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Oversight Hearing: State Plan For AIDS/HIV Disease

Senate Select Committee on AIDS

OVERSIGHT HEARING:
STATE PLAN FOR AIDS/HIV DISEASE

CALIFORNIA LEGISLATURE
SENATE SELECT COMMITTEE ON AIDS
GARY K. HART, CHAIRMAN

March 31, 1989
The State Building
350 McAllister
San Francisco, California

HEARING

SENATE SELECT COMMITTEE ON AIDS

STATE OF CALIFORNIA

OVERSIGHT HEARING ON THE STATE AIDS PLAN

STATE BUILDING

AUDITORIUM

350 McALLISTER

SAN FRANCISCO, CALIFORNIA

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SENATOR MILTON MARKS

ASSEMBLYMAN JOHN BURTON

ASSEMBLYMAN BILL FILANTE, M.D.

STAFF PRESENT

KATHRYN DUKE, Consultant

DEBRA SMITH, Secretary

ALSO PRESENT

KENNETH KIZER, M.D., M.P.H., Director
California Department of Health Services;
Co-Chair, California AIDS Leadership Committee (CALC)

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San Francisco Department of Public Health;
Member, CALC Executive Committee

PETER CARPENTER, Chairman
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LIFE AIDS Lobby

JOHN BELSKUS, Board Member
Community Health Coalition, San Francisco

HARVEY MAURER, Citizen

I N D E X

I N D E X (Continued)

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I N D E X (Continued)

I N D E X (Continued)

P R O C E E D I N G S

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CHAIRMAN HART: We'll call the hearing to order.

I'm Senator Gary Hart from Santa Barbara. With me is Assemblyman John Burton from here in San Francisco. We are expecting later this morning Senator Milton Marks, also from Francisco, and Assemblyman Bill Filante to be joining us either later this morning or in the afternoon.

The purpose of our hearing today is to understand the progress that's been made on the development of a State plan for battling AIDS and HIV infection. This plan is a result in part of legislative budget language that was adopted last year in the adoption of the State budget. The plan is due to be presented under this legislation by April 1st, that is tomorrow. So, we're here to understand the progress that's been made on this report, understand what the report is saying, and try to get a better understanding of where we are in dealing with this awful disease that has caused us much pain and suffering and death, and how much it also has cost the State of California and local agencies.

We have a number of outstanding witnesses. I want to thank all of them for joining us today.

Assemblyman Burton, would you like to say anything before we get underway?

ASSEMBLYMAN BURTON: No, I'd just like to commend the Chairman for bringing this hearing to San Francisco. I look forward to hearing Dr. Kizer's comments and look forward to trying to get the administration as involved in the problem of

dealing with AIDS, both in research, prevention, care and treatment, as the legislative branch of government is. I look forward to Dr. Kizer's testimony.

CHAIRMAN HART: With that ominous introduction, let me ask Dr. Kizer, our Director of Health, to come forward. He's our first witness, the Co-Chair of the California AIDS Leadership Committee.

Dr. Kizer, thank you very much for joining us this morning.

DR. KIZER: Good morning, Senator, Mr. Burton.

It's a pleasure to be here. I've spoken with your staff. The document that is the subject of discussion today is in an advanced stage of completion, but it's not yet finalized. Comments are still being received by members of the AIDS Leadership Committee. They're being incorporated into the document.

What I thought would be useful to do in the minutes that I have with you this morning is talk a little bit about where we've been; how -- what the process has been in development of this; where that fits in with the overall other efforts that have been undertaken; what you can expect as far as the completion of the document; some of the general concepts that have guided our thinking in development of this document; and then what some of the priority recommendations are that you will see when the document is completed, realizing that the document will contain a long list -- probably a hundred or more -- more specific recommendations. I want to focus on probably a dozen or so primary recommendations.

I think it's perhaps useful to just reiterate a point, and then I don't want to take a lot of time to do this, but much has been done in the State of California, and certainly in cities like San Francisco, to combat the AIDS epidemic in the past several years.

When I joined the Department of Health Services in 1984, the Department had a budget of $500,000 to deal with AIDS, and we did not have a single individual that was specifically devoted to AIDS. Since that time, the budget has grown markedly; the State AIDS budget now exceeds $100 million. We have an Office of AIDS that has about a hundred staff and numerous other people in other parts of the Department that are working on AIDS, either primarily or as a corollary to their other activities within the Department of Health Services.

Much planning has occurred in the State. We've issued numerous documents. These are just some of the things. You've seen many of these we've shared with the Legislature. Many of the planning documents we have developed have been submitted to peer review medical literature. I've enclosed copies of three of these articles in the packets that were prepared for you today. It's not my intent to go back through all that.

The point I would like to leave with you here is that I think the efforts that we are talking about in the document that we have had under development for the past several months builds upon those, and, indeed, in many cases, underscores the value of things we've undertaken, why we need to continue certain things, where we need to refocus or enhance, other things that we have undertaken in the past.

Let me just be a little bit more specific about the process that we have undertaken in the past several months. The Department has utilized a variety of advisory committees to deal with AIDS, beginning in about 1983, prior to my joining the Department. Since then, a number of groups were convened. It was apparent to me last winter, early spring, that we needed a new vehicle, a new advisory group, that combined certain other elements and also was a little broader based. That was the genesis and thinking of the California AIDS Leadership Committee, which is a group of about 35 individuals that covers a wide spectrum of expertise in the State. I think it's representative of the major factions that are involved in combatting the AIDS epidemic. And that was formally -- invitations went out in the spring, and as I recall, our first meeting was in June of 1988.

Since then, we have met on a monthly basis and have produced a number of things. Again, I'm not going to take the time to review all the things that the Committee has done; focusing instead just on the plan document that is the focus of this Committee.

Well, in addition to the Leadership Committee, we also have set up a number of subcommittees that also have broad representation. There are nine subcommittees. In addition, there have been several ad hoc subcommittees set up. Those have memberships ranging from anywhere from 15 to 25, and in some cases a few more than that, individuals.

