you've got a Title 20 taking care of this type of social service, Title 19 taking care of --

DR. KONIGSBERG: Hey, but that's true for many things. You'll find Medicaid more often in a social services agency than you will in a health agency.

DR. ALLEN: I would argue in favor of what Charles is doing and I hear the problem of totally separate management, both at the federal level and at the state level, and it causes a real problem but it may be one that really ought to be addressed here because one of the things, for example,

that the AIDS epidemic has done is to force everyone to realize that the public health side of the issues, and the drug abuse treatment side of things have been totally separate in too many states.

MS. FRANK: That's true.

DR. ALLEN: One of the things that we've got to do is to get those two groups working together. I think the same is true here. In many areas even if you got reimbursement from medical care, if the social service side of things aren't in place, people don't have access to that medical care.

MS. AHRENS: But I think we have to define that because we will get into a real quagmire. I mean, when you start talking about social services are you talking about AFDC, are you talking about child protection, are you talking about foster care? I mean, you get over in that group --

MS. FRANK: Social support services is about this long, some categories that I've got are about that long, the same with --

MS. AHRENS: We have to define what we mean and not just lump it under human services. That's everything.

DR. KONIGSBERG: I think we can be more precise but let me try to bring it down to earth a little bit from a standpoint of actually trying to deliver comprehensive services and I'll pick on my Florida experience for just a minute. Here's what we have to deal with in a comprehensive

AIDS clinic setting. Yeah, we dealt with the patient care and the acute care and we gave AZT and even blood transfusions in the public health clinic if you can believe that. The biggest problems, though, and they were part of the total network approach built in the front end was housing, was income maintenance, the suppport services that community-based organizations and AID service organizations provided, long-term care, we began to bring in the substance abuse, then we began to bring in the mental health aspects. We don't very often do that with the way we deliver health care so when you're trying to deliver services, that's what's got to be done. Is it complex? That's incredibly, enormously frustrating -- oh, we dealt with the SSI; I never did understand it and probably never will. I understood Medicaid a little bit but I never understood the SSI. When you talk about a lack of clarity about the roles and relationships between the three levels of government, I mean, having spent a lot of time with NACo in a former life, knowing a little bit about how the states think, and being at a lot of federal meetings since Mr. Reagan came in in 1980 or 1981, whenever it was, there is a lot of finger pointing, buck passing, the Feds saying, "Well, that's not our responsibility anymore although we're going to continue to pour $400 million dollars into community health centers, we're going to continue to put money in paternal child health -- oh, but we might not do this with AIDS because on the side we've got HRSA getting a

social advance." The states may have a legal responsibility for care and in some states the counties do. I think that is one of the most complex areas that we're going to have to deal with and how to separate it from social services is going to be fairly difficult, I think.

MR. ORTIZ: But I think anytime you begin separating it from social services it's going to be a problem and that's just part of the problem, at least the locality decision that we're facing right now. We have a situation in which we have to provide health care and we have to provide -- and the health care in the local areas involves not only treating that person when he comes into the community health center but we've got housing needs for the drug abusers, and so on; and the lack of integration in terms of the overall human services, not talking to each other, and the state mandated services that then -- like you said, a funding stream, all may be different but funding streams are not getting down to the city levels. So what you have is a situation where AIDS is increasing child abuse, and with child abuse you have all of the other connotations that go along with that. You have to begin looking at it from the health care system and the human services system and an integrated sort of situation and if you don't do that I think we'll be having confusion.

MS. FRANK: I guess I have two thoughts about it. It's integrated from a service delivery perspective but we

also need to know the roles of various people. You've got to pull it out before you can put it back. Do you know what I mean? Jim, what were you going to say?

MR. BULGER: I started all of this so I feel that I should say one more thing. I don't know who said it, it may have been Charles, but someone said that AIDS or HIV is a public health epidemic. I don't think it is. I think it's in large measure a public health epidemic but it's an epidemic that is being worked on. We've listed 16 categories, many of which go beyond public health. We've already identified this as more than a public health issue.

MS. FRANK: Oh, definitely.

MR. BULGER: And I think there's a basic tenet, if you're going to look at reimbursement, you have to look at more than health reimbursement. The only reason for my point earlier was that if you're going to set up a separate subgroup of workers to identify reimbursement issues, you can't ignore those others. Then when you get in service delivery, all of the other comments that were made are right on the mark. I mean, it really is a wholistic approach to the individual that has to be coordinated and simplified and delivered.

MS. FRANK: How do we do that? How do we say this?

DR. KONIGSBERG: I think you just said it and I think several of us would agree with that. It depends on how

you define public health and whose responsibility it is.

DR. WOLFRED: How do you pay for it?

MR. ORTIZ: And that's the key question I think the localities are facing.

MS. FRANK: I think that's one of the key questions, too.

MR. ORTIZ: Because how do you pay for it? Right now we're mandating in the city of Philadelphia to provide adequate services by both the state and the federal government because funding is going to pay for the services that's not forthcoming in terms of Medicare, in terms of third-party payment control, and so on all the way down the line. We never get the money to pay for the treatment and for caring and for hearing and right now that's breaking the back off of our city budget. That's one of the problems that we have.

DR. WOLFRED: What occurs to me on our whole list of 15 issues or whatever, number one is a policy issue; two, three and four are financing issues; all of the rest are service. So we're getting in trouble because we've got a hybrid list here of some sort. I think financing is an issue across all of these items and a very important one. When we look at government responsibilities, in some cases one arm of government has the financing responsibility, another arm of government is going to have the delivery responsibility, another arm may have the regulatory responsibility and so -- and then the actual

provision may be by a nonprofit ideally, and I think somehow we've got to work by the nonprofit mode in here, we're talking about a whole area.

MS. FRANK: Okay. What do we need to change?

DR. WOLFRED: And then a big issue, I think -- I've sort of saved up a lot of things to say -- is that of the relationship among things. The problem is in relationships and not in integration as is being said here. Our picture is going to get more complex and more isolated with more problems.

MS. FRANK: Can you help us do that, Tim? Is there a way -- we're looking now at issues and as you pointed out what we've got is some overlapping in proximity to financing related things, and we've got some service related things and some functional things mixed-up under our issues. In terms of sorting out issues, eight or five major issues, let's go back to that task. What are the five major issues, what do people feel absolutely passionately about as issues?

MS. AHRENS: I feel passionately about two, three, and four; and somehow those three, if you put them all together, they have to be put together and it's got to be among the top five.

MR. WOLFRED: Health care financing.

MS. FRANK: Okay. Would you call it health care financing or would you just simply call it health care?

DR. KONIGSBERG: It's more complex than financing. There's some system problems.

MS. FRANK: Organization, delivery, and financing and health care and social services.

DR. KONIGSBERG: There you go.

MS. FRANK: Whew. Organization and delivery and financing of health care and social services. That is it. I think that's the roles, that's what we're talking about because we're different levels of government responsible for organization, for delivery, and as Tim points out public and private sector involved in delivery and all three levels of government and a private sector involved in financing in the United States. So it's really the organization, delivery, and financing and health and social services.

DR. ALLEN: Why don't we restrict it just a little bit.

MS. FRANK: Are you kidding?

DR. ALLEN: Let's say health and the social support services.

MS. FRANK: Why do we want to say services? That's a nasty word.

DR. ALLEN: Because the social services -- there may be social services that are really very coordinated through all of this.

MS. FRANK: How does that help us

recognize --

DR. KONIGSBERG: Although I didn't find too many with that AIDS project. I forgot to mention foster care, that got in there too.

MS. FRANK: What do other people feel passionately about? We're down to passion now, folks, it's now ten after ten o'clock and I think -- what are major problems for jurisdictions?

MS. PALMER: Well, coming from the great state of Texas but with the native blood of Minnesota, discrimination is a problem and nobody wants to really address that because it's just such a sensitive issue. That is where leadership is often the weakest.

MS. FRANK: We have had discrimination in the area of education, employment, housing, and public accomodations.

MS. PALMER: That's right and leadership acquired at all levels is real critical and needs a solution so we're not going to agree on the fact that it is clear that that is a three-level responsibility then I would like to propose that that be included on the list.

MR. BULGER: So we can hurry things along I have three.

MS. FRANK: Great.

MR. BULGER: Housing, the recruitment,

training and retention; and also planning capacity and technical assistance because I think number ten really begins to integrate the various levels of government.

MS. FRANK: Yes, they do. I agree.

DR. KONIGSBERG: I think that laboratory issue could be a subsidiary under number ten anyway.

MS. FRANK: Okay. So what we've got here, Maureen, we've got anti-discrimination and I would like to bring over education including housing and public accommodation under anti-discrimination as sub-categories so that we know what we're talking about.

MS. BYRNES: Why don't I make a note of that and I'll rewrite these when we have a break?

MS. FRANK: That's great. Jim has just given us three more suggestions. The first is housing, the second is recruitment and retention and training of health care personnel, and then the last planning, capacity building and technical assistance. We've got several hands.

DR. KONIGSBERG: Number eight is my number one policy issue, education, prevention and information.

MS. FRANK: Prevention, education and information.

MS. AHRENS: We've got to have patient care.

DR. KONIGSBERG: You're putting the cart before the horse.

MR. BULGER: I think HIV prevention and education and information dominates with some of these other topics. Dominates what is going on in the HIV and the AIDS environment today. However, in New York where nothing works right, I think there is reasonable clarity with respect to the roles and responsibilities of government around the prevention issue. I don't see that as being as pragmatic as some of the other issues, but again, I'm not minimizing the importance, it's absolutely essential.

MS. FRANK: Larry?

MR. KESSLER: I guess for me one of the top five is number nine but I would just rephrase it a little bit for under substance abuse prevention and treatment as a public health issue.

MS. FRANK: So our list is growing.

MS. AHRENS: I think we shouldn't leave out patient care. Patient care, acute care, drug treatment, primary care and home care. I think we should group all those together.

MS. FRANK: Did we need it?

DR. KONIGSBERG: Yeah, we had that under organization, delivery and financing.

MS. FRANK: In health care and social services did we agree to take everything? I know that's a huge category and yet.

DR. ALLEN: Does that include housing also?

MS. FRANK: No, it does not. Housing is a separate issue.

MS. SILVER: Did we delete number 8, should I take that off? Is there agreement about that, I wasn't sure.

MS. FRANK: Number 8?

MS. SILVER: Yeah. Was there agreement about that? I wasn't sure.

MS. FRANK: Prevention and education? What is the sense of the group about prevention, education and information?

MS. PALMER: The problem that I see there, Pat, is that we have some states that are unwilling to assume responsibility for that.

MS. FRANK: Absolutely.

MS. PALMER: And I think that that is not a reality. It cripples the local communities in extremely serious ways and it puts additional emphasis on federal health in that area and it puts just a lot of communities in a very, very unadvantageous position in being able to function.

MS. FRANK: There's a complete absence of that on the part of some states and localities in their AIDS prevention, education and information area. It's a totally volunteer and nonprofit conducive effort.

Is it the sense of the group that now we have before us the issues -- how many do we have?

MS. BYRNES: We have seven.

MS. FRANK: So we have seven issues. Is there anything on this list that you want to add?

MS. PALMER: We can consolidate them, too.

MS. FRANK: Is there anything else -- is it the sense of the group that there is anything that should come off this list? Okay. I would like us to take a one and-a-half minute break -- no.

MS. AHRENS: There's coffee out there.

MS. FRANK: There's coffee outside and let's take a little break.

DR. WOLFRED: Just before we break, what are we going to do then with these seven issues?

MS. FRANK: We're going to run through these issues and for the first crack we're going to say is it primarily federal, we're going to do those things, go through that exercise. Then we're going to look at the specific roles we want, as Diane said, "The ideal roles." What do we need more of under these things? Does that make sense? And we're going to do it very thoughtfully and very fast.

MS. AHRENS: Within two hours.

MS. FRANK: Within two hours.

(WHEREUPON, a recess was taken.)

MS. FRANK: On the break Diane mentioned she was uncomfortable grouping together the organizations, delivery

and financing of health care and social service and I want to go back and revisit this for a minute and see how many people are uncomfortable doing this?

DR. WOLFRED: I'm very uncomfortable.

MS. FRANK: Lumping together organizations, delivery and financing of health care and social services?

MR. BULGER: I think somehow we made a quantum leap from financing of those services into organization and delivery as well.

MS. FRANK: I helped you make that. Would you like to -- should we come down off the ladder and break it down again?

MR. JONES: In expressing my discomfort, I don't want to loose sight of the issues around social services, social support services, but I think for what it tends to be suggesting is that we need to establish a small working group to specifically address the issues of public and private health care and I think to lump social support service in that makes it too heavy. Also I think for support for a working group the more narrow it is the more likely to get more specific issues that you're trying to get out of it; the broader it is we will have paperwork around the room.

MS. FRANK: Okay. How would we best break this down? Should we go back to calling it patient care and under a separate category social services?

MS. AHRENS: Could we start by talking about the financing part of the health care system or the -- could we find a way to word that?

MS. FRANK: We can talk about public health insurance. We're here to talk about --

MS. AHRENS: But it's more than just that, I think. It's more than just public health insurance. I think they're talking about the financing of a health care system. I think we have to be somewhat politically relevant here and it seems to me one of the things that the Congress is looking at and I think the pressure is there from all kinds of sectors, national sectors, local sectors, hospitals, everyone involved in the health care field to address this issue in the '90's and I would like to see us to begin to coalesce with some of those folks, but if you throw in how we organize this with human service I just don't think that's going to be politically realistic and we need to address that but I think in another way or in another category. I guess that's the way I feel about it.

MS. FRANKS: Do we want to say the public and private financing of health care and let it go at that?

DR. KONIGSBERG: I guess what I'm uncomfortable with, I guess I could see breaking the social services out although I could argue it either way, but are we just going to deal with financing and not the organization and delivery?

MS. FRANK: That's my understanding.

DR. KONIGSBERG: I have a real problem with that.

MS. AHRENS: No, no. I'm suggesting we pull the financing out and then we look at what's left. I'm not saying we drop it, absolutely not.

MS. FRANK: Let's break it down into two issues, okay?

MR. ORTIZ: We want to deal with it separately?

MS. AHRENS: Right.