So, throughout the development process of this comprehensive plan that we've been working on, I think it's fair

to say that at least 250 individuals have been involved in that process -- indeed, many more in one way or another -- so that what we are working on has broad based input. It really has tried to incorporate the views and perspectives, the thinking, and the wisdom of a whole lot of folks who have been involved with this from the beginning.

All of that was pulled together earlier this year. An initial draft document was reviewed by the Executive Committee of the AIDS Leadership Committee, and that produced a first draft document of the overall plan that was reviewed last month for the first time by the overall AIDS Leadership Committee. They had a number of comments and things they wanted -- and I should step back a minute and say that the purpose of that first document was to make sure that all of the important things that had evolved from the subcommittees were indeed incorporated in the first document. I think that's largely the case. Now we're working on some of the editing, tying it all together. Anything that has as much input as that needs to be pulled together to a document that will truly be useable, will be succinct, something that, indeed, Legislators will read as well as everybody else. I don't think it serves any purpose to produce a document like New York City has, two inches thick, that probably no one would read.

But in any case, where we are is that the next iteration of that will be reviewed by the AIDS Leadership Committee on April 12th. Subsequent to that meeting, we will make whatever revisions or fine tuning is necessary based on input at that time. We will then proceed, assuming that the Committee agrees

with this, to disseminating the document more widely, schedule some public hearings on it, and again revise it based on that, and hopefully have the final document to you and to the Governor in about June.

So, that is what I think you can expect as far as a time line.

It's probably worth mentioning a few of the general concepts or some of the thinking that has gone into this.

CHAIRMAN HART: Dr. Kizer, if I could just interrupt on this point about the completion date.

I'm a little concerned. It's sort of a complex process, but part of what we were hoping would come out of this, with this report, would be some assistance to us this year during our legislative deliberations on adoption of the State budget, on hearing bills, and we're right now getting into the heart of that process.

If we do not have a final document before us, say, before the Legislature adjourns in early summer, we're going to lose a substantial opportunity this year to react to the advice that the Committee sets forward.

DR. KIZER: I understand what you're saying, and this is something we've discussed with your staff and with other legislative staff. I do -- I understand that many Legislators are interested in this, have copies already of this, based on calls I've received from the Members.

We expect that with the next iteration that will go out in April that it will be further along, and that the further

process will be more fine tuning it and letting a wider audience see it than has been involved with it to date.

I think that what will be in it, though, will be certainly sufficient to guide and provide directions to the Legislature and the administration on both budget matters as well as legislative matters. Indeed, one of the points or requests that was made at the last meeting was that we go through and specifically look at what things require legislation and make that a little bit more clear, as opposed to things that may be able to be achieved by administrative action or may not even be State government focused at all.

So, your point is well taken, and it's appreciated, and I think that you will have something that can be useful in a time frame that will be needed.

CHAIRMAN HART: All right.

One thing, in looking through the draft, that is appealing to me is the degree of specificity. There are some very specific recommendations.

Sometimes plans are so kind of conceptual that they aren't much help. In this regard, in many respects, this plan is quite specific. That's very helpful to us, I think, in the Legislature.

You mentioned impacting the budget process. One thing in the report that strikes me is how little attention is given to money -- I know that's a difficult issue with the Gann Limit and the Governor's positions -- but how do you see this plan impacting the budgetary process when there is so little

attention, almost no attention, given to what this plan is going to cost? What are our costs going to be a year from now? What do you see our costs being three or five years from now?

DR. KIZER: That is a good point, actually. It saves me from having to initiate that discussion.

That was a conscious decision that was made on the part of the Committee as we went through this process, to not get hung up on -- to not prepare a document that was budget-driven.

In other words, we would prepare a document that we thought charted where we needed to go in dealing with the AIDS epidemic in California, realizing that we will not have funds to do everything that's recommended in the document this year. Certainly in the context of current budget constraints this year, we're not going to be able to do everything that's in there, nor should we necessarily, maybe, expect to.

But having been involved in some of this planning process before, and realizing that when you start with a budget-driven document, you may not be able to lay out quite the vision and the recommendations that you may want to, it was a conscious decision on our part early on in the development of this that we would ignore some of that, realizing that you can't ignore it in the long term, but that we would be able to produce a better document if we laid out where we thought we needed to go, realizing that we would lay out priorities, lay out agendas that, as resources became available, we could then fill in some of those gaps.

If we started with the idea that we had X number of dollars, and that it was going to cost this, then we might not be able to provide the guidance and the agenda that we'd hoped to be able to.

CHAIRMAN HART: Just one other question on that area.

If you've got a whole series of recommendations, are you willing, after you've completed the reports, to prioritize those?

Again, as we're dealing with the budget, we obviously have to make some very difficult choices in terms of priorities. Are you willing to say, "Of our recommendations, these are the ones that we think are most important and the ones that, for whatever dollars are available, are our highest priorities in terms of funding." Is that spoken to in the report?

DR. KIZER: I don't see how we can escape doing that, although I'm not sure that we'll see all of that discussion in the document. Indeed, I think often that's the sort of discussion that occurs at forums such as this as we talk about specific issues, whether they be specific pieces of legislation or specific items in the budget.

So, we would hope that the document that's being prepared lays out a template for where we should go and puts priorities in there, and then as we look at the specific resource questions, that we would use that as guidance to decide where monies and personnel and other things are going to fit in.

CHAIRMAN HART: Mr. Burton.

ASSEMBLYMAN BURTON: Thank you, Mr. Chair.

If we don't have some monies, either allocated or whatever, I mean, this is like a document some college could put out and say this is what the government ought to do if it feels like doing it.

I mean, this thing is an agent of government. It's a result of a law, if you will -- you know, the Legislature and the Governor agreeing -- and to come up with a great plan for which there is no funding, I mean, to me -- and I know the State is broke. I think it's broke; the Governor doesn't -- doesn't make a lot of sense because we'll have a great document that will sit there with all of the great documents that government has created, and there's no follow-through program.

We had a State law -- we have a State law that I think requires counties to come up with a comprehensive plan on AIDS. I put, you know, some money in the budget so that could be implemented. That money goes out.

In a report, we can still say we have a plan that says something should be done, but if there's no gasoline to drive the engine, you know, it's just going to be a great historical document, but we've got to have -- I agree very much with the Chairman -- we've got to have something to bring it into focus in this budget process to see what we can do, given the limited resources that the State has.

I don't know. I mean, I know you don't want to be driven by the budget, but that's what we're driven by; otherwise, we've got a hell of a document, and it's all over and nothing happened.

DR. KIZER: In a way, I think we're all on the same thinking here, but also I think there are -- one of the other conscious decisions and thought processes that we went through early on in conceptualizing how we would develop this -- well, there are two things, I think, that are worth pointing out so that you understand where we're coming from.

One is that this is intended to be a State of California guidance document, not necessarily or solely the State of California government document. There's a lot in here -- recommendations are made that may or may not apply to State government per se. State government may have a role there, may be able to facilitate things, but there's also direction being given to other players in the State of California.

By the same token, one of the concepts or thinking that went into this is that we have to view AIDS within the overall context of public health and the health care system that we have, and the problems that exist there. To perhaps make it a little bit more specific, one of the recommendations that you may or may not have seen has to do with providing grief counseling for individuals who are HIV infected or who have partners who are infected. We support that.

But by the same token, if you can't provide funding for many of the mentally ill people who are roaming the streets of San Francisco and elsewhere, somewhere that balance, or those sorts of considerations are going to have to be made with you all, and, hopefully, in context with the administration, and that we have to look at these things. While that may be very

desirable in the overall State priorities, we may not be able to do that this year, but that'll be a target for next year or the year after, or as resources become available.

So again, your points are well taken. Those are things that were discussed, how we should do this, early on. The overwhelming consensus of the group that has been working on this was that we should lay out a template that would be for the State of California. It would not be budget-driven, realizing that we can't escape those things as we actually implement the different recommendations that are made.

CHAIRMAN HART: There were some other points I think you wanted to make.

DR. KIZER: Well, I think some of them we've kind of touched on already as far as some of the general thinking that has gone into the development of this.

I guess two other points that I would make, and one of them follows on the heels of what I just said about AIDS has occurred in a very -- the epidemic has occurred at a very difficult time in health care overall. There is, indeed, a revolution going on in health care. There are many, many serious problems in the health care system over all, and indeed, AIDS probably couldn't come at a worse time as far as stability in the health care system.

So, one of the other thoughts or general concepts that has guided our thinking on this is that we would like to use AIDS also as a vehicle to perhaps develop some better models of how we provide health care over all. There are other conditions out

there that are analogous to this, and we think that, using AIDS, we can also provide some overall guidance to how the health care system might be changed in the future, as it certainly is changing. We think AIDS can be very useful in that regard.

The other point I would make is that the changing nature of the epidemic, and that information about the epidemic, and the wide array of situations and circumstances that exist in California, require that there be considerable flexibility in the document. And that certain things may be more or less applicable to different parts of this very large and heterogeneous State.

I think with those -- those were some of the general concepts, the five or six of them, that I wanted to lay out for you. It may be worthwhile in going down some of the more specific priority recommendations that will be contained in this, and indeed, I think you may already have gotten a flavor for this by your review of it. And these are not necessarily in a priority order. I'm going to list them.

One, we think that we should implement coordinated State-local HIV disease planning throughout California. We have previously prepared a document that was a State document; it was also one of the articles that you have in your packets in the peer-reviewed medical literature that lays out an agenda or a framework by which the State and local government can join together in a partnership. It is at this time largely a concept which we think needs to be implemented throughout the State. So, that is -- will be one of our priority recommendations.

Building on one of the -- some of the comments already made, both by yourselves as well as me, that we need to develop a comprehensive statewide system of ambulatory, community-based health care for persons with HIV infection, expanding on existing models and programs where needed, and focusing on elevating the role of primary care physicians within managed care delivery systems in particular.

We need to look at the financing of health care for HIV infected persons through a combination of public and private means that distributes the burden of that care equitably among the payers and encourages a cost effective and compassionate delivery of services. We have a number of specific recommendations in there, even with that, some of which are currently undergoing review and further analysis.

We need to continue to emphasize prevention of HIV infection through education, taking particular advantage of the work site. We think there's a -- much that can be done through the work site in HIV prevention and education.

I think we -- in the general rubric of education, some of the specific activities in this regard that we should focus on, including continuing the general public education campaign about HIV disease that we previously embarked upon, we need to look at expanding programs, some current, and both current and projected: high-risk persons, including teenagers, intravenous drug users, closet or fast-lane gays, bisexual men, minorities, homeless youth, high-risk heterosexuals, persons having other sexually transmitted diseases, correctional facility inmates, and public safety and emergency response personnel.

Indeed, you may have read comments that I made previously that we believe every incarcerated person should receive HIV prevention education and have the opportunity to be tested for HIV infection.

A fifth recommendation, we believe that all the schools should have an age-appropriate HIV disease prevention program, beginning no later than the fifth grade. That's not to preclude earlier, but we think that as a minimum, all schools should have that beginning at the fifth grade.

We think we need to --

CHAIRMAN HART: Could I ask on that point.

I've had bills that, as you know, on a couple of occasions have not been as ambitious as that, have suggested seventh grade. That that's when we ought to start, we ought to require it. The Governor has vetoed the legislation.

In that context, when this report is completed, what's going to be the process? Is this hand-delivered by you to the Governor? Is this something that's going to be debated in the cabinet by the Governor? Or, do you sort of deliver it and hold your breath, and see if anyone reacts to it?

Do we have any kind of sense as to what the process will be on some of these recommendations, such as this, that the Governor previously has rejected?

DR. KIZER: Well, again, going back to some of the comments made before, the conscious decision was made that we would provide a document that provided the best advice and thinking of people who have been involved in AIDS and health care in dealing with this epidemic in California.