MS. FRANK: We want to deal with it separately. We want to say public and private health care financing as one issue?

MR. ORTIZ: And organization under human health?

MS. FRANK: Organization of -- we could say patient care and social support services.

DR. KONIGSBERG: We should at least say health care. I think what I'm uncomfortable with a is real narrow medical classic medical approach to a problem that many people know, that we all know, is much more complex than that. And if for practical expediencies they want to separate out social services -- I'm having trouble trying to figure out how we separate the financing from the organization and delivery?

MS. FRANK: Well, unfortunately it is separated and that's part of the problem.

DR. KONIGSBERG: Then I think we ought to say that.

MS. FRANK: Part of the problem is that the financing of health care is separte from the organization of health care and the delivery of health care.

DR. KONIGSBERG: If we're not careful we're going to wind up throwing money, recommending throwing money at a problem and we'll wind up with a situation like Medicaid which nobody has really addressed in the delivery system accept just picking at it occasionally.

MS. FRANK: Can we say the organization on delivery then of health care and social services? Public and private health care financing?

DR. KONIGSBERG: I think financing ought to be specifically identified.

MS. FRANK: All right. We can identify it as Medicaid, Medicare, private health insurance, and care of the uninsured. Those are the four aspects that I'm aware of in financing. We have public insurance and that's Medicaid and Medicare; we have private insurance including health maintenance organizations; we have the care of the uninsured, we have people who are uninsured for which there is no clearcut responsibilities for payment of that care. Is that

satisfactory, people, to break that down? That's very explicit about where our concerns are related to health care financing. Do we want to talk about the organization and delivery?

MS: BYRNES: Organization and delivery go on the top, right?

MS. FRANK: Yes. It goes under health care and social services. I think we're going to come out okay. I think by the time we get done -- remember, this is just structure to lean on, it's substance that counts. It's the structure to lean on, it's the substance that counts. What we're going to do now is -- and this is where most of our work is going to get done in terms of we're going to start with anti-discrimination and we're going to talk about what should be the federal role in anti-discrimination? I want people to speak again passionately about what the federal role in anti-discrimination and civil rights ought to be in these four areas.

MR. BULGER: Are we including confidentiality with anti-discrimination? New York State has relatively new confidentiality legislation that addresses the issue of maintaining a confidential nature with respect to testing and so forth.

MS. FRANK: Is it in regard to insurance or is it in regard to access for health practitioners or --?

MR. BULGER: It's in regard to access to

confidential information by employers, health practitioners, anyone. I'm not saying we should include it with the anti-discrimination category, I'm just asking what the consensus would be?

MS. FRANK: I would prefer to leave it with public health and not to anti-discrimination because I think these are major discrimination areas. What should the federal role in anti-discrimination be?

DR. WOLFRED: They need to pass a law.

MS. FRANK: Passage of the Americans with Disability Act. Now, let me remind you as Maureen reminded me that the Americans with Disabilities Act only covers -- basically focuses on employment public accommodation and housing is not covered and I'm not sure about education. Does anyone know the answer to that question about the Americans with Disabilities Act whether education is covered?

MS. AHRENS: Maureen is going like this. (Nodding head affirmatively).

MS. FRANK: Okay. No one has a copy of that legislation? Okay. So the first -- the federal role should be in passing an omnibus disabilities act that covers persons with HIV infection, not just AIDS or a person with HIV infection as well as other disabled persons. There are other various civil rights protections and disabilities protections that persons with AIDS are already covered under but this is the most

comprehensive disabilities act we've ever had and the most important thing is it covers both public and private so it applies to the private sector as well as the public sector. It's the most comprehensive law that has ever been introduced to deal with discrimination against disabled persons. It crosses many classes of disability, many persons with disability and it crosses many areas of discrimination. That's our first priority. Should there be other --

MS. AHRENS: I think the number of people who are near the front already know the commission has taken very strong initial AIDS support of that act and we have sent this to the congress and the President. Just so if you're not aware of that, we have already done that.

MS. FRANK: So we're saying in a generic way that we think that a universal protection at the federal level disagrees from the way that generic discrimination of civil rights issues?

MR. ORTIZ: Yes, it's essential.

MS. FRANK: That's the sense of this group?

MR. ORTIZ: Yes.

MS. FRANK: Okay. What would we say about the state role in anti-discrimination? What if this act was not passed?

MR. BULGER: Surely in the absence of federal legislature we need state legislature.

MS. FRANK: Are there other areas of discrimination that states have a right, a statutory right over that if the federal government makes a rule and it's binding, is it binding on everyone?

MS. AHRENS: One of the roles that the states, I think -- at least this state does, is the area of insurance. I think that the issue of discrimination in insurance programs --

MS. FRANK: That's the missing category.

MS. AHRENS: I think the states do have a role in -- some of it could be to pick up the gaps in the federal legislation, but there are some states that have maybe better laws than the federal law as well so I think it's a state responsibility as well. In some areas, particularly in terms of how it can be made a local responsibility. There are many local ordinances that deal with discrimination.

MS. FRANK: There are many, many local ordinances passed on discrimination.

MS. AHRENS: In my judgment, this is a responsibility of all levels of government.

MS. FRANK: But is this a case where we're getting into conflicting -- and if you're trying to assure protection to the greatest number of people with HIV infection and other problems, you would pass something at the federal level because it would be protecting those people, it would be a

national standard so that we didn't have inadequate protection from one state and good protection for people in another state which makes living really not equal in some states.

DR. KONIGSBERG: If we follow the pattern of civil rights legislation then we need national legislation and that doesn't prohibit the states from following through but if the states are having to fill in gaps now it's because there's an absence of national legislation. I don't know why there's been a failure in congress to really do this comprehensively. I mean I know as a state health official when we took over, for example, I'm going to introduce a Bill to have HIV recordably looked at. I had the attorneys look at the area of discrimination and in parts of the statutes we had a couple of gaps like no one could --? We've got to fix that. The lawyers would say, "Well, theoretically something nationally in certain precedence might cover it." Well, theoretically wasn't good enough. It just wasn't real clear and specific.

MS. FRANK: So we want to say, is there a state -- we want to say, now, we're relegating the state role then to gap filling, the state and local role to gap filling? Is that what we're saying?

DR. KONIGSBERG: If it's a national problem, it ought to have a national solution. I mean, I don't see that from state to state to state that there is some wide variations about the way this ought to be.

MR. KESSLER: But aren't we talking about a break where the federal is the minimum standard?

MS. FRANK: The boiler plate.

MR. KESSLER: The boiler plate, and the states can broaden it, not narrow it.

DR. KONIGSBERG: That would be a good way to put it.

MR. KESSLER: For instance in Massachusetts our disability protections that deal with AIDS also includes many people who are perceived to be at risk. You can't discriminate against someone because you perceive them to be at risk here.

DR. KONIGSBERG: I think that would be a good way to get at that.

MR. KESSLER: It's stronger than the ADA.

DR. KONIGSBERG: Yeah.

MR. BULGER: Larry, I'm not sure how the commission is going to play this out but if the commission is going to make a recommendation that congress and the President pass a law that deals with human rights and discrimination to include -- perhaps not be limited to the the problem issues -- we went through everything from insurance to public accomodations and that would be health and life insurance, and then the next statement would be something like, depending upon what comes out of the federal process, if there are gaps then we

would want the states to pick up those gaps?

MS. FRANK: In areas that are not addressed by federal civil anti-discrimination legislation that then the states should act in those areas but I think the most valuable thing that Larry said is states should act to broaden human rights.

MR. KESSLER: For instance with ADA it really doesn't kick in to deal with AIDS for two years but states could speed that up.

MS. FRANK: That could be a model.

DR. KONIGSBERG: Are we satisfied with ADA, though? We're back to gap filling. It doesn't sound like we're very satisfied with them.

MR. BULGER: No.

MS. FRANK: ADA doesn't do everything. Like I said, it doesn't do housing and it doesn't have anything to do with insurance. As we know in districts, jurisdictions in the past statutes relating to insurance discrimination have had insurers -- the District of Columbia is a good example -- have insurers in many of their area, choose not to do business in their area or find other ways to get around as they have in California. So there are still problems relating to discrimination and the most serious problems, as Jim as pointed out very eloquently, there are problems in human behavior relating to discrimination, but there are problems related to

inadequate statutes. I guess the sense of the group -- what is the sense of the group about the most important discriminatory issues that need to be addressed by the state and local government?

MR. KESSLER: Insurance is a big one.

DR. WOLFRED: Housing.

DR. KONIGSBERG: Insurance.

MS. PALMER: Employment is a major one.

MS. FRANK: Major.

MR. KESSLER: But that is covered by ADA.

MR. FRANK: Yeah, it is.

MS. AHRENS: That's covered by ADA.

MR. KESSLER: But in the meantime it certainly would be useful.

MS. FRANK: Are we comfortable with that around this issue? Is there anything more we want to say?

MR. BULGER: What do we want to say about local government?

MS. FRANK: Local government? How do folks from counties and municipalities feel about the local government role?

MS. PALMER: I think you will find that the most progress made in those will be with your city ordinances and many have been passed and many will be probably, but the majority of cities will not be protected.

MS. FRANK: Is it important that people be protected in the cities?

MR. ORTIZ: Well, in the absence of the state legislature, in the absence of the federal and state, the municipalities have to step in with action. I think the localities of the cities act as a prodding mechanism for state legislature to begin to take action.

MR. KESSLER: Well, I think it starts with cleaning their own house so that each municipality, each county, each state must have its own methods because it's covered and inventoried by government. Then -- otherwise you can't go to the local corporations and say that thing you were going to do you haven't done.

MR. ORTIZ: There are many of them trying to get Philadelphia to act as a prodder for the state legislature so that they move.

MR. KESSLER: Mm-hmm.

MR. ORTIZ: If we pass it, hopefully our state delegation will then move because it's not moving, at least at the state level it hasn't moved.

MS. FRANK: Is that a role then that we want state and local government passing model statutes and ordinances, and then also advocating first aid to the state statutes?

MR. KESSLER: And in lieu of ordinances or

laws, there's always protective ordinances that can set state law.

MR. STOUT: It's different in every state. Some states reserve that right for themselves and local government doesn't even have a role in that and that's the way it is in North Carolina. But local government does have a role in city policies for their own employees there. That's, of course, in our report in the recommendation to the local government that they do that so we've seen some progress in that area so I think that Bill is appropriate in North Carolina.

MS. FRANK: The state reserves the power --

MR. STOUT: The state reserves the power.

MS. FRANK: -- to make civil rights?

MR. STOUT: Yes.

MS. FRANK: Do problems come out in that civil rights ordinances?

MR. STOUT: Yes.

MS. FRANK: Meaning?

MR. STOUT: Well, in federalism, the state just decides what it's going to delegate to local government and they just never decided to do away with that.

MS. FRANK: So is there anything more we want to say about this? I know this is very important.

MS. AHRENS: I think we should simply have a sentence that says that every governmental unit should have

adequate policies for their employees, anti-discrimination policies in the work place.

MR. ORTIZ: Well, enough for their employees, if you're going to pass legislation as to all of these different sectors of our cities, corporate sectors, private and public.

MS. PALMER: From a local perspective here I would agree with what Mr. Ortiz is saying because it's real important that within the framework that's agreed upon that there be as strong a consensus as possible about the local role of government because what that helps us do is it helps give some courage --

MS. FRANK: Yes.

MS. PALMER: -- to local officials who either want to be able to do something or they are neutral and would like to be part of the nation's scheme of things, this is our role, we do have some responsibility in the community but I think where it can be expanded on, it should be, and how this is flushed out I don't want to go into with this group. But it just does seem that it will help in the long run for cities to get some sense of their own responsibilities.

MS. FRANK: How can we say something to encourage them?

MS. PALMER: I think certainly broadening anything the federal government has done. There are some cities that would want to take it further than that, perhaps, and we

should certainly encourage those cities to do that. There are some cities that do have active relationships within the city government and their delegations at the city and state levels and should do that, and I think those that really -- so I guess those are the three. Our own employees, encouraging positive state legislation, and broadening the federal and state legislation.

MS. FRANK: That's great.

MR. KESSLER: I would add to that is simply to educate why discrimination is invaluable, why it's wrong, why it's not in the public's interest, et cetera, and usually when you do that you'll find that the lawyers and the AMA say we're going to do the right thing, and once you have got it written out and direct a policy, educate about that policy, make sure it's posted, that's half the battle.

MS. FRANK: Absolutely.

MR. KESSLER: But once you have got it written out, direct that policy, educate about that policy, make sure it's posted. That's half the battle.

MS. FRANK: If people aren't working, who's going to pay for their mental health care?

MS. SILVER: Just one point of clarification. Lori, were you saying policies for employees both governmental and private sector?

MS. PALMER: My attempt was to try to bridge

that and say a minimum change of public employees, and certainly cities should be encouraged to broaden federal legislation which would include toughening things out depending upon what the final act is but I think my hesitation is that to try to frame it in such a way that the majority of cities can look at that and say, "That's right," without too many of them saying, "It's not our job to deal with the private sector."

MS. AHRENS: Don't you think the issue here is where legally possible. Now, for instance in our state this is not something the counties could do, to be to mandate on a private sector. We can do it for our employees, and I think that is the very minimal thing. All jurisdictions have the power to establish policy for their own work force. If that is the minimum, where is it legally possible then to broaden it out?

MR. BULGER: Is it incumbent upon the commission to articulate -- not the ideal, but what you really want the federal government and/or the states and/or local government ordinances to say? I mean, shouldn't the commission be basically articulating, "This is what anti-discrimination of legislation should address with respect to health insurance, with respect to life insurance, et cetera, et cetera, et cetera, and we would recommend that the federal government adopt an omnibus piece of legislation that addresses all of this. However, if all of it isn't adopted in the federal legislation,

then the state and/or local government could supplement with the federal government." Rather than saying things like the federal government should have minimal requirements and then the states and/or local government should add to that. Shouldn't you go for the whole mark?

MS. FRANK: I think that's a good point. Where is government now? Do we want to make it a negative statement -- it's a negative statement in a way to say the federal should do the minimum rather than the federal should do period.

MR. ORTIZ: I agree. That makes sense.