It is my intent, certainly, to present this to the Governor. He's my boss; he's my primary boss. We will provide it to the Legislature as well. And we -- I will advance it up through the chain, and I expect that there certainly will be discussion and review within the administration. I do not at this time know exactly what course that will take.

But again, the thinking here is that we would provide a document that reflected the best thinking that we can at this time. And it's quite possible that not all the recommendations, or not everything that is in it, will be acted upon immediately, but certainly that would be our hope. These are recommendations that we think need to be taken to combat the epidemic here in California.

CHAIRMAN HART: Would you hope that the Governor would basically accept and endorse the recommendations? Maybe not dotting every "i" and crossing every "t", but like the President's Commission, I think President Bush has basically embraced the recommendations of his Presidential Commission.

Will you be hoping and lobbying for the Governor to endorse these recommendations?

DR. KIZER: Well, I suspect, not dissimilar to anyone that puts a lot of work into something, that they hope that the product will be well received and embraced by those that it's presented to.

ASSEMBLYMAN BURTON: Kind of a nonresponse.

Are you going to go in and, I mean, lobby? Fight for it?

Let's take a simple one. The Senator's bill that is more modest than yours, saying that this education should be started in the seventh grade. It's down on the Governor's desk, you know. Be kind of a piece of cake deal for him to sign it. He's not committing future generations of Californians to impoverishment through taxation; he's probably doing something to provide there will be future generations of Californians.

Are you going to go heavy?

DR. KIZER: Well, Mr. Burton, your --

ASSEMBLYMAN BURTON: You and [U.S. Surgeon General] Everett Koop, you know, could go down in history.

DR. KIZER: We certainly could go down.

(Laughter.)

DR. KIZER: You're very familiar with the process by which bills or positions are recommended on bills, and reviewed, and critiqued. We will be asked for our input on that bill, and obviously we'll be espousing the position of the Department.

I cannot speak for the Governor.

ASSEMBLYMAN BURTON: No, I know that.

But I think the thing is forcefully espouse it. I'm not saying, "Sign the bill or I quit," but --

DR. KIZER: I know what you're saying. All I can do is say that I will advocate to the best of the ability that we can.

CHAIRMAN HART: Let me ask, if I could, another question.

One of the things that strikes me in my limited knowledge of this is, when you deal with a plan, one of the

things in addition to, I think, sort of establishing your priorities, both legislatively and funding-wise, is kind of organizationally.

You've got a lot of different government agencies, both State and local, that are involved in dealing with the AIDS issues. I'm struck by a lack of focus on, like, should there be an overall person, like an "AIDS czar", for example. I'm wondering if that was discussed?

You've got a prison policy. Some of the prison policies seem to be somewhat inconsistent with what's in this report.

You've made reference to mental health, and what's going on in mental health areas.

You've got a lot of different agencies in State government that are grappling with this issue in one sense or another. But is there someone that's overall in charge? Is that the Director of Health, or is it the Office of AIDS, is there really no one in charge in the sense of trying to resolve some of the turf and policy differences that may exist on a variety of AIDS issues?

Were those kind of organizational issues of who's in control, who's in charge, or how will these things be resolved when there are differences among departments? Is there a process through the plan, like an ongoing steering committee that's going to be meeting and that's going to try and resolve these kinds of matters?

DR. KIZER: You raised several points there.

To the last point, yes. One of the recommendations and discussion that has occurred among meetings is that this will be an ongoing process. We will deliver something to you; that is not the end of the story. This will continue to be reviewed, critiqued.

Of the many lessons that have been learned with AIDS, one of the ones that clearly jumps out is how much the situation changes over time. There's been tremendous change. So, we're going to have to continue to look at that, whatever recommendations we make, in the context of changing circumstances with regard to the epidemic, with regard to resources, with regard to everything else here in California. So that will be an ongoing process.

Now, your question, should there be an AIDS czar, or whatever, I personally have mixed feelings and am generally not all that supportive about that, because I think the way that you make things happen in government and within any large organization is that you have to institutionalize them within the organization. You have to make the individuals that are managing little, specific parts of the program part of the overall team. And that is, I'm not convinced, most effectively done certainly with something that touches as broad a cross section as this does, with one individual.

While the Director of the Department of Health Services has been designated as a point person on the epidemic, he certainly does not administer the several other departments that are involved with AIDS. The best way that we can do this in the

long term is to get all those departments involved. At times it may take a little longer, may be a little bit more arduous, a little bit more painful as we argue and debate these things, and not everyone shares the same perspective that either the Director of the Department of Health Services, or the AIDS Leadership Committee, or members of the Department of Health Services might have, but through discussion and working through the process, that's the way that ultimately we will institutionalize the changes that need to be made.

ASSEMBLYMAN BURTON: Two questions.

You mentioned what is really, I guess, the most rapidly growing population right now, in the minority communities. And you talked about targeting some educational things here.

Do you have specific plans in mind, or are they things that are in, like, formulation?

DR. KIZER: Well, if I understand your question correctly, there are some things that we have done, and there are other things that we would like to see done.

One, two years ago we made at that time what was somewhat of an arbitrary decision that we would put 35 percent of all the money, the information-education-prevention monies, into minority communities, minority contractors. Although, at that time you certainly could not justify it based on caseloads that existed at that time, but it was our thinking that, given where we thought things were going, that's where we needed to focus attention. So there has been that policy direction in place. And indeed, our concerns, unfortunately, are being realized.

Likewise, we think that within the local planning processes, that that has to be brought into it. We think local planning and local development is so critical, and while San Francisco has done a very good job there, I'm not sure that they are the norm throughout the State. And in different communities, there are different circumstances with regard to minority communities that have to be addressed. So, we think that that should be and really must be in the future incorporated into the local planning process in addition to overall State guidance, State policy, both as far as where we're going to direct monies as well as other guidance to encourage education.

ASSEMBLYMAN BURTON: Could you comment on the -- I'm trying to phrase it right -- the desirability of the State at least approving a pilot project concerning the San Francisco Health Department's free needle exchange program?