MS. FRANK: I prefer positive statements about the roles and I'll leave it to the group. Do you think we have a good sense of this? We've outlined the areas of discrimination, we've outlined an action at the federal level, we've outlined potential actions of the state and local levels related to discrimination and civil rights. Is there something else that we need to do or can we move on to the next category?

DR. KONIGSBERG: Are we satisfied with picking it up on the ADA or a point well taken, perhaps we ought to call for the idea and say that if that isn't passed then the states have to follow it.

MS. FRANK: Have we maybe not done that? Is it the sense of the group that we're in support of the American's Disabilities Act as a broad federal legislation

protection of disabled? Yes, it is the sense of the group?

MS. ASHTON: You have already said the commissions done that, so yes.

DR. KONIGSBERG: Did we mean that though in the sense that that's all we were satisfied with or was that, you know, we were just simply taking a political stand of what was before us?

MS. FRANK: Do we feel we've gotten the best from us today? I don't want us to be curtailed by us doing so much, I want us to look at the issues and see --

MS. AHRENS: I think the federal government also needs to address A, B and C not covered by the ADA.

MS. FRANK: Okay. That's good, Charles, for taking us back there. In other words, it's not just what's do-able, it's what's needed.

DR. KONIGSBERG: Yeah. We haven't been shy in any other areas so I couldn't figure out why we were appearing to be shy with this.

MR. KESSLER: The only thing I want to say is we don't want anything to cause the ADA to be put on the back burner.

DR. KONIGSBERG: Exactly, I agree.

MR. BULGER: We have an attorney in the AIDS Institute and as the staff begins to write this up, we have an attorney who is an expert in civil and human rights. If you

would like, you can call me and use that person as a telephone consultant. He knows the language and knows the issues and I'd be happy to offer him for resource information.

MS. FRANK: That's great, Jim, to have that resource. When do you want to address public and private health care plans; Medicaid, Medicare, private insurance and the uninsured issues, what do we want to say about this?

MR. KESSLER: It's more than adequate.

MS. AHRENS: It's a disaster is what we want to say.

DR. KONIGSBERG: Somebody said that already.

MS. FRANK: Lori said it while we were talking about the federal, state, local, private sector mixed in these areas. If we were to say how things would work better in terms of public and private health care financing in the United States at the federal level, what would we want the federal government to do to improve the health care financing system?

MS. AHRENS: To assure a basic array of health services to all people in this country.

MS. FRANK: So it's universal --

MS. AHRENS: Don't use that, don't say it that way.

MS. FRANK: All right. To assure a basic --

MS. AHRENS: Basic level of health care services.

MR. KESSLER: Can we throw comprehensive in there?

MS. FRANK: Comprehensive array of health care services to whom?

MS. AHRENS: To everyone.

MS. FRANK: That is a federal role?

MS. AHRENS: That's a federal role.

MS. FRANK: That's what we would like the federal government to do?

MS. AHRENS: Yes.

DR. KONIGSBERG: We need to be sure that that's what we mean because that isn't the federal role right now. That doesn't mean that has the final implications for what does happen to the role of state and local government. The federal government has given very mixed messages over the years. They moved into comprehension community health centers in a big way during the '60's and early '70's and then left it kind of hanging there except for when they could lie to us some more, and yet now we're hearing, oh, we can't do all these things, it's a state and local responsibility. Now, what is it? Now, when it gets all mixed in with Medicaid and Medicare, that's what we want the federal government to take responsibility for. I'm not arguing against it but we just need to make sure of what we're saying here and how that's going to be used.

MS. FRANK: What is the sense of this group

in terms of what the federal role should be related to the financing of public health care?

MS. AHRENS: I think we need a generic statement and then -- we're not telling them how to do it, we're just --

MS. FRANK: Tell them what to do but not how to do it, right?

MS. AHRENS: But I do think we need after we make our general statement in terms of this working group, it's my feeling that the National AIDS Commission does need to have a working group to take a close look at this whole issue, a much more detailed look at this whole issue.

MS. FRANK: What do we want the federal government to do? You people must feel passionately.

MR. KESSLER: How about the federal government assuming the responsibility for the national public comprehensive array of health care services because if the state --

DR. KONIGSBERG: Unless we mean the government is going to deliver it directly and I don't think you mean't that.

MR. KESSLER: I do mean that. I do mean that the states and the cities are not going to do it.

MR. ORTIZ: I think that's good. You want the federal government to guarantee it?

DR. KONIGSBERG: Yeah, I see the assurance function which could mean -- I guess I would have a real problem about -- and this goes back to the old APAH debate about national health insurance versus national health system and I would argue that this commission ought to be extremely careful about advocating a national health care system. I think that's exceedingly radical but I think it may be appropriate for this commission to argue that we need universal coverage and would use that as the assurance that -- and boy, the implications of this. I mean, there's got to incentives, there's got to be money in it, there may have to be regulatory aspects to make sure that both the public and private sector deliver the care that's needed.

MR. KESSLER: Where does New York get its $80 million dollars it's going to need in the '90's without federal responsibility?

DR. KONIGSBERG: I'm agreeing with the federal responsibility but not the federal responsibility to actually deliver the services.

MS. FRANK: What are we going to tell the federal government about the financing of health care in the United States?

MS. AHRENS: I'm very concerned about the way he worded it. We're talking about access to health care. If we just say that they provide an array of health care services,

that doesn't insure any access. So I think access is the key word here and I guess I would want them to assure access to a comprehensive array of health care services.

MS. FRANK: Okay. Let's go with that.

DR. KONIGSBERG: How do they do that then?

MS. FRANK: They pay for it.

MS. AHRENS: They pay for it. Some way or other the whole combination --

MS. FRANK: They figure out a way for all the people -- a financing strategy.

DR. KONIGSBERG: To pay for -- and this is beyond the scope of today's conversation but --

MS. AHRENS: That's why we want to do another working group.

DR. KONIGSBERG: I know but I think it needs to be clear that if you went to the -- a lot of people in the federal establishment and they say, "Oh, we pay for this and that and everything. We pay for it through Medicaid." And yet we all know that the Medicaid has all sorts of problems to get the delivery system to deliver the care. Anyway, we don't have the time to go into that and it varies like crazy from state to state.

MS. FRANK: Well, we're sticking with the what issue and not the how issue. What do we want the the federal government to do related to health care financing?

DR. KONIGSBERG: All right. If we want them to be a payer, then let's say that.

MS. FRANK: I don't think we're saying we want them to pay for it all, Charles.

DR. KONIGSBERG: I don't know. What are we saying then?

MS. FRANK: We want them to develop a financing system that assures access to a comprehensive array of health care services for everyone. We want the federal government to develop a health care financing system.

DR. KONIGSBERG: Okay. That sounds pretty good.

MR. BULGER: Is everyone HIV and AIDS or everyone?

MS. FRANK: All Americans.

DR. ALLEN: Let's just be very clear then that we've got short-term needs that are very critical. I mean, not only today but next year and the year after. If you're talking about developing a whole new system we're not going to see anything for years. Now, that may be a long-term goal but it very clearly needs to be stated. I think if you do that there also needs to be something in there that applies to short-term needs.

MS. AHRENS: Yeah, that's right.

MS. FRANK: I think that's great. So would

you give us a second suggestion about that? What else do we want to tell the federal government? That's about all Americans.

MS. AHRENS: Yes.

MS. FRANK: What do we want to tell them about financing -- is there something we want to tell them about financing care for persons with HIV infection specifically, or about setting national standards for Medicaid so that the scope of benefits and eligibility standards across states is uniform?

MR. ORTIZ: I think it's obvious that without massive federal funding over the next five to ten years the states and the cities are not going to be able to take care of the AIDS crisis and we have to -- that's a federal responsibility to finance and to be able to finance that. Now, the states can't do it at this point, and the cities obviously can't do it, and you have to be able to bring in the state funding necessary for that. I think that has to be stated in there. During the next five to ten years where we have critical mass development across the country, especially in the urban areas of this country, in the big cities. We're going to have the whole health system delivery system just collapse unless you have massive federal intervention and if you don't say that in there, I think --

MS. FRANK: So the health care financing system isn't working and that the states and localities can't

support it.

MR. ORTIZ: We can't survive it under the current situation.

MS. AHRENS: I think we have to have something in there.

MR. KESSLER: I think in the second sentence then there may be a paragraph that says that we recognize that first goal is going to take time but due to the nature of the debt and the breath of this crisis, the HIV crisis, immediate action is needed, this sort of thing, and then seconded by the primary goals.

DR. KONIGSBERG: I think we've got to say that.

MS. ASHTON: Maybe you don't have to tie it into Medicaid or something. You could just say to provide adequate funding for the AIDS and HIV infected populations.

MS. AHRENS: I think it's important that we say that here but once again the details here is terribly important to people with AIDS. I mean, the detail as to how we spell this out in terms of what needs to be done with Medicare and Medicaid and that's why I think another meeting where we can -- another group, perhaps, of the AIDS commission can take a close look at what really needs to be changed here and spell that out. We don't have time to do that here.

MS. FRANK: I agree. We don't have the

technical expertise and we don't have representative health care planning to the administration at the federal level, but we must make a strong statement about what needs to be done is my feeling but we can't just redesign the health care system here this morning in Saint Paul.

MR. ORTIZ: But we understand that without massive infusion of federal funds the state and local health system is going to collapse under this crisis, if we don't have that during the next five to ten years.

MR. KESSLER: I don't think you've got a policymaker that's going to believe that if we don't get the impact --

MR. ORTIZ: And in Philadelphia.

MR. KESSLER: So there's an education component here.

MS. AHRENS: But part of the job of the commissioner, Larry, is to educate these people, and we have to get going around a table like this and we all have a go at this.

DR. KONIGSBERG: What I'm hearing -- I may be taking this a little bit further -- is in terms of sorting it out for three levels of government roles and relationships -- see how this sounds. We're saying to the federal government, "We want you to seriously finance now the care and treatment of persons with HIV disease." Okay. Are we then saying in terms of the state and the local role that it's the roles of those

levels of government to actually come up with a delivery systems in case the local government delivers the care for those who can't get it through the private sector? I think we need to be clear if we're taking this recommendation to congress what we're asking them to do, what I'm hearing is we want funding, serious funding now, and you'll have details within that area as to there are too many strings aloud for state and local flexibility and all this. Is that what we're saying here?

MR. ORTIZ: That is the reality of what is happening now. We're at the local level having to develop systems to be able to take care of that but without the necessary funding, and we are developing the mechanisms for delivery services, however, we don't have the necessary funds to be able to maintain them and I think that's the critical mass, that's why we're calling it a political issue.

DR. KONIGSBERG: As long as the funds allow you to develop your system in Philadelphia the way you need to and I guess I just have this fear that we've got to say something. I don't know how to word it to the federal government but it in effect says, "For God's sake, don't do it like the Medicaid program."

MS. AHRENS: Right.

DR. ALLEN: That's very clear.

DR. KONIGSBERG: The Medicaid program is not system delivery oriented. Oh, they've picked at it and tinkered

with it but if the money runs out -- let me give you a little --

MS. FRANK: Charles, don't give us an example. We have got to make an affirmative statement about the federal role, the state role and local role, we've just got to do it, and --

DR. KONIGSBERG: Money and flexibility.

MS. FRANK: Okay. That's good. We'll use that but we just absolutely have to do it right now. We have to say what we want the federal government to do related to health care financing. We've said one thing as a long-term goal. What do we want them to do relating to financing for the care of people with HIV infection? What do we feel the state role ought to be? We've got to just say this now.

MS. ASHTON: I would think we need to have this infusion of money. I think that the money should probably come through the state health department to the appropriate local delivery systems, whatever it is, so that it's equitably distributed where the need is. So if you've got the greatest need for care of people in one area of your population that you're sure that your money gets into that particular situation.

MS. FRANK: So we want a financing formula for states and localities heavily impacted by the HIV epidemic?

MS. ASHTON: That's what I think. I think there's a difference between trying to put money where you've got the prevalence when you're talking about delivery of

services there's this prevention and education so I would support giving more money on some kind of a formula basis to where they have a greater need for care of actual people with.

MR. ORTIZ: But we aren't making the mistakes of the block grants.

MS. FRANK: Yeah, okay. But we need some financing formula.

MS. ASHTON: But I certainly don't want it reduced to the states that don't have high prevalence the monies that are needed for prevention and education. We don't want to get up to that point.

MS. FRANK: What about localities? We heard from our leaders yesterday from the cities and counties that they want a more direct relationship with the federal government.

MR. ORTIZ: Simply that's the way the block grant programs started in this country. Specifically, when you have insolent and provincial state legislature, a lot of the block grant monies don't get down to the places they are needed and I think the system is referring to putting in a system where it's actually going to work with us. Wording as to that effect has to be put in there.

MR. BULGER: I'm just wondering where we're going -- I'm sorry.

DR. WOLFRED: We always say we want some

immediate infusion of cash via appropriate funding formulas to locally designed delivery systems in high HIV impact areas.

MS. FRANK: Yes. Cities, counties, states.

DR. KONIGSBERG: What about other areas that are not so high?

DR. WOLFRED: Well, we may not be --I'll tell you some of the crisis that the heavily impacted areas are feeling right now -- this is a very short-term goal.

MS. FRANK: Very short-term goal.

MR. BULGER: Relative to the impact.

DR. WOLFRED: Relative to the impact.

DR. KONIGSBERG: You know, I'll have to put on my midwest hat a minute here. I'm having problems supporting something that left out a large segment of the population.

MS. ASHTON: Well, I don't think it would leave out that segment. It would be done on the basis of how many actual people you have to take care of. That's why, I guess why I think it's better coming through the state because they have the ability to assess the need.

DR. KONIGSBERG: Right.

MS. ASHTON: I don't think the local communities, particularly those that are smaller, have the ability to do some of that kind of --

MS. FRANK: I think it varies from community to community.

MR. ORTIZ: I think some flexibility has to be put in there.

MS. ASHTON: If you have to do this across the United States in some equitable way it seems to me the state is the appropriate agency to deliver that and we ought to find out why the money isn't getting there because I know this varies in different states and if there is some hangup in the state as to why it doesn't get there because it has to have legislative approval or something like that to distribute it, then we ought to address that. We don't have that problem in Minnesota. We can go ahead and distribute that money even though we have to let the legislature know it, it's more a red tape kind of thing.

MS. FRANK: We need the option of having the federal government give assistance to states, counties, municipalities and not address that right now?

MS. ASHTON: You have to account for this money? There's a lot of administrative stuff that has to go on.

MS. FRANK: Absolutely. I think planning will bring and capacity building will bring us money because you don't give people money without a plan.

MR. ORTIZ: Maybe if you phrase it along the way you just put it?

MS. FRANK: So that they have the option of funding states, counties and municipalities according to a formula, an impact-base formula.

MS. AHRENS: I think Don Fraser though yesterday said it very well, he talked about a plan that there has to be a good plan in place for the utilization of this money. I do think that's important.

MS. FRANK: Absolutely, yes. That's what we have to tie this to and one of the things we could do and it would probably be a lot of fun is to maybe skip down and talk about the planning and capacity building and technical assistance.

MR. BULGER: Can I say something because I'm really confused?

MS. FRANK: Are you?

MR. BULGER: Yeah, I really am. Are we talking about financing for the uninsured right now or financing for all people who have HIV disease or who are HIV positive right on through the end of the continuum, and what are we saying about the Medicaid system that is already in place? As deficient as it might be in some areas or all areas and if, for example, in New York where there is a relatively liberal Medicaid benefit packet, are you suggesting that the commission ought to put a matrix in there that reads, any Medicaid package should be no lessly enhanced?

MS. ASHTON: Pick and choose what your benefits should be.

MR. BULGER: Here are the full range of

benefits that should be available and accessible for people who are HIV positive and with AIDS, and the federal government will pay for that benefit package at some percentage and a percentage greater than that which is in existence.

MS. FRANK: Yes.

MR. BULGER: So that's how you get more federal money into the system. But then you have to deal with the uninsured population as well and that's a different issue.

MS. FRANK: Absolutely.

MR. BULGER: I think some of what's been said here is like putting a square peg into a round hole, it just doesn't seem to fit. I have heard a discussion about categorical or some formula funding to states so if the state health department in Minnesota denied monies and that money went out through a planning process to localities for the people with acute care or long-term care or short-term care?

MS. ASHTON: Well, I agree with you. I mean, that's the planning process, I would think, and you did mention that this needs a lot more detail.

MR. BULGER: I would just make a statement that there is a need for the federal government to do "X" and that planning group or work group number three will --

MS. ASHTON: This is a short-range kind of thing so you have to take into consideration those that already will have insurance coverage, those that will be eligible for

Medicaid, but there are people who are not eligible for anything right now.

MR. BULGER: Yeah.

MS. FRANK: Are we asking for flexible or impact aid?

MS. ASHTON: The whole assessment.

MS. FRANK: Is that what we're asking for or are we asking for health care financing --?

MS. AHRENS: For care and treatment so that the other funding package that may come through for education is not touched innocently. We don't want them to take the money that they're spending for education and then say, "Well, we're just going to ship this over and we'll be patient for ever." I think that's what we're saying.

MS. ASHTON: That's the danger of sort of a block grant for AIDS, is that it is based on prevalence or something and I do think these are two completely different tracks that the federal government has to recognize. That one of them is appropriate to do on the basis of prevalence, the other one is appropriate on the basis of controlling the spread of the disease.

MS. FRANK: I think that's a good distinction. One type of aid that we're talking about, as Jim points out, has to do with the health care system as it exists, which is really Medicaid and Medicare, and then we're also

talking about something outside that system and the reason we're talking about it is because that system isn't working well and we're asking for glue, actually. When you talk about impact aid and that kind of thing, you're asking for glue to stick a system together that isn't working very well. That's my perception, because as Jim put it, "Who are you asking for this money for?" Are we asking for it for indigent care or are we asking for it for ADT or are we asking -- when you ask for money for HIV disease, you have to ask for something.

DR. ALLEN: Okay. Let me just back up and try to reiterate a bit. First of all, there are really two essential problems in terms of the epidemic. One is prevention so that we don't have more impacted people and I think it's very clear that the distribution of the prevention monies is going to be given to whatever distribution is seen fit for the health and care of people who are already infected and either are or will become sick. Prevention distribution despite it's best effort is one of the things the public health services tries to make very apparent that you don't want to lump everything all together because you're going to be shortchanging people in that process. The second then becomes what monies are necessary for people who are infected with AIDS, and there are a range of things in there. One of the needs is very clearly in areas like New York and San Fransisco and any of the other large cities for acute care, for people who are currently symptomatic and need a

lot of medical care and support services now. The second, and this is much broader, includes a lot of people who have access to very good insurance otherwise, as for the need for prophylactic medications such as aerosol pentamidine while they're asymptomatic, otherwise able to hold down jobs and totally functional and their insurance coverage, whatever type they have, won't pick up the medication, very expensive medication coverage, for that kind of care.

MS. FRANK: Right. That's a good distinction. So what areas are we trying to fill?

MS. AHRENS: We have to make a very broad statement.

MS. FRANK: We either have to make a very specific statement or a very broad statement.

MR. BULGER: I think that this group should make a very broad statement and delegate the specifics to the next working group. We're spinning our wheels here and there's another work group that going to be --

MS. ASHTON: We need some people who know more about financing.

MS. AHRENS: We need to bring in federal people for the financing area too.

MS. FRANK: What more do we want to say about this? Do we want to stop?

MS. AHRENS: I think we should turn it over

to you, I think you've heard us.

MS. FRANK: Okay. I think I would like to move on and talk about health care and social services and organization and delivery of those services. Here it's clearly -- the organization and delivery of services is clearly in both local government and state government play a role and both of them in organization and delivery of services. The federal government does to some extent through community health centers.

DR. KONIGSBERG: Through the VA and the Department of Defense.

MS. FRANK: Pardon me?

DR. KONIGSBERG: Through the VA and the Department of Defense.

MS. FRANK: Yes. And the direct delivery of patient care services in terms of what do we -- is there something that we want the federal government to do about organization and delivery of services in addition to financing the state that we want to make? Like yesterday one of the themes was that there wasn't a comprehensive or coordinated array of services for persons with HIV infection and that didn't exist in your localities and the states. Do we want to make a statement about that? What do we want the federal role to be?

MS. AHRENS: Perhaps there is already federal policy and I just don't know about it. I think the federal

government needs to say something to the states and counties and municipalities where appropriate in this country that they have got to get on with the job, that they have got to do planning and have a delivery system in place to deal with what is coming. Now maybe the feds have already made a statement but I do think it's sort of nice to get your marching orders, at least to have something of the national level that we can say, "The feds, this is their position," because we've gone ahead and done -- most of us have done it anyway. I mean, we did it without any, I think, encouragement. Has that been said or we're just not hearing it?

DR. ALLEN: It's been said but not from the very top levels and whatever that has been said has not been adequately backed up with monies to clearly implement that. If you look at money in your long range planning, do you remember where we stand for the fiscal year '90 budget? It isn't very much, if anything.

MS. FRANK: It's been taken out. It was blue penciled out.

DR. ALLEN: It was something like $4 million dollars?

MS. FRANK: I think it was $3.9 million dollars.

MS. BYRNES: Incentives. It wasn't a directive from the federal government, it was an incentive.

DR. ALLEN: That's the problem. Whatever has

been said hasn't been backed up with the real speech.

DR. KONIGSBERG: The federal government said the right thing with the HRSA Demonstration Project, but one of the things I've said privately, and I'm going to say it again, is somewhere in this commission process we have got to get a number of people from the federal health establishment in here that we haven't had because when you try to translate what the the HRSA Demonstration Grants were trying to say, setting a standard of care and a very good one I might add, translate that out to where the real bucks are, federal bucks, which is in HIPCA (ph.) in the Medicaid program. The two don't relate very closely. As a matter of fact again, and I know you don't want any more examples but we tried to run one of these clinics, trying to translate the HRSA concept into how you handle Medicaid and then the AZT distribution, and then Medicaid and SSI got into that and it was an absolute nightmare. Now, who's going to put this together at the federal level, that's who will make a statement to us and then some streams for the money will come down. The streams aren't always bad when they're done in a positive way and leaves some flexibility.

DR. ALLEN: But to reiterate and carry that one step further and to reiterate that, someone asked I think it was yesterday afternoon, "What happens once the demonstration projects come to an end?" The problem is that we have suddenly without saying so turned the demonstration projects into a

pitiful attempt to provide the services that are needed.

DR. KONIGSBERG: Right.

DR. ALLEN: Demonstrations are suppose to show the best way to do it, it's suppose to look at the innovative ways and there shouldn't be violation, there should be statements that come out as you come to an end that say, "Here is something that worked well."

DR. KONIGSBERG: Right.

MR. ORTIZ: And then we fund it so it can be implemented.

DR. KONIGSBERG: Yes. That's the point I'm trying to make.

MS. FRANK: Let's make that point.

MR. ORTIZ: Once that project is done, it's done and it's never refunded again.

DR. ALLEN: They never come to that kind of conclusion. There's never the statement out there, there's never the public figures that say, "Here's what we've learned and here are the lessons."

MS. ASHTON: That ought to be part of your demonstration project requirement.

DR. KONIGSBERG: Yeah, but RWJ is doing evaluation and Brown University is doing them, whether that will be shared with anybody, I don't know.

MS. FRANK: Okay. So the problem is the

evaluation of the HRSA Demonstration Projects since the efforts have been made, the reports are out there according to the background regime I'm reading; and, yes, the demonstrations were a success and we made the statement to the federal government that the power in the demonstration projects were developed to enhance out there social service organizations and delivery for persons with HIV infection ought to be expanded.

DR. KONIGSBERG: I think we need to go further than that. I think we need to make some statement to the federal government that if we agree that the concept behind the demonstrations was appropriate, the comprehensive delivery system which comes back to social services includes it, then we ought to say to the feds, "Now, what we want you to do is incorporate that concept into your total approach of your health care financing and how you deliver that emergency money," and I think that's an appropriate statement to the states, and if we do that then we can get around let's throw more Medicaid money at the issue and try to deal with the delivery system. I think that's what's missing here, otherwise what was the purpose of the demonstration projects.

MR. BULGER: I thought the purpose of the demonstration projects was more under the group of coordinating services rather than --

DR. ALLEN: Well, that's one part of it, and as you say, those have been published very, very recently.

MS. FRANK: Right. Yeah, they were a success. They were innovative models that were a success and worked and so as one of the recommendations you want to make is that stop calling them demonstration projects and call them projects and start -- that you want to have a program, a grant and aid program to support more of these in highly impacted areas.

MR. BULGER: Isn't there an AIDS legislation now that includes $300 million dollars, half of which would be for the purpose that we're discussing here?

MS. FRANK: Mm-hmm. Are you in support of that concept, grants and aid to enhance the organization and delivery of services at the local, regional and state level? Are you in support of that concept until a revolution comes and we have a new health care system? I think Tim is absolutely right to ask that and to bring us back to reality. We're not going to have universal national health insurance coverage tomorrow. In the absence of that for the localities that are struggling, and my goodness, we heard the counties speak yesterday, we heard the cities, there are 21 metropolitan areas now that are heavily impacted, there are 22 states that are heavily impacted, do we want to make a statement that we need some types of grant and aid to enhance organization and delivery of health and social services?

DR. KONIGSBERG: Comprehensive, yes.

MS. FRANK: We're talking about today deliveries and delivery systems. Do we want to also say that we want to enhance these institutions that exist in institutions? Are we trying to create new institutions to provide care or do we want to see that these monies go to community clinics, to existing institutions --

DR. KONIGSBERG: I don't think we ought to say.

MS. FRANK: Okay.

DR. KONIGSBERG: The only thing I would add to it is that somehow tie that statement back into existing federal financing systems so they get brought under concept is just what we're saying.

MS. FRANK: How do we want to say that, Charles?

DR. KONIGSBERG: I'm not sure exactly how to word it except that the intent of what I'm saying is how to drag Medicaid under the delivery system concept that we're putting out there.

MS. FRANK: I think one way to do it, we know there are several states, a number of states have federal waivers that are supplying -- public community-based waivers that are supplying a package of services, and Jim said, that's broader. We want something flexible and broad. Can the federal government provide incentives to states?

DR. KONIGSBERG: It needs to be stronger at the federal level. There has been some flexibility but it kind of depends on the innovativeness of the state.

MS. FRANK: It takes a long time. Can we provide incentives for states to have waivers that are home and community-based waivers for Hospices, case management? In their existing waivers the states already have, I mean, there are new ones that comply for chiefly Section 21 to 76, home community-based waivers. So we need incentives for that?

MS. AHRENS: That helps.

MS. FRANK: That does help.

MR. BULGER: I'm not an expert so maybe what I'm going to say is wrong, but in New York we pay an extra 30 percent if a hospital provides inpatient care and we put it with HIV. We pay up to 300 percent to a nursing home and up to 100 percent more to a health-related facility, we have new primary care rates for people who are HIV positive or infected with AIDS.

MS. FRANK: Yes.

MR. BULGER: It's Medicaid. We didn't get a waiver for this because the state plan adopted these enhanced rates and the federal government contributes 50 percent.

MS. FRANK: Yes.

MR. BULGER: Now, my expertise ends at this point in time. I don't know what we have to do to the federal

government to get them to say, yes, we'll bump up our 50 percent. Will the federal government -- I mean, do we need anything unique other than the federal government perhaps saying the minimum benefit package go to people who are HIV positive or already with AIDS should be "X", it should include the benefits and we will pay, we will provide whatever we can.

MS. FRANK: Let's write it down. We don't have to be experts. We can go back and --

DR. ALLEN: It's certainly working within the existing system to revise regulations to enhance benefit packages.

MS. FRANK: Yes. To improve service delivery.

DR. KONIGSBERG: It needs to be stated in a stronger tone. The HIPCA Panmaila (ph.) issue was one of the last things that Bill Raifert (ph.) did for HIPCA. HIPCA went from went from supporting certain things to combat infant mortality that were kind of the same thing, kind of in the background to making an active policy statement saying, this is an initive of HIPCA, it's important for the following public health reasons and it's been pretty damn convincing to some of us. That was a real change for that agency.