DR. KIZER: Well, you may have read in the Chronicle my comments on that a few weeks ago.

ASSEMBLYMAN BURTON: No, I didn't.

DR. KIZER: Okay. A couple weeks ago I --

ASSEMBLYMAN BURTON: I mean, I didn't happen to see them.

DR. KIZER: One, that is an area that clearly requires statutory change. There is no way, based on my own reading as well as my attorneys' reading, that I or the Health Department could authorize any sort of needle exchange program.

I understand that my counterpart in New York State was able to do that, but the law in California is very strict or very explicit as to what can be done.

Now, I personally would support that within certain parameters. I think that the literature is not altogether clear, so I think there would be several conditions that I would put on them.

First, I think it has to be done as a control demonstration project so that whatever information comes out of it, we have some confidence and reliability that indeed it was done in a way that we knew that the results were meaningful.

Secondly, I think it can only be done, or should only be done, in the context of a campaign that is both anti-AIDS and anti-drugs. We have two epidemics in this State. Clearly, we have the AIDS epidemic, but by the same token, we have a drug epidemic that is starting to create major problems in a number of other areas of health care. So, I think that this could only be done with the context of an anti-AIDS, anti-drug, comprehensive, education program that brought people in to get them off drugs.

Third, I think that it would have to be done within the context of strong local community support. It's something that the community would have to accept and want and implement it.

And lastly, it by no means could be a substitute for drug treatment. As I said before, it has to be way of getting people off drugs, bring them into the system of care, and could not be viewed as a substitute for getting them off drugs.

ASSEMBLYMAN BURTON: What I'm hearing is that it's not a program that is without merit as a prevention.

DR. KIZER: Well --

ASSEMBLYMAN BURTON: And I understand your conditions and your concerns.

Unfortunately, I think the growth of the drug epidemic is not with needles but with pipes, with free base, or crack cocaine.

But the thought, the free needle program, the free needle exchange program is not a program without merit as far as prevention, and I'm not trying to put words in your mouth.

DR. KIZER: No, I know what you're talking about. Let me just expand on that a little bit.

The AIDS epidemic, and I think in many ways the drug epidemic, both are making us rethink what may have been conventional wisdom. It has been conventional wisdom, at least among many folks, for a long time that providing free needles would encourage or somehow put the stamp of approval on drug abuse. That -- I can understand why people would come to that conclusion; however, I'm unaware of any evidentiary base that actually supports that.

So, what it is, it is a view that has been long held by a lot of folks, and now we're put in a context of saying, well, is that really true? Let's find out.

That's where I think that it has merit as a demonstration project to answer the question of whether it really does have a role, or whether the preconceived notion may be actually true. That's why I think it has to be done in a controlled way so that we get reliable information that we can then generalize and make sound public policy on.

ASSEMBLYMAN BURTON: I don't -- I mean, I wouldn't know that I would think the needle would be the easiest part of, you know, the fix to get. In other words, I don't -- I would think it's tougher to go out and buy the drug than it is to figure out a way to scam a needle. Just personal comments.

Thank you, Mr. Chairman.

CHAIRMAN HART: Dr. Kizer, if I could, I wanted to ask a couple other questions.

I also wanted to welcome Senator Marks, who represents this area, as well. He's also a Member of the Select Committee on AIDS. Welcome.

Two other questions that I wanted to ask, things that I don't believe are in the report that I wanted to just get your reaction to.

I was reading the President's Commission's report, and one of the recommendations made in the Executive Summary of that report, one of the major recommendations, was to focus on the shortage of nurses, and particularly in areas where there is a high AIDS incidence. The report recommended scholarship programs, sort of an active recruitment and subsidy program for nurses.

Was that issue looked at by your Committee, and are there any recommendations that you have as it relates to either financial or other enticements to get people to become nurses and serve in areas?

The implication being that in the future, with increasing cases, and nurses providing the brunt of the health care in a sense, we're going to have a special need in this area.

DR. KIZER: Yes, it has been looked at. It was discussed at considerable length at the last meeting of the Committee.

And I would agree with you that one of our priority recommendations -- and it would appear, based on time, that I probably won't get through the list of things that I was going to -- but one of the recommendations is that we have to ensure that the resources are here to deal with AIDS, and resources includes health care personnel, which includes nurses, but it also includes physicians and a wide array of other folks. And we do have -- although some of these are things that came out of our last meeting, we will be making some specific recommendations on areas that will deal with this, having to do with programs to reduce the needle sticks.

Let me just step back a minute. The nursing shortage here, and again, what I said at the outset, we have to view this in the context of what's happening in the overall health care system, and there is a nursing shortage overall, and AIDS just adds another dimension or another complication to that. So, when we look at dealing with nurses and AIDS, we have to look at how that fits in overall in increasing the supply of nurses, or at least returning nurses to the bedside as opposed to, maybe, something else that they've chosen to do because of work circumstances, family concerns, or other things.

So, we have to look in that context, but there are some very specific concerns that health care workers have in dealing with AIDS patients. And I think there are some things we'll be

recommending there as far as programs to reduce needle sticks, testing of persons who may have been exposed to contaminated needles or other body fluids, post exposure programs for health care workers that may have been injured, as far as getting them on AZT, or whatever else may be appropriate based on current thinking at the time.

We think that this may be an area where legislation is required in having to do with workmen's compensation benefits for health care workers, and they'll ask for the confidentiality of those injured health care workers to be maintained.

There are some other things, and I don't have those all laid out for you, but your basic question is yes, we've looked at it. Yes, there will be recommendations dealing with it, and it's quite likely that some of those may require legislative remedy.

CHAIRMAN HART: Maybe one last thing I'd like to ask, and maybe it would be a way of beginning to sum up. You've been involved in dealing with this AIDS epidemic now for a number of years. This planning process that you've gone through in the last six months or nine months period, it's not like we're starting from scratch.

I'd be interested to know, as a result of this process that you and your Committee members have gone through, is there anything that really particularly strikes you as an important finding or recommendation, perhaps, that's different from what your assessment and your recommendations were, say, two or three years ago?

You mentioned earlier that the disease is changing rapidly, and with that our assessment and recommendations change. Is there one thing or two things that particularly strike you as important that we need to acknowledge at this point in time as opposed to two or three years ago in our understanding and battle against the disease?

DR. KIZER: Well, I think the concerns or many of the things that we've been talking about recommending for some time are still there. We're also in the position of seeing some of what we were talking about and being concerned about two or three years ago coming true.

Probably the most difficult area has to do with AIDS and IV drugs. And I have been saying for quite some time, looking at some materials that were written a couple of years ago, making this forecast, I think it's becoming very clear that the long-term course of the AIDS epidemic in California depends on what we do with IV drug use. We have historically not had the impact that New York City, Newark, other East Coast cities have had in that regard. Clearly, our numbers are changing.

We feared this and had made some comments about it quite some time ago, and then have continued to. I think that that's probably also the most difficult area to deal with since so much is related to crack and cocaine use. There is no methadone equivalent for cocaine. The ability to deal with cocaine use is, I think, more difficult than with opiate abuse.

But clearly, in our view, in the long-term, it's what we can do where it will substantially influence the long-term course of AIDS in California.

ASSEMBLYMAN BURTON: Do you find -- in other words, I don't think one does crack IV; do they? Have they been doing it IV instead of smoking it?

DR. KIZER: Yes.

ASSEMBLYMAN BURTON: IV cocaine, but I mean free basing would be smoking it.

DR. KIZER: Free basing is smoking it, yes.

ASSEMBLYMAN BURTON: And crack is base; right?

DR. KIZER: That's correct, but the issue --

ASSEMBLYMAN BURTON: Let me get the question.

Do you see, in other words, that if somebody's, let's say, free basing, using the crack, smoking it, that then, you know, I mean, I happen to know, unfortunately, that it alters everything they do, but then that gets them into at-risk sexual behavior?

DR. KIZER: That's correct. There is the disinhibiting effect. There's also the effect that -- well, to give you a specific case, not AIDS, but in the last five years, congenital syphilis has increased 460 percent in California from 1984-1988. The primary reason for that is the young girls' prostitution, who are selling themselves for crack.

So, certainly, insofar as this encourages prostitution, it encourages unsafe sex behavior, it's encouraging the spread of the disease.

But the other thing we're seeing, as I started to say, when we were on the East Coast last December or thereabouts, on the day prior to our meeting in New York City, I visited some of

the drug treatment programs over in Newark. And one of the concerns that they had at that time, and since we've had some of the same concerns here in California, that even people who were undergoing methadone treatment are [sero-]converting -- becoming HIV seropositive -- because they're in the methadone treatment, but they're going out and shooting up with cocaine.

So, the issue is just not a simple or straightforward one to deal with, but it is one that has tremendous importance as far as the long-term course of this epidemic.

CHAIRMAN HART: Any other concluding comments that you'd like to make, Dr. Kizer?

DR. KIZER: Well, there's a probably a number of things, but I think that in fairness to the other people who have come here to make some comments, let me sit down.

There are a number of other priority recommendations that are likely to be touched on during the course of the day, and I'll be around for some further time this morning as well.

CHAIRMAN HART: Well, we thank you very much for your testimony and your work on this particular Committee report.

I'd just like to again emphasize the importance of the Committee concluding its work. We have the draft document, and we'll work with that, but the extent to which this can be finalized in a timely fashion is going to allow us to make, I think, better use of the document and have its impact be more influential this year.

I also want to encourage you, as we have before, to the extent to which you can be an all-forceful advocate with the

other key individuals in the administration and, obviously, the Governor, we desperately need that leadership.

DR. KIZER: Thank you, sir.

CHAIRMAN HART: Thank you.

Our next person to testify is Dr. David Werdegar, who's also a member of the Executive Committee of the California AIDS Leadership Committee, and he's the Director of the San Francisco Department of Public Health.

DR. WERDEGAR: Senator Hart, Senator Marks, Assemblyman Burton, thank you very much for holding these important hearings. Ms. Duke, thank you for your help in preparing for this hearing.

I would like to congratulate the Co-Chairs, Dr. Kizer and Professor Conant, for the effort that has led to the three-year AIDS plan for the State of California. I think it will be of great value to the State.

I share your view, Senator Hart, that it has to be a document that's available to the public, to health professionals, but most certainly available to government, to the Legislature, and I hope it will be a guide both to policy issues and funding issues. A lot of my interest in the project was that it would have that particular value.

I was asked to comment on two items or two broad areas. One was the San Francisco experience, and community response in San Francisco to AIDS, which I will do quite briefly, tying it into the three-year plan. And then, most importantly, talk about drug abuse and AIDS, and that's where the full force of my comments will be.

First about the San Francisco experience. It's been well described. Let me say it's guided by a five-year -- a detailed five-year AIDS plan with careful financial projections, policy statements. It's updated annually. It's approved by the Health Commission. It's delivered to the Mayor and to the Board of Supervisors, who review it and accept it. And it serves as a document for the public and for health professionals.

Our plan is of no value, however, if it is not coordinated with State plans and federal plans. We can't do it by ourselves. So that in the attack on AIDS, we need coordinated, synchronized local, State and federal plans, and ones that mutually reinforce one another and are consistent with one another.

I think the three-year HIV plan that has been presented in draft form is a great step in that direction for the State.

In the San Francisco experience, some of the salient features are that we have the Public Health Department serving as a coordinating vehicle.

You had raised in a question, Senator Hart, where is the focal point or center of gravity? Should there be a czar? How do you deal with the multiple agencies?

By common consent here in California -- here in San Francisco, the Health Department has served as the focal point. You need a point of coordination. So, there are many agencies, many health professionals, volunteer organizations, but the focal point for coordinating it rests with the Health Department.