MS. FRANK: And also kids. Kids and moms were covered, we now have more uniform standards for kids and moms through Medicaid.

DR. KONIGSBERG: Why can't they do the same thing for AIDS and HIV?

MS. FRANK: Why can't they do the same thing for everybody. I don't like categorical things too much.

DR. KONIGSBERG: I agree but this commission has got a somewhat narrow charge.

DR. ALLEN: Just be aware in terms of specific categorical disease specific issues that the administration is very much opposed to that. I mean, that we have to work around and within those restrictions.

MS. FRANK: How can you improve the system for everyone by using HIV as the source?

MR. ORTIZ: The administration may be opposed to that but I think we're trying to put forward what we believe is needed. They may be opposed to that but if the commission goes forward that's what this is all about. If we're suppose to just give the administration what they like then --?

DR. ALLEN: I'm not saying that. I'm just saying that to the extent that we can come up with innovative ways of doing within the restrictions of the administration --

MR. ORTIZ: I think what we're doing is putting a matrix of policies that we believe should be implemented. The how and where and so on later on to be discussed. I think what we're saying is these are the things that we see is needed out there and we want you to move towards

implementing those.

MR. BULGER: The commission has a responsibility to balance.

MS. FRANK: I agree.

MR. BULGER: You can't just throw out this plan and start a plan.

MS. FRANK: No. Maureen?

MS. BYRNES: Which is partly why I think options are a nice idea. I see this as being different than the suggestion of grants and aids to enhance organizations one way of existing systems. I thought I heard -- Dr. Konigsberg, you were saying that those grants and aids should not be provided in a vacuum as though the Medicaid funded system doesn't already exist, but this talks about what we would do for the Medicaid funded system. The group could be suggesting that there are a variety of ways of addressing this immediate --

MS. FRANK: Yes. Organization and delivery system. See, now we're -- and we're also taking more time and I want to bring us back to process and then, Diane, you wanted to say something?

MS. AHRENS: I want to leap from specific and get into generic. I think the President should step up to the microphone and say that we have an epidemic on our hands, that every municipality and/or county in this country should have in place a strategic plan for dealing with this epidemic when it

reaches their community.

DR. ALLEN: It is there already.

MS. AHRENS: Well, for some counties I'm not sure whether they've got -- they've all got one AIDS -- I don't think we all have AIDS cases right now, but that does alot of things. I mean, first of all it sets the tone that this is an important issue and if the counties or municipalities that haven't done this -- and I'm talking about counties with 5,000 people, if they pool together and do this a lot of things happen. This is a very polarizing issue when it reaches your county, especially in some of the more remote conservative areas. If you have a plan in place, that means that you have educated your community leaders about this and they can step forward and minimize the polarization. This probably doesn't cost any money. I mean, people can maybe do this kind of work.

MS. FRANK: Okay. Can I stop us for a minute? I'm looking at the time and I know that some of us are going to be leaving before 1:30. We're going to have a working lunch together and we have until 1:30 this afternoon. We're doing a lot of hard work, we're doing a lot of difficult work. We have a large agenda and let's give ourselves the option of a couple of things. Is there anything -- is there a way that you would want me to proceed with you differently at this time or do you feel that we're on track and we ought to keep doing what we're doing? Is there anything that in view of the urgency of

some of these issues we want to cut them from the list because it's not of equal importance to our time?

MS. AHRENS: What do we have -- we have four more: housing, recruitment, planning, prevention and substance abuse. We have five more to go through.

MS. FRANK: Yes, we have. I think what I would like to do is make an order of priority. I would like us now to take the time to prioritize these issues and then move in terms of priority. Maureen, can you help us do that? The number one priority, and please bear with me, anti-discrimination and then we want to shift over to the second sheet to Maureen's right, public and private health care financing, health care and social services, organization and delivery, and then we want to shift back to housing, recruitment, retention and training of health care personnel, training, capacity building and technical support assistance, prevention, education and information and substance abuse. What is the first priority on that list. If you feel that this is the first priority for you, anti-discrimination, can we get a sense of hands? Okay. Can we get a show of hands around public and private health care financing? What do we have here; four? Let's write down the numbers of folks. Health care and social services, organization and delivery. A first priority. Housing? Recruitment, retention and training of health care personnel? One. Planning, capacity building and technical

support and assistance? Are staff voting? Jim, were you voting?

DR. ALLEN: No, I wasn't.

MS. FRANK: Do you care to vote?

DR. ALLEN: No, I'll let the others.

MS. FRANK: Prevention, education and information? Two. Substance abuse prevention and treatment as a public health issue? One. Among the people here and we'll pole the other people who are missing when they come back, it looks like public and private health care financing is first.

MR. STOUT: I want to go back to something you said in the very beginning. You said in San Fransisco the four things to stop the epidemic. Now, tell us what those four things were again?

MS. FRANK: The first priority was to end the HIV epidemic; the second priority was to care for the sick, to care for people who were ill; the third priority was to protect the human rights of all citizens; the fourth priority was to provide adequate funding to support a continuum of prevention and care and support services.

MR. STOUT: That was a pretty good list then and I still think it is.

MS. FRANK: They were policy goals and it was to end the HIV epidemic through prevention, education and research. Are you thinking, Herb, that we need to have some

articulation to policy goals at the federal level?

MR. STOUT: Mm-hmm. It's a pretty clear statement of what we want to do. Then you decide who's going to do it.

MR. FRANK: In terms of other priorities, number two, what is your number two priority?

MS. BYRNES: Pat, I'm confused. Are we prioritizing so that we can use the rest of the time we have left to decide as a group what level of government is responsible for what?

MS. FRANK: Yes. We're prioritizing so that if we are short of time we can either knock some out at this point or take less time with them.

MR. BULGER: You may want to just have us raise our hand -- as you go through these one at a time have us raise our hand as to which ones we feel we should deal with. It might just take less time.

MS. FRANK: Okay. So we've got our first priorities so let's go through the rest.

MR. BULGER: You can raise your hands for more than one.

MR. FRANK: Yes, you can raise your hands for more than one. Health care and social services organization and delivery?

MR. JONES: I guess I'm confused, too. I

thought we'd already done that.

MS. FRANK: All right. So we've done the first two, are we saying that?

MS. AHRENS: Yeah. I think we need to start with housing and go through the next five and decide which ones we're going to do, what order we're going to take those in so if we do run out of time we've all agreed just what we're going to talk about.

MS. FRANK: Okay. Housing, how many people feel strongly about housing? Four.

MS. AHRENS: Are we voting only once?

MR. BULGER: No, as many times as you like.

MS. AHRENS: Except that if everybody -- some people will vote two times and some people will vote five times and that's not going to be helpful.

MS. FRANK: Let's stop this because I'm getting confused too. Let's stop this process and let me just ask you a single question. Is there any of them that we want to take off the list in the interest that they're just not of equal importance?

MR. BULGER: Maybe we should limit a 15 minute discussion on each of the 5 and you just keep the clock.

MS. FRANK: Okay, I've got it. Are we finished with health care and social services organizations? Did we say anything about the states?

MR. ORTIZ: We said everything.

MS. FRANK: About what we want the states to do in relation to that? Did we say anything about localities, we believe that every locality should have a strategic plan, I believe.

MS. AHRENS: Well, the state has to have a plan, they have to.

MS. FRANK: We'll address this in two ways. We could have a national plan, do we want the states to have plans, a lot of the localities don't have plans.

MR. BULGER: Why don't we start by talking about plans.

MS. FRANK: Let's talk about plans. Do we need a national plan? Is this something we want to say to the federal government?

DR. KONIGSBERG: Yes. I think we need it desperately.

MR. STOUT: Is this commission not just going to do that?

MS. FRANK: A national plan, a plan for what? Because we have plans for prevention and information at the national level. We don't have a plan for this comprehensive prevention and care support services and financing and human rights we identified going back to those four broad roles, a public plan that crosscuts those four areas like New York's plan

basically that has such broad areas. Do we want a plan that addresses prevention, education and information cares for civil rights and financing; a national plan?

DR. KONIGSBERG: Yes.

MR. BULGER: Yes.

MS. AHRENS: Yes.

MS. FRANKS: That flows from those four policies?

DR. KONIGSBERG: Yes.

MR. ORTIZ: Yes.

MR. JONES: Yes.

MS. FRANK: Great. Let's get that down. I like that.

MR. STOUT: How in the world can the President stand up and say, "You localities, you counties ought to have a plan. Oh, but by the way, we don't have one at the national level. And by the way, fund it yourselves." That's ridiculous. He's got to stand up and say, "Yeah, we ought to do it. Here's the national plan and here's the money to help get it done." That's it.

DR. KONIGSBERG: That's right. That didn't take 15 minutes, did it?

MS. FRANK: What about states? Do they have plans?

DR. KONIGSBERG: You bet, yes.

MS. AHRENS: Yes.

MS. FRANK: Okay. What about counties?

DR. KONIGSBERG: Yes.

MS. FRANK: What about municipalities?

MS. AHRENS: Well, whether they have the function.

DR. KONIGSBERG: You should say local government because do you want a county of 3,000 in Kansas to have a plan?

MS. AHRENS: Yes.

MS. FRANK: Absolutely.

MR. BULGER: It's kind of like anybody can say states should have plans, localities should have plans, but I think this commission should be just a bit more descriptive as to how, not just what.

MR. STOUT: When you say you have a plan, that's the first statement, and the second statement is, here's what it consists of and then you list the things it consists of.

MR. BULGER: I agree with that and I think you've listed most of the minimal essential elements, at least the functional elements, but when a state builds a plan, and my presentation yesterday talked about this partnership approach with both the government and providers --

MS. FRANK: That's the planning process.

MR. BULGER: I mean, the state can't -- your

recommendation should not be for New York to sit quietly in the background.

MS. FRANK: Absolutely.

MR. BULGER: It should be for New York and Kansas and Massachusetts and the other states to integrate its planning process so that it's not an amount that you've got now and I think it should have something to do ultimately, perhaps in an update later on in a public document.

MS. FRANK: Should it be public and private sector of planning?

MR. BULGER: Absolutely.

MS. FRANK: And the development of the plan has to involve the public and private sectors including a nonprofit sector and community-based agencies so persons with HIV infection could now be -- change their mind so that at all levels of planning and decision making we need to involve people with HIV infection. Do we want to be that explicit, do we want to be explicit about the content and the process of the plan at the national, state or local level?

MR. STOUT: I think we need to be explicit as well if we could do that in about half a page but if you do it in a 30 page document about the plan then you have made a big mistake. We've got to stay general in policy level.

MS. FRANK: We don't want to do that. What else -- Lori, glad you came back. We're talking about planning

right now. We're talking about the need for a national plan, we're talking about the content of it, the planning process for state and local plans.

MR. BULGER: One of the things I didn't say yesterday at the end of my presentation is that all of a sudden in New York State we find out about a certain grant program or a grant that's happened and it just doesn't fit into what has been sort of articulated for that particular area, one of the square pegs in a round hole. If there could be some process for involvement on the part of the state, local government and the private sector for federal agencies in specific planning, that would help.

MS. FRANK: The other thing that seems to be missing at the federal level is that, yes, we have a PHS Task Force, and yes, we have a National AIDS Program Office but I know, Jim, that paper comes into some of those discussions but PHS is the leading agency at the federal level for responding to the HIV epidemic. It would seem to me that the development of a national plan that we need the inclusion of more of the federal agencies in the development of that plan. I know The Department of Defense, The Veteran's Administration, The Department of State, The Department of Justice --

MR. KESSLER: It didn't work in the past.

MS. FRANK: That's right. When I look across federal agencies there is a broad involvement within the Public

Health Service within, within the Department of Health and Human Services and federal agencies outside so that what we're talking about is really a plan that reflects what the federal government is going to do among and across those agencies and not just what PHS -- I mean, I've heard an awful lot, we all have, about what PHS had done and I think PHS has done a commendable thing, but I think now what we need is a broader look at what other federal agencies there are. Specifically, the Health Care Financing Administration, the Social Security Administration through SSI, through Disability Insurance, and when we look at the federal budget now we don't just look at PHS and say, "I think that has to be done, " so that we have an interagency with the task force. The PHS Task Force is no longer appropriate for dealing with all aspects of the HIV epidemic and a national planning effort has to be governed by and has to be integrated with the National Drug Control Strategy. It's a pity to see the National Drug Control Strategy to have mentioned AIDS I think four times. I think it's sad. So somehow this kind of planning has to be done at the federal level which is more inclusive and abrasive because all of the issues -- in the beginning prevention and research were the major efforts of the government but the fact is government is picking up their share of Medicaid and when we look at the budget it's not just PHS, it's not just approximately $1.6 billion dollars for this fiscal year, it's $2.8 billion dollars across government. So if the government is

spending money I would only think that they would be involved in a planning process on how to do it most effectively. It's the same way at the state level. Sister addressed this, that plans have to be -- Sister addressed it and Jim addressed it very eloquently in interagency plans. The Department of Education is another so you have to crosscut from agencies and they have to be public and private sector plans and this is true and I think we can make that statement at all levels of government.

Is there anything more you want to say about planning? Then I would like to move on and talk about capacity building with technical support and assistance so that we have reinforcing capacity building that flows from the federal level to the state and from the state to localities because we don't have that right now.

MR. BULGER: One quick last comment on planning. I think that the recommendations would go further if we say that the President should authorize this interagency group in that perhaps Jim and his office seated in the right agency of the federal government should have control of -- there has to be a vocal point somewhere.

MS. FRANK: As the assistant secretary he has offices currently -- Jim Mason (ph.) is Jim Allen's boss so that's --.

MR. BULGER: But somebody has to make it all happen once it's established.

MS. FRANK: Okay.

MR. STOUT: Let's not talk about who it should be, let's just say that in the plan it should be there.

MS. BYRNES: In the plan that should be part of what happens; is that what you're saying?

MR. STOUT: Part of the plan should say who the vocal point is in the federal government and it should say that there should be somebody there from state and there should be somebody from local government, every local government.

MS. FRANK: So what we need here is to identify the AIDS coordinators throughout the states. Now, do we want to identify these coordinators in Jim's role at the federal level. Is there anything -- I think the things that we're saying is that's a national plan or very similar to state and local governments. How would you possibly view capacity roles in technical assistance as a group at the federal level or are there areas that you would like to see the federal level more involved past its role now. I mean, in capacity building and technical assistance we have talked about laboratories, we've talked about CDC advisors in highly impacted areas, we talked about education and training. Capacity building could take several forms: loaning money and federal staff, education and training of state and local staff, capital improvement funds for facility structures. Bill?

MR. JONES: I guess when I was speaking

yesterday I had in mind the need for hands-on skill building, particularly for occupations that are within the community because the education, prevention and information that often end up relying on government funds through the federal, state or local funding to do the work that they do and then when that money is cut back they are not able to continue the funding. Particularly when we talk about supporting grass root community-based agencies.

MS. FRANK: Do we want to say anything about capacity building for the nonprofit organizations that are feeling the full front of AIDS prevention and education and information?

MR. JONES: If I can add a little bit. The weakness of the currrent technical assistance of skill building efforts is that the communities basically don't have the money to get to where these events are happening and in the national organizations, even organizations like the U.S. Conference of Mayors, doesn't have sufficient funds to send people to their functions so everybody is stuck exactly where they're at. And the people who are waiting for technical assistance can't get it or can't get to it or can't get to where it's needed the most to deliver it. What I would like to recommend or see is that a part of the funding is used for that type of mobility or for travel funds or for a specific line that is specifically for that so that people can get the skills. I mean, we can advocate

for it but if the government doesn't put money in -- I mean, what we hear the most is "I don't have the monies," "I need that but we don't have the monies to come." So there is a struggle to try to get scholarship monies or discretionary funding and everybody acknowledges that it's needed but they don't have the budget.

MS. FRANK: That's definitely capacity building.

MR. JONES: Yes, capacity building.

DR. WOLFRED: I think the training needs to go to the state or regional level. I mean, there are existing regional organizations that were given state or federal money to bring in training to their regional gathering.

MS. FRANK: What were you thinking about existing organizations?

DR. WOLFRED: Which ones?

MS. FRANK: Yeah.

DR. WOLFRED: There's one in the southeast, I'm not sure what it's called, that covers several states. There's one in the southwest that covers New Mexico and Arizona and some other southern states and I think California has a system somewhat state-based now. Some other states do as well.

MS. FRANK: We have the Regency HHS which were divided up into 10 regioncies.

DR. KONIGSBERG: Are you talking about the

AHEX (ph.), the training of physicians, Tim?

DR. WOLFRED: No, I'm talking about the regional groups that have sort of emerged out of the Aid to CDA.

MS. FRANK: We've got several ways. We've got ENCAP (ph.), we've got HHS, HRSA has done lots of regional things. And in terms of support planning one of the tragedies of the health plan is loss of planning monies to localities and one of the recommendations we simply have to make is we need to restore planning monies to low incidence, medium incidence, high incidence areas. There were 22 grants made and that money was blue penciled out of the budget this year so that no ones going to plan unless they have assistance. One of the things that we talked about yesterday was moving towards regional -- I can't trust states that now have had minimal approaches, sub-state regional approaches, they're putting their own dollars into it, state-owned dollars, and so as an incentive to the development of regional approaches to planning which worked well in metropolitan, rural, suburb areas. Sometimes a regional approach is very efficient to plan, so that's one recommendation I would urge us to make that congress restore that funding, increase that funding for HIV planning.

MS. AHRENS: But the states have some responsibility there too, I think.

MS. FRANK: Yes, they do.

MS. AHRENS: I think we should say that.

MS. FRANK: Oh, definitely.

MS. AHRENS: I don't just think we ought to say, "Feds, this is their responsibility and you have to find it." I think the states have responsibility and I think the states also have responsibility to fund some of that.

MS. FRANK: To fund planning efforts?

MS. AHRENS: Mm-hmm.

DR. KONIGSBERG: Some states may need a real prod to do it, like mine, for example.

MS. FRANK: The growth and the planning, the network planning, the saving of funds has been one of the areas of greatest growth so that the states are --

MS. AHRENS: Yeah, but I think that's appropriate. I guess I'm simply saying that we should reinforce this is also a responsibility of the state.

MS. FRANK: And that's a good point Sister made yesterday about the partnership between states and localities in terms of capacity building and technical assistance.

MS. AHRENS: It's in the state's best interest, economic best interest to do this. That's why they ought to play a role in it. They share in the medical costs to a large extent and so far as the system, the local planning system can mitigate their extra costs by the plan that they have for serving their population.

MS. FRANK: Are there specific areas in which we feel that capacity building and technical assistance from another state as Bill has pointed out?

DR. KONIGSBERG: One of the areas -- and I'll just use my state as an example, my current state, is that we dismantled our formal health planning capacity when the federal support for health systems agencies were gone. I mean, I hate to say it but we could use technical assistance on how to plan this. And I don't think we're the only state that got themselves in that situation. I was sitting around trying to figure out in a number of areas, not just HIV, how to restructure and how to plan. It's a very unpopular subject in some areas, considered kind of academic, egghead, associated regulation and lots of other bad things. There is a variety of technical assistance. I mean, we've got the health care personnel capacity and then we've got health care personnel in a separate area and there are some ongoing efforts through the area of health and education to try to build the capacity of our health care. You know, we don't just have a shortage of health care personnel so much as we have in some cases a shortage of people who have the professional capacity to take care of this whole new disease complex, and there needs to be more efforts in that.

MS. FRANK: Well, there's health professions, yeah, there's health professions, there's patient training,

there's a small amount of money in HRSA for the AIDS educational training centers. Can this be addressed for that kind of program through the AHEX or is this a --? This is a whole different book. What Billy is talking about, what Tim is talking about, are they different issues that need to be addressed in different ways?

MR. BULGER: We're sort of talking about a lot of different things.

MS. FRANK: Yes, we are.

MR. BULGER: And I'm not reaching conclusions on any of them. How many CDC cooperative agreements are there, Jim? Are they all over the country or are only a dozen of them?

DR. ALLEN: It depends on what you mean in what specific area. If you're talking about the combined surveillance prevention cooperative agreements, every single state in the union has one. There are in addition cooperative agreements where the majority, if not all, of the most heavily impacted metropolitan areas and some of the territories, for example, at least Puerto Rico and I'm not sure about the Virgin Islands, and some of the trust territories also have cooperative agreements to begin with, many of them do, if not all of them do. But there's something in total, I believe there's more than 60 cooperative agreements.

MR. BULGER: Well, that's the answer I was hoping I would hear. Assuming that to be so can we make a

recommendation, or the commission make a recommendation, that CDC either mandate that portion of its funding to each state to be used for capacity building in the form of technical assistance? I know we do it in New York.

DR. ALLEN: We spend a lot of money, Jim, bringing in consultants to train the CBO's using CDC money. If CDC mandated that two percent or one percent or something like that be used for that, that's something that could be employed, and we'd recommend that money be congressionally allegated to CDC for that purpose.

MR. BULGER: It just seems like the system is out there.

DR. ALLEN: Yeah.

MR. BULGER: So let's use the system in place and augment it and direct the monies for what Bill is talking about.

DR. KONIGSBERG: Well, when you're dealing with the kinds of low levels funds that low-incidence states get from the CDC you start spreading those funds further to produce virtually nothing. I mean, they don't take away from direct service delivery for nothing. I think that's a legitimate approach from the states but I think what I'm trying to say is that there's a wide variation in the ability of the states to do this, and that some of us, we need the capacity building on us first before we can give a hell of a lot of it to the locals.

The sophistication level varies and it's to be desired and I haven't heard anything here that's not legitimate. I think the point about pass the Bill for CBO's is extremely important. For example, my agency puts a fair amount of money into CBO's and the local health departments but I think we lack the ability to help them get to where we want them to get. That's a little different than the monitoring functions.

MS. FRANK: That's true. I think we need to move on past planning, capacity building and technical assistance and move into -- let's do housing. Is there a role for the federal government in housing and what should that role be?

MR. BULGER: HUD spends precious few dollars on housing in general.

MS. FRANK: Yeah, we have learned that.

MS. PALMER: I know that even helps.

MR. BULGER: Right. But they're deleting HIV and AIDS housing in the suburbs. There are very few U.S. set asides, very few specific programs, there is the Section 42, 63, something like that. It's not even there. I mean, there's this patchwork of funding, matrix of funding that really has very little impact.

MS. FRANK: Yes, almost none.

MR. BULGER: They have a $4 million dollar program, nationally.

MS. FRANK: Isn't there a Bill before the congress now that deals with housing?

DR. WOLFRED: It's a $200 million dollar Bill.

MR. BULGER: I think this commission needs to support that bill.

MS. FRANK: Yes. The McDermott (ph.) Bill.

MS. AHRENS: Even in the housing stock that HUD has foreclosed on, when they want to turn it back to public or private sector the regulations are such in Minneapolis/Saint Paul we just turned it down because of the regulations that HUD laid down, it's not even in law. And I think we have to speak to some of that. There's housing out there that the private sector and the public sector could make use of if their regulations weren't so overwhelming to us.

MS. FRANK: What are some of them?

MS. AHRENS: Well, one of them is if you spend all this money in refurbishing the house that usually needs it, a facility, and then you cannot charge any rent for the use of that. Well, if people have some income, it ought to be able to be -- it's this kind of stuff that makes it unappealing to put forth an effort and certainly there's a private sector in there, the not-for-profit sector. They have to have some recovery of the money that they spend. So I'm saying they need to look at the regulations. It is the most

regulated bureaucracy that we deal with.

MS. FRANK: Let's say that we need to review the regulations for ways of the various housing titles at the federal level. Let's for starters say that. We don't have to solve everything. That doesn't mean there's a lack of incentive.

MS. AHRENS: It would encourage --

MS. FRANK: That we encourage --

MS. AHRENS: -- the private and the public local sectors to utilize the housing that -- the foreclosed HUD houses.

MS. FRANK: Okay. Is there anything else that we would like to hear about the McDermott (ph.) Bill?

MR. JONES: I would just like to say that when we go back and review these regulations, that we not loose sight of why those regulations were put in place. There were very good reasons why those regulations were put in place and in our effort to review that, that we don't end up fighting with other activists who set -- and other programs and undue things that make good sense and they may still make good sense and I guess we need to do that but housing still has to be looked at in the overall picture. I'm waving the red flag there. It makes me a little nervous.

MS. FRANK: Remove these restrictions?

MR. JONES: It feels like one of the -- I

mean, housing is such a big one. Part of the problem is housing for HIV infected and those with AIDS, and actually the government hasn't even looked at the particular issues for persons who have not been diagnosed and how they may get this housing. We've run into the same problems that we did when we tried to establish homes for recovering addicts and mental health patients, all those populations that no one wants these problems in their back yard, in their neighborhood or next door to them. So these are issues that need to be looked at. My other concern is housing versus shelter programs. We have this mentality that what works best is if we can get a massive number of these people into one segment of one block and we loose sight that those are necessarily not very effective or very humane-type programs. And seriously looking at people who get displaced by real community-based private homes, being able to set up group-type homes of smaller types, we support those nontraditional type home settings. And if you look at shelter for them as temporary --

MS. FRANK: That's emergency housing. There's emergency short-term housing and long-term housing.

MS. AHRENS: These are also state and local issues.

MS. BYRNES: That's my question. What is the state's responsibility in this list?

MS. FRANK: Okay. What is the state's

responsibility in this list? What role do we want the states to take? States license residential facilities, we know that and are creating new categories of the licenser in some cases with alternative settings. Should we encourage states to do that, although that's not strictly housing. Should we encourage states to be flexible about alternative residential centers for persons with HIV infection; is that one thing?

MR. BULGER: One thing we can do so that they don't start setting up these buildings that are identified with HIV and AIDS is -- what New York State has not been successful in doing is to set up a separate stream of funding, SSI stream of funding, level three housing for people with HIV and AIDS. The legislature disapproved it but we hope it will be approved this year and if it is, it's where an individual would normally get something like $600 per month to live. If he or she is HIV positive or has AIDS they would receive something around $1,000 per month to live. That's an area that state government could do more for, rent support.

DR. KONIGSBERG: You can get into conflicts between state and local government on this and I have been through some real war stories on that.

MS. AHRENS: I go back to generics on this. Can't we simply say that federal and state and local government leave policy in place that would encourage smaller living units, something to that effect?

MS. FRANK: They tell me that our lunch is outside and I think we have worked very hard and I think we need to go out and have our lunch.

(WHEREUPON, a short recess was taken.)

MS. FRANK: This brings us back to our next issue which is recruitment, retention, and training of health care personnel.

MS. AHRENS: I think it's a state function and I'm in favor of it.

MS. FRANK: What's the federal role in this? What would you like the federal role to be?

MS. AHRENS: Well, I don't think we ought to let our medical schools off the hook. It seems to me that there are other segments out there that ought to plug into some of this.

MS. FRANK: Because they are state funded.

MS. AHRENS: Medical schools.

MS. FRANK: Medical schools. Health science campuses.

MS. AHRENS: Mm-hmm.

MR. BULGER: For the most part it isn't medicine, it's nursing, the sciences --

MS. FRANKS: It's nursing.

MS. AHRENS: Yes.

MS. FRANK: What do we do now because it's a

severe problem, it is a severe problem? The only good thing that we have at the federal level right now that addresses health professions, education and training is administered through HRSA and those are on Aids Education and Training Center financed basically to university-based groups and throughout the country to enhance development of primary care of physicians, nurses, dentists and to -- I have no idea how well it's working, there is not a lot of money in that but that's the purpose of that program.

MS. AHRENS: What I'm saying is why should the medical schools be reaching out to train nurses? Why do we have to segment everything and say we can only do what's within our ability, historic scope.

MS. FRANK: We've got a problem in that there is a major nursing shortage because people don't wish to be nurses anymore.

MS. AHRENS: I'm talking about training those that are already -- I mean, if we're talking about training we're talking about retraining or continuing education or something like that.

MS. FRANK: Oh, okay. Yeah, there's recruitment, recruitment is one issue and retention is another issue and training is another issue. I mean, these are separate issues.

MS. BYRNES: In terms of what is I can just

say that last October a meeting was held and sponsored by both HRSA and the National Association of Research where they did plan a five year agenda for nursing relative to practice, research and education so that they at least have a plan in place in relation to nursing education.