We have always used education as the cornerstone of our prevention program. We have tried to give care as much as possible out of the hospital and in the community. Those, I would say, are strong planks of the local program.

And furthermore, we have always encouraged research at all levels, not just basic research and clinical research with new drugs, but research on how more effectively to reach into the community educationally, how to improve prevention programs.

Our Mayor has provided leadership in the City, as he had when he was in the State Legislature, where he sought a coordinated State plan to battle the epidemic.

Now let me comment about -- good morning, Dr. Filante -- let me comment about the next three years of the epidemic in California, which I regard as posing great difficulty and great danger. And I say this even though there are some points of optimism. Drug treatment is improving. We have found that education can, indeed, prevent new HIV infection, and in our community has reduced new HIV infection to very low levels.

But I see the great danger to California because of rising numbers of cases. There will be a major burden of care reflecting infections that were acquired years ago and are now becoming clinically symptomatic, people developing illness and AIDS and needing care.

And the next one, which is the main point of my presentation, is that the epidemic is changing. Substance abuse in all forms, IV substance abuse, but substance abuse in all forms is becoming intertwined with the AIDS epidemic, and it

poses a very great danger. In Northeastern States -- New York, New Jersey -- it has led to health and social devastation of very significant proportions.

We have an opportunity still to check it in California, but the window of opportunity, I would say, is fairly narrow. And we really have to pursue our attack on substance abuse/AIDS, the double-headed monster, in a very vigorous way and without any delaying measures.

The drug addiction-related AIDS -- incidentally, I regard drug addiction of itself as the number one public health problem in the State, probably in the nation. And substance abuse has as a corollary: it causes illness and social devastation in many ways, and one of the ways in which substance abuse causes illness, death, and social devastation is through HIV infection.

The drug addiction epidemic has fallen most heavily on the minority communities, and in the minority communities, most heavily on the Black community. It affects men, women, newborn children. We are quite fearful that it could very easily involve large numbers of teenagers, and teenagers who use drugs orally, taking them orally, smoking as well as intravenously. We're concerned here in the city right now about a crack cocaine epidemic that has teenagers in the Black community with very high rates of other sexually transmitted diseases, notably gonorrhea, and in the setting of other sexually transmitted diseases, it is quite conceivable -- in fact, there's a body of evidence that says it's much easier for AIDS transmission to occur.

So, between drugs, other sexually transmitted diseases, and AIDS, you really have a three-headed monster.

Now, a State plan for preventing HIV infection from drug abuse has to be vigorous, has to be underway yesterday, has to be well-funded, and it will have to have imaginative approaches. We don't know fully how to prevent addiction. And we don't know how to fully prevent HIV infection in the setting of drug addiction. I can certainly name some of the elements that will be required.

We need greatly expanded capacity for drug addiction treatment. At the same time that you're educating individuals about the dangers of substance abuse, the dangers that they expose themselves to with regard to AIDS, you have to have the door open and immediately available for drug abuse treatment.

We have used an outreach program to teach hard-core drug addicts --

CHAIRMAN HART: Dr. Filante has a question.

ASSEMBLYMAN FILANTE: Doctor, can I interrupt you for just a moment.

DR. WERDEGAR: Please.

ASSEMBLYMAN FILANTE: While you're talking about drug treatment, and drug abuse, and AIDS, the President's Commission came up with some numbers that I thought were, although general, were very striking in terms of what we need to do for treating drug abuse. And the percentage that was of what we're going to have to do for AIDS treatment if we don't.

Do you have those numbers, or do you have an update on that? I think that's crucial.

DR. WERDEGAR: Dr. Filante, in California, perhaps these numbers will be pertinent.

In California, it is estimated that there are close to half a million IV drug users. That's one in 50 people, or thereabouts. Then you add to it those that are using crack cocaine or using drugs, not intravenously, and using alcohol.

I think we've had to recognize that the drug abuse problem is a polydrug abuse problem, and that while intravenous drug abuse has caught our attention because through the contaminated needles, the AIDS epidemic has certainly spread, other drug addiction leads to sexually transmitted diseases and sets the stage as well for AIDS transmission.

I would say that half a million in California of IV drug users is a highly pertinent number, and it is included in the three-year AIDS report. It also says that of that close to half a million there, perhaps 200,000 that have been long-term, chronic IV drug users. And of that population, perhaps only 10-15 percent are in treatment at any given time.

So, it's quite obvious that it's a big problem with a lot of work to do.

ASSEMBLYMAN FILANTE: Specifically, though, and I hate to beat this, but it was so striking to me, they were talking about -- and this is one of the members of the Commission -- talking about maybe the need to spend $5 billion to treat or try to do away with the drugs -- now, I know it's all poly abuse, but still it's a drug abuse problem -- as opposed to 15 billion or more. And when you're dealing with big numbers like that, I

think they need to be either refined or repeated, or what have you, because, like you say, it's a desperate situation and that small window of opportunity in a short budget time.

The question is, do you spend a dollar now or $10 later?

DR. WERDEGAR: Well, I know you and I share some similar views on this, Dr. Filante. The dollars spent now, even in a tough budget year, because they step in early and they are preventive, obviously, save many, many more dollars some years later.

This is just one of those kinds of budget expenditures where the Governor, the Legislature, the body politic has to grit its teeth and do it, quite frankly.

I'll depart from my testimony in this regard and just say, because I am a health director with a lot of --

CHAIRMAN HART: Doctor, Senator Marks had a question.

SENATOR MARKS: I'm a San Franciscan. I'm very pleased with what you're doing.

I'm also very concerned with the problems affecting our budget, our San Francisco budget.

Is your program in any way being hampered by the effect on the budget?

DR. WERDEGAR: Surely is. Let me tell you, I'm greatly worried. That was the vein of conversation I was just going to open, and it departs slightly from the discussion of AIDS and HIV.

As Director of a health department in a city that has a big public hospital, the San Francisco General Hospital, which is

still the main resource for AIDS care, and has community clinics, and has mental health clinics in the community, we are greatly concerned about what's happening at this juncture up in the State in terms of all health care programs; principally, the medically indigent adult programs, which is one of the main sources of support and revenue for our Health Department program.