MS. FRANK: Okay. Jim?

MR. BULGER: The federal government used to have a nice little program called the National Health Service Board and I believe that's all but extinct right now. In New York where we have really a nightmare of the situation with respect to nursing, especially, we've created a thing called the New York State Health Service Board of Women. Not a whole lot of money, but basically to recruit people into nursing, pay for their tuition, find jobs for them and finance related costs. I don't know whether it's going to work or not because it's only a year old, but I think what we have to do is -- it's bad enough getting -- finding people to enter the nursing and other therapy professions alone, let alone putting them into an environment where they are dealing with AIDS. It's just that much more difficult to recruit. So what you have to do is build a series of incentives or enhancements --

MS. FRANK: Okay.

MR. BULGER: -- and what are they? Well, that remains to be seen and, yes, the state should take some responsibility for that but I still think that the federal

government shouldn't just obligate it's responsibilities.

MS. AHRENS: Yes. If we catch it in terms that the federal government must play a major role in this and then talk about -- illustrate for the federal government how they might do this --

MS. FRANK: Give some examples.

MS. AHRENS: -- and give some examples like this.

MS. FRANK: What is the state role in this? In education and training of health care personnel states now license health care professionals? Some states have developed programs specifically for educating and training of primary care personnel related to AIDS educations

MS. AHRENS: I think that role in terms of public health departments around the state seems to me that they would play a key role in training some of that personnel.

MS. FRANK: You know, one of the things that I have thought is to be HIV incompetent is to be incompetent to practice for dentists, nurses and physicians. And some things states can do in licenser and in state board examinations is to say that unless you have credits of these kinds, I'm sorry, you can't renew your license. You can enhance, shall we say, this participation in the community in the area of continuing education by saying you're not allowed to practice unless you have it.

MS. AHRENS: We do this in education.

MS. FRANK: Yes, we do.

MS. AHRENS: We do this in terms of attorneys in this state.

MS. FRANK: One of the problems is that still a handful of health professionals in communities throughout the United States are bearing the burden of the health case load of persons who are HIV infected. Part of those are reimbursement problems, part of those have to do with urban discrimination and fear on the part of the health care personnel, physicians and dentists. And that has not been adequately addressed and as the simple ethic of it grows and as HIV disease becomes a chronic illness, people are going to need health care over a longer period of time. How is that going to be done? It can't be done by a handful of physicians, by five physicians with a case load --. And this is where we are in terms of primary care in health personnel. The signs that it's generic in product, the shortages of nurses in nursing. I think it is a major, major problem and I think that it's a complex issue because it has to do with education and information and it has to do with retention and education, it has to do with reimbursement so it's a very complex issue. The fact is without enhancing the participation of health care professionals is epidemic, we're just not going to make it. I don't know how they're going to be cared for.

MR. STOUT: This is not a problem that's unique to this particular situation.

MS. FRANK: No, it's really not.

MR. STOUT: There any many other situations that experience the same problem; for instance, handicapped have the same problem and so I don't know what the proper way is to approach it, but back to one of the comments that Diane made earlier, "It would be nice if we could approach that with something really great instead of with respect to this specific problem." But I believe this is a common problem throughout the health care industry and doctors do invite and just pick and choose in a lot of places just what they want to do.

MS. FRANK: To say that you won't see anyone with HIV disease is a great error because you don't know who they are.

DR. KONIGSBERG: Did the group agree to that controversial statement up there, that mandating sort of thing --?

MS. BYRNES: I don't think necessarily that the group agreed on it, I'm just writing everything down.

DR. KONIGSBERG: That is an approach that's been used by at least one state that I'm aware of. I would submit that's probably not not the best way to get at it.

MR. STOUT: And it probably won't be done in a lot of states.

DR. KONIGSBERG: I wouldn't recommend it in mine.

MS. FRANK: What's the sense of the group about what state or about what roles states might take, or is there a generic statement that we could use and is there a role for local government in this issue?

DR. KONIGSBERG: I think the problem is when we're talking about physicians and being available to really take care of persons with AIDS, I think the problem is not so much the training as once they're out. I think the state and local medical societies need to take a strong role and I don't think it's inappropriate for the state public health agencies to stick their nose in it although they need to tread carefully.

MS. FRANK: Is there any role for government in this at all?

DR. KONIGSBERG: In terms of encouragement and education and that sort of thing, but when you start mandating what physicians can and can't treat then I think we've got a bag of worms that's going to be something else.

MS. FRANK: So we can't think of any kind of role for the government?

MR. BULGER: The private practices of physicians are essentially excluded from the line of regulations by the government, but this goes back perhaps to the work group on reimbursement or financial issues. You can't build

incentives into Medicare and Medicaid financing to treat people who are HIV positive. You can build incentives for people, and I mentioned this already, like perspective nurses and perspective therapists for AIDS, the sort of quasi-professionals, the LPN level, something like that.

MS. FRANK: Right.

MR. BULGER: We've set up a title called Case Management Technician in New York State and we'll recruit people, we'll train them, or put them into training and then find them a job. It's that kind of role that I think the goverment should get involved in.

MR. SMITH: I think educational presentations to second year medical students at university medical schools is essential. I think the thing that constantly distraughts me is there is very little difference between second year medical students and physicians and nurses that are already out in the field, it seems they go through exactly the same fears that prolong these human right issues as the general public does. If we want more than one or two percent of our doctors treating those who are HIV positive or infected with AIDS there has to be something very basic besides the encouragement of the medical schools and the medical societies with just some type of basic education to the current physicians as well as those coming up.

MS. FRANK: So it's physicians in training, physicians and nurses in training that we're trying to reach,

physicans, dentists and nurses in training that we're trying to reach; and we want to reach practicing physicians, dentists, nurses, nurse practitioners and the issues are not only education and training but continuing education and training and reimbursements. Is that a good summary of generic issues that need to be addressed?

DR. WOLFRED: That's great.

DR. KONIGSBERG: Sure.

MR. JONES: And you probably said this as part of it is wanting HIV and AIDS courses somehow incorporated in their education --

MS. FRANK: Mm-hmm.

MR. JONES: -- as part of their certification requirements, as part of their licensing --

MS. FRANK: Licensur, examinations and --

MR. JONES: -- and somehow we need to put together a statement that says not so much the stand-alone courses, but that it's incorporated because it reflects what is going to be happening in the 1990's.

MS. FRANK: So the curriculum --

MR. JONES: -- needs to be revamped to incorporate HIV and AIDS issues.

MS. FRANK: Okay. I think we've covered some essential basics on that. I'm going to move on. I'm going to move on and talk about prevention, education and information.

MS. AHRENS: Very important.

MR. ORTIZ: In fifteen minutes.

MR. JONES: There seems to be many that sort of feel like okay we've done the education and therefore we're finished. And somehow we need to say that this is an ongoing process that has to be continued and if anything that we now recognize that educational models need to address substandard behavior training changes. We need continually to look at innovative and creative educational models that need to be culturally specific in certain cases. I guess the main problem now is needing to make it clear that that is not a process that ends with the ending of demonstration of policy issues. I'm especially concerned with the end of a number of the NIDA five-year funding cycles and other NINH funding cycles.

MS. FRANK: Ending next year.

MR. JONES: A lot of those funds are ending and what's going to happen to all of these educational efforts?

MS. FRANK: The point that Tim made yesterday was that his greatest concerns were about the attention would lag, and I think there are several issues. There's the concern of what we're doing and whether we know what we're doing works and a great number of operations in terms of risk production and withheld information to the general public and other groups and the lapsing of effort. There are lots of issues here and we're at the very heart, because if we fail at this we're at the very

heart of the epidemic, then we don't get those first funds to end the HIV epidemic.

MR. STOUT: I think right now it's the only thing we can do. We don't have that silver bullet, we'll have to find another way, but it's the only thing that we can do right now. I think one of the things that's very important is we fix the responsibility for doing that and the recommendations from the commission be very clear about that, who is suppose to do what. What the federal government is suppose to do, what the state government is suppose to do and what the local government is suppose to do.

MS. FRANK: That's right.

MR. STOUT: I think you need to make a strong statement about the responsibilities of local government in this regard.

MR. FRANK: Okay. Let's start with local government, Herb, let's do that.

MR. STOUT: Well, I think there are a number of things that the local government ought to do. We have got committed and what we've done with the counties, we've told them what they're suppose to do in the area of education.

Some of the things that have already been mentioned here are included in that and there can be that statement about what needs to be included in the educational effort, it does need to be culturally specific. You really can't say to a particular

group, "This is the curriculum." You really can't do that. You have got to say what the end product is suppose to be. And I think you do have to continue the -- maybe not continue the demonstration process but certainly publish the results and in some way give resources to local governments so that they understand what has worked in other places and they understand what needs to be done because there have been successes.

One of the things that we need to be concerned about is that we have new generations coming along all the time, every year there's a new group that has to be educated and that's the first place to start the education with our young, with our young people and so that will never end, not until the epidemic itself has ended.

So we have a continuing responsibility plus the fact that we continue to have local governments who are just now awakening to the fact that they have that responsibility. I mean it is indicative and it is applicable to their community. So I don't think that it should be so specific that you say you need to do this, this and this, but you do need to specify the outcomes and you do need to specify that local government has the responsibility to educate its citizens.

In fact, we went a step further than that, we said it's irresponsible not to do that. You must accept this responsibility as something that must be done. I think it's particularly a federal role also and I think the federal

government has done some things in this area but I'm not giving it up, I'm not 65 yet, when in fact it should not end, the federal effort should not end. I think the commission needs to work hard for that continued funding.

The last thing I'll say is we do need some resources and they need to be flexible in nature and this goes back to the funding that we talked about before. I think it does need to be done on an incentive basis such that you can apply for it, a grant program or however you want to do it. It needs to be substantial funding but not only needs to be at the local government but perhaps to private nonprofit agencies that are doing this type of work. But whether you fund it through local government or you fund it directly I'm not so concerned with that as long as the possibility exists that it can be done. So I think it's a very important part and it needs to occupy a host of different parts of the commission's work in these relations.

MR. ORTIZ: I think the role of community-based organizations in the overall structure is important because they're the ones that are very basically most effective from an educational aspect.

MS. FRANK: What I hear you're saying is that we need federal support to the states, counties and community-based organizations.

MR. BULGER: You sort of have to look at prevention through at least two windows, one is community-wide

prevention which would be through research in families or it might be the federal government mandating HIV curriculum in grades K through 12. I know in New York State the state mandated that, but conceivably the federal government with all of its federal educational reimbursements to states could not so I'm saying let's include it in the curriculum.

MS. FRANK: What's the sense of the group about that broad a mandate at the federal level, mandating AIDS education K through 12 through the Department of Education?

DR. WOLFRED: I think it would be great.

DR. ALLEN: Most of the money for health education so far has come from HHS.

MS. FRANK: Right.

DR. ALLEN: Although Education has worked with us on that.

MS. BYRNES: Because the Department will continually tell you it's not a federal role to mandate RIVCA (ph.), that's a state responsibility, so that CDC serves an advisory and clearing house role of models, possible ways in which material could be presented in part, but I think the Department of Education will continue to tell you that it is not the goal of the federal government to dictate curriculum.

MS. FRANK: Well, we might tell the Department that we believe it is.

MR. STOUT: I think there's a little bit of a

different philosophy that might be applied here when you say to them, "Yes, that's true," with respect to the types of curriculums that your dealing with right now. But there's a kind of danger to our people if they are not educated and it's their only defense in this case.

MS. FRANK: Absolutely.

MR. STOUT: And therefore it is a matter of public safety and the matter of public safety falls squarely on the service of local government, state government, federal government and it's there, and to be cognizant of the danger to our people and fail to take reasonable measures to advise them of that danger is irresponsible. I think that you can push all of the bureaucracy on that particular point and I don't think it would make any difference.

MS. FRANK: It's negligent in the way that we first communed the panacea. Just as a physician would be negligent in not caring for his or her patient, a policy maker is negligible in not caring for his or her constituents.

MR. STOUT: Right.

DR. ALLEN: Two other points on that. One specifically to the education responsibility and that is that the school approach it and we do feel that AIDS education has got to be part of a broad health education program, that if it hangs out by itself it is not going to be nearly as effective.

MS. FRANK: Right.

DR. ALLEN: The second point in terms of federal responsibility fits on the research agenda and that is we need good research in terms of how one influences behavior and --

MS. FRANK: Good evaluation and research.

DR. ALLEN: Yes.

MS. FRANK: And as Billy pointed out and other people culturally sense evaluation and research around behavior changes, people who have a key role on the different cultures and we need to know what the measures of success are with the cultures. We need that and that's what NINH and NIDA are funding through some of their things so that there is a role of being in research here for the federal government. States, what's the role of states in prevention, information and education?

MR. JONES: I would like to say since there are a number of institution settings such as prison settings and mental health settings, drug abuse programs, under the jurisdictions of local, city and the state that we somehow say to them that this is overlapping in the area of education, planning and a number of issues, but the point is that since it's under that, that it seems to me that they really need to develop educational curriculum targeting their staff and their clientele on those hugh programs and I'm appalled at how many of them have not. And so somehow I'm saying that all of the

institutional entities that are under their jurisdiction --

MS. FRANK: Under government.

MR. JONES: -- that they need to develop education and curriculum --

MS. FRANK: Good place to start.

MR. JONES: -- to target their staff personnel as well as the constituencies and just go through those institutions and maybe filling out some of this language. What comes to mind immediately is our substance abuse program, incarcerated program, mental health program and others, but I'm saying, whatever they are they --

MS. FRANK: Emergency service worker or -- I mean, there's a long list.

MR. JONES: Now, what is currently happening is that when you go directly to the entity, they will say, "I do not have -- my budget does not permit me to do it."

MS. FRANK: That's right.

MR. JONES: And therefore they will point at someone else and the department of corrections will say, "I just don't have the budget, it should come under the jurisdiction of public health." The reason I'm laughing is because this is a real scenario of someone saying, "We'll hire Bill and he'll do it." So what happens is the community organizers gets called in to get through it.

MS. FRANK: Yeah, that' right. Then the AIDS

Foundation is called in, that's right. What do we do about this? How can we help this situation? Is there something the federal government can do?

MS. SILVER: Well, I have been trying to be very quiet but I can't resist. One of the things I think that can happen at the federal level that needs to happen better at the state level and probably happens at the local level is that everybody takes responsibility. Everybody sees different levels of education and everybody needs it, the kids, the adults, the doctors, the nurses. I mean, it can't be all HHS's responsibility to do it all.

MS. FRANK: No, absolutely.

MS. SILVER: Education has a certain amount of responsibility, the Department of Corrections, and they need to state what it is.

MS. FRANK: Good, that's very good, interagency again. It gets back to the interagency task work.

MS. SILVER: It's just like once in awhile they need at the New York State level with corrections and mental health new roles and everybody else and you need someone -- perhaps maybe you really do need someone from the federal level to do the same thing. That's my view, it's not a suggestion but a view.

MS. FRANK: Yes, that's good.

MS. AHRENS: We might just recommend clearly

at the state level and I think at the federal level, too, that there be a mechanizm for interagency action with respect to the prevention, education issue. Sister Ashton described that very well, I thought. I don't know -- do they have that at the federal level?

MS. FRANK: Well, yes they do, they have the PHS Task Force and they also have subgroups; don't they Jim, on the task force?

DR. ALLEN: Yeah, subgroups -- we're toying with the exact role of the subgroups. We do have a interdepartmental -- it's not really an interagency but an interdepartmental working group. The problem is that people coming to that are more at the working level and not at the policy-setting level.

MS. FRANK: Yeah.

DR. ALLEN: And I think one of the things we need is to take a good hard look at how we can increase the level of those.

MS. AHREN: Is there an interdepartmental group --

MS. FRANK: Yes.

MS. AHRENS: for the Department of Defense?

DR. ALLEN: Yes. What I was going to say is that the people -- there is usually one person from the department, one or two people from the various departments that

come. The involvement is transient, it's not always the same people all the time and they basically are not at the policy-setting level.

MS. AHRENS: Maybe we need to look at this because how in the world are we going to put everything together if we don't have the policy makers really at the highest avested together in these departments of education. This Blegzar (ph.), is he meeting with you?

DR. ALLEN: There is -- Secretary Sullivan has on his staff a person who relates directly to Dr. Bennett's office, Ms. Byrnes's office, and Jim Mason and I meet with him on a regular basis also. There is a direct link through Secretary Sullivan's staff.

MS. AHRENS: But, Jim, that's not the same as them interacting with education.

DR. ALLEN: Yes.

MS. AHRENS: -- and defense and whoever in how they review prisons. I mean, I think we've got to bump it up a bit and do it much more verbally because that's the way the states have found, and that's frankly the way the counties have found when we have to deal with child protection, we're dealing with this department, and county attorney, and public defender and we've got them all there at the table and we say, "We've got a problem here and we're not going to leave this room" -- well, we don't quite say it that way but, "over the next year we are

not going to leave this room until we get it how we're going to do this and do it better." It seems to be that's what needs to happen at the federal level.

MS. FRANK: I think that's a wonderful point and I think we need to note that. I think what we're saying here -- in the report to the President, one of the things that was mentioned in the December report to the President was the need to bring all the players to the table and we're asking to bring the players to the table at the federal level, state level and at the local level and since the players crosscuts so many agencies, that's the first step, that's the first step in planning, that's the first step in coordination, that's the first step in developing policies and guidelines whether it's about prevention, education and information, whatever it's about.

MS. FRANK: Lori, did you want to say something?

MS. PALMER: No, I'm listening.

MS. FRANK: I think that's one of the key things we can recommend here because we started out with the themes of this day being leadership and partnership. Leadership and partnership, and roles and relationships.

DR. WOLFRED: I don't want the partnership at the CBO level to get lost either.

MS. FRANK: No.

DR. WOLFRED: We have one statement in here about some funds from CBO that involves state and local levels.

MS. FRANK: How do you want to handle that, Tim?

DR. WOLFRED: Well, we can stress something about CBO --

MS. FRANK: About prevention?

DR. WOLFRED: CBO on the prevention level needs to be an equal partner, a full partner in prevention strategies.

MR. ORTIZ: That's where the creative thinking is done at the CBO.

MS. FRANK: How do we do that with the issue that we mentioned about the -- how do we make the point that prevention includes all of the people at risk in terms of risk prevention and all of the people in the general population, young, middle-aged, whatever, how do we make that point in our inclusiveness of the effort that has to take place that the epidemic isn't at such a point that we can drop out?

DR. ALLEN: The biggest problem here are the legislative restrictions on the use of money. I mean, when it is in there, placed in there by congress, and overwhelmingly voted by both Houses that you can't do that, the rest of us sit there with out hands tied.

MS. FRANK: I understand that. Even though

the CDC often make grants to CBO's and congress says on one hand instructor reminders to include CBO's, when they're granted their activities; and on the other hand --

MS. AHRENS: The CBO has got money, though.

MR. JONES: Also, Jim, it seems to me that there is some disparity when they institutionalize in, such as corrections and mental health agencies and all these others and call them CBO's to do education and prevention as volunteers when there is no money, but when there is money they forget that they're there.

So clearly they do have the capacity and many do subcontract specific services and community-based agencies sometimes are the best persons to respond. And particularly the ones that go through this and sometimes they have found a combination of the agencies that will thank you for saying you did get around to accepting the confidentiality, the reality that when they come out of these institutions they have to come back into the communities, and so somehow we need to say that that partnership needs to be nurtured, developed strongly and continued.

MS. FRANK: You know something else I think we might want to say and this is again the consensus of the group, why do we need the restriction language on the use of funds? It seems to me that some restrictions in language were removed from congress's language this year, could it not be --

DR. ALLEN: We need to be specific what was removed.

MS. FRANK: Well, didn't it have a little drop back on bleach? I feel strongly that when we're sitting around talking about nurturing and supporting the CBO's, I mean, we wouldn't have this problem if we didn't have this language. You're basically discriminating against a private sector group or groups in not giving them government funding. It's basically as I see it an issue of discrimination and so -- discrimination in the language, in congressional language. Now, it seems to me that one of the reasons --

MR. ORTIZ: It's basically an issue of political control.

MS. FRANK: Yes, but one of the things --

MR. ORTIZ: Well, that's not really --

MS. FRANK: You could say that such language is discriminating against a group of people most affected --

MR. ORTIZ: Well, it does, but realistically that's not realistic. I mean, it's an issue of control, it's the way that the political structure maintains control over the funding and that's a reality.

MS. FRANK: Do we accept that restriction of language within this room?

MR. ORTIZ: Well, no, but --

MS. FRANK: Is there an acception to that?

MR. ORTIZ: -- but you've got to be able to face that that is part of the overall process.

MS. FRANK: Do you remember what Robert Kennedy said?

DR. WOLFRED: That's right.

MR. ORTIZ: Yes, but that's --

MS. FRANK: I'm saying to you that if you accept someone elses political realities it's not your own.

MR. ORTIZ: I'm not saying that we accept it. I'm saying that it isn't just discrimination, it's essentially political control.

MS. FRANK: It's also discrimination.

DR. WOLFRED: Can't we make a statement in our report saying that we think those restrictions ought to be removed, lifestyle restrictions? Couldn't we do that?

MR. JONES: Those restrictions should not be imposed by the government --

MR. ORTIZ: I think that sort of --

MR. JONES: -- at the hands of the community.

MS. FRANK: Couldn't we work on some language to include in the report?

DR. WOLFRED: We've got to start somewhere.

MS. FRANK: Yeah, I think we've got to start somewhere, folks, I mean, I'm not from North Carolina.

MR. JONES: You know, one of the things we've

got to know is when we want the government to be very specific and when we don't want the government to be very specific, there has clearly been -- I clearly don't want the government in my bedroom, but at other times I at least want them to say something about my bedroom. It gets very confusing.

MR. ORTIZ: At least you have a bedroom.

MS. FRANK: Can we work on some language that this is the sense of this work group that restricts language on the use of funds for information and education is counterproductive?

MR. ORTIZ: I like that word.

MS. AHRENS: If they agree to that I'm going to go somewhere else. It seems to me that it's important that we say something about a broad-based monitoring structure within -- an advisory structure within each of the three levels of government that will include community-based organizations, effect the population to promote and monitor the educational program that is going on in those three levels.

MS. FRANK: Better be careful with that one.

MS. AHRENS: Well, --

MS. FRANK: When you get the sensor -- you know, the reviewer's commission, the sensor's commission I think you have to be very careful. As part of the problem now CDC has that requirement, you have to have a cap of thousands approving --

MS. AHRENS: No.

MR. BULGER: I don't think the word approval has to be in the sentence. I think it's advice, it's consultation, it's just bringing the constituency into the decision making.

MS. AHRENS: How do you insure that what you're doing is relevant? I think it would be quite the opposite.

MS. FRANK: Here's a case where the federal government is really setting community standards for the nation.

DR. ALLEN: No, I don't think so because it's a local group and what flies in one area is not wrong for another.

MS. FRANK: That's my meaning and that's why the federal government shouldn't even have a nation-wide restriction on these funds.

DR. WOLFRED: I think Diane is kind of coming from another direction in getting the community involved. When you're talking about community just say what's working, not working.

MS. AHRENS: Because what I think would happen, at least in some areas, if the federal government continues with their descriptive language and at a local level and says, "We've got to have this kind of information for this population and we can't use federal money because we're not

going to get any so either we devise ways of maybe getting it out of the state or maybe we'll have to go out and raise our own at the local level." And it's easier done and better done if we have a broad-based group that is marching to the same tune and that begins to happen as you sit around a table and you get the right kind of sellers that are involved in the system in your local communities.

MS. FRANK: Okay.

MR. BULGER: Are we back -- are we into planning this again for this level?

MS. AHRENS: Well, we're talking about education and prevention here.

MR. BULGER: But are we talking about planning for education and prevention at the federal level and should the federal government involve local constituents in that planning process before they implement their programs?

MS. AHRENS: I'd think be happy if they talked to each other.

MR. BULGER: But that's sort of like a minimum requirement. I think that they should talk to each other in terms of governmental and interagency support but they should also bring in the outside world into those discussions, if not directly, then indirectly.

MS. FRANK: Folks, we're bumping up against 1:30 and we're loosing our colleagues and before we loose any

more colleagues I want to thank you as a group. We are not finished with our discussion, we have not discussed substance abuse prevention and training. We have done a tremendous lot of hard work and I'm not sure that even much better planning could have taken us much further to any stage in the issues at all.

What I would like to do now because I don't want to work without the group as a whole, I like to work with the group as a whole, is to end the discussion and say thank you very much. I'm amazed at all that we have done. You don't sit down and figure out the federal, state and local roles in a problem that's ten years old like the HIV epidemic in four hours, but we've taken a very good crack at it in a constructive, respectful way and so I would just like to stop and thank you all.

MS. AHRENS: Pat, I think we want to thank you. I didn't know how in the world we would address this and then you came along and you moved us through it and we are very appreciative of what you've done.

MS. FRANK: Thank you very much for asking me to come to work with you.

MS. AHRENS: I think just in fairness to those of you who have been participated so wonderfully in this whole process, the next step is that we will be meeting -- those of us that are left here on the commission and the staff, for several hours this afternoon to sort of work through how we're

going to put this together and it will be drafted, it will be presented to the entire AIDS Commission late January in Los Angeles. I don't know how we can distribute this back to those who have participated but I'm sure they would be interested in seeing the outcome of what our report shows. Then it's really up to the commission to determine whether we've done our job, whether they like it, whether they don't like it, whether we've said too much, whether we've said too little and then it will move on from there. As I understand it, that will be the process and we're just enormously greatful of the time you've spent and your effort and your thoughtful comments of yesterday and certainly of today, and we want to let you know how appreciative we are, and also of what you're doing when you return home and will continue to do.

MS. FRANK: A wonderful group of colleagues. I wish I could take you all home.

MR. BULGER: I would make a very quick suggestion. That being that many, maybe everyone of the issues that we have dealt with today, in reality can't be dealt with in a four-hour period. I mean, we could have spent four hours dealing with whatever and really not done a suitable job and I think the commission when it accepts your report on the twenty-fifth, really over the next year or two needs to refine some of what's been said today, talk to some other people, get some other ideas, and in sort of an incremental approach because

I think everybody has contributed a little bit.

There is so much that really hasn't been dealt with today on these issues relative to federal, state and local funding and responsibilities. I think you'd be doing yourself a disfavor or a disservice to just sort of take the report and submit it to the commission and then present it and then go on to the next topic, whatever that is.

MS. AHRENS: I think that will be a job for the entire commission to examine and I've just a notion --. For instance, we didn't get to substance abuse, and as Larry said so well, this is the growing area. I can't believe the commission isn't going to take that area that we didn't deal with and somehow deal with it. The commission is, I think, an incredibly astute group of people and they're going to see the holes that we have left and I'm sure they're going to move to fill it somehow. Fortunately we have another 16 months of commission time.

MS. FRANK: Mm-hmm, yes.

MS. BYRNES: It's my hope that this will provide a structure for the commission as we looked at all of the issues the commission chooses to look at. When I say "all of" we're hoping to keep it to a limited few and do a great comprehensive job on those, but that in fact it will always raise those questions for the commission at large. As we look at the issues, as we look at the problems, as we look at the

solutions that we'll always be asking ourselves, "What's the federal role here, what's the state role, what's the local role, what's the private sector role," that this working group will give us a structure and a framework to look at all these issues.

And I certainly agree with you, I would certainly expect the commission will continue to look at substance, drug treatment needs, substance use, those kinds of issues, and be able to ask itself, "When we look at what the solutions are, who's responsible." I think we're adjourned.

(WHEREUPON, the proceedings were concluded.)

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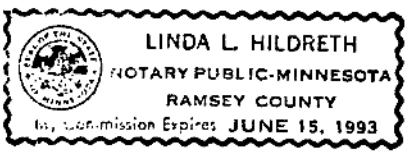
REPORTER'S CERTIFICATE

I, Linda Hildreth, a court reporter, do hereby certify that the foregoing transcript, consisting of pages 1 through 164, is a true and accurate record of the proceedings in the aforementioned matter.



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Dated this 20th day
of January, 1990.