If we were to lose the medically indigent adult support -- and the Governor's budget, as you know, the proposed budget has eliminated it and partially substituted the tobacco tax -- we would not be able to fund health services in San Francisco adequately. And unless we are providing overall health services adequately, there's no way we can take care of the particular problems of substance abuse and AIDS. It has to be part an overall system of health care.

So, we're greatly concerned.

SENATOR MARKS: Has your budget, the budget of your Department, been cut by the Mayor?

DR. WERDEGAR: The budget of our Department at the moment, because it's a fluid situation that will depend on the Legislature, has in it some assumptions that MIA funding, and perhaps even some additional money through the tobacco tax, [Proposition] 99, will come through.

If the MIA funding isn't there, we will -- there is not andy way that we can --

SENATOR MARKS: Some of us feel that the use of the money from the tobacco tax is not proper.

DR. WERDEGAR: For supplementing health care to the underinsured?

SENATOR MARKS: It's thought some of the money that's being taken out of the tobacco tax, we feel, at least some of us feel, is not appropriately being done.

DR. WERDEGAR: Well, our sense, just looking at it from a local Health Director's point of view -- and I'm speaking for myself in this -- is that I read the ballot measure and spoke for it, as did all others, as supplementing existing funding for health services, and not substituting for.

SENATOR MARKS: That's why some of us are not very happy with the proposal.

DR. WERDEGAR: Thank you, Senator Marks.

I know there are other speakers, so let me just say a few more words about IV drug abuse and the AIDS epidemic.

This is the most serious turn of the epidemic. I mentioned how much devastation it has caused in Eastern States, Northeastern States.

We have a chance still in California if we get busy. The programs will have to be quite imaginative.

Three years ago, we started a program which at that time was highly controversial. Dr. Harvey Feldman gets credit for introducing the idea: teaching drug users how to sterilize their needles and syringes with bleach. That was something we could do immediately; it was legal. It was done as part of the educational effort, combined with AIDS education as we did it.

And it has helped us, we think, hold down the rate of increase of HIV infection in IV drug users in this community. And the model has been copied throughout California, in fact, throughout the world, these bleach reaching out programs where, if you don't want the sterilization of the needles with bleach to be a substitute for overall health care and --

SENATOR MARKS: Have you taken a position regarding the issuance of new needles?

DR. WERDEGAR: I've given my own personal view. This subject has been reviewed by the members of the HIV Task Force. My position, I think, is consistent with theirs, and the entire matter is going to come before hearings and seek approval of the Health Commission in San Francisco.

Basically it's this -- I would say it's quite consistent with what Dr. Kizer described. I think needle exchange should be provided as a demonstration project. There is at least enough evidence from different cities that needles exchange -- and the emphasis, I might say, is not so much on the needle as on the educational process that occurs with the needle exchange -- may be very, very helpful in holding down HIV transmission amongst drug users. It should be a demonstration program.

It obviously needs community support. It will only work if it's part of a more comprehensive program with access to general health care and substance abuse treatment for those requiring it, AIDS testing, and counseling, and so on.

But I support the concept and am hopeful, in fact, that it will receive, after proper testimony and review, Health Commission support here in San Francisco.

And we then will need some support from Sacramento, because the laws governing needles and syringes are State law.

We believe we can apply for a permit to the Department -- to the Pharmacy Board, but even there it's not clear if that will suffice, or whether clarifying legislation might be needed for demonstration programs.

But again, given the danger, given the suggestive evidence that it can be helpful, given the narrow window of opportunity that we have, the need to really apply any and all possibly helpful approaches, I myself would strongly urge it.

CHAIRMAN HART: Doctor, could I ask on that point, the focus has been on needle exchange and getting a change in State law for a demonstration project.

But it seems to me as if, from what little I know of this, the cleansing of the needle, bleach kits, that's something that currently is allowed under State law. It's something that has been used here in San Francisco, and I presume pretty effectively.

Shouldn't we be focusing, perhaps, more of our attention on cleaning the needles rather than exchanging the needles?

Exchanging the needles, from a politician's standpoint, is a little more complicated and controversial than something that's already in place.

I guess my question is, is this bleach program that you have here, is that being replicated throughout the State? Are other communities doing that? Is there a down side to really focusing our efforts on cleaning the needles rather than to exchanging needles?

DR. WERDEGAR: The program has been widely replicated throughout the State. We have evidence that it is at least partially effective, and many drug users are cleaning needles and syringes, if they have needles and syringes, with the bleach. It's combined with education, and education about condom use, and how AIDS is transmitted sexually as well.

But I don't think it's the complete answer, and we see that in still rising numbers of HIV infected. And I would view the needle exchange as a complementary -- as a program that adds to what's done through the bleach program.

I know it's difficult politically, and I know it's controversial. But if one views the needle exchange, really, as an opportunity to bring somebody drug-addicted into the health care system, if it's done under Health Department auspices, if it's done legally as a demonstration program and evaluated, I think for the political representatives it becomes more acceptable. It becomes then a symbol of a way of bringing a person in to the health care system, rather than as some way of condoning drug use.

And the symbol of the needle, which has been in the past a symbol of drug use, the needle exchange, I would say, could become truly a symbol of a way of bringing the addict into the health care system, where eventually the individual may seek drug treatment. The individual certainly could get general health care, and if continuing the drug habit, could do so not only with safety to himself or herself, but preventing infection of a sexual partner, and prevention of the birth of newborn children with AIDS.

I think the risks are so awesome that I'm hoping there will be the political courage to support the demonstration program. And it should be understood by all that it would be done to see how much it works, and if it really works, and I think scientists in the community can apply themselves to proper evaluation.

ASSEMBLYMAN FILANTE: On the subject of the tremendous risk and cost in newborns, let me just ask you one more, because this is as necessary for Legislators as it is for doctors.

You're talking about the window of opportunity, and comparison with the Northeastern part of the country, where there are some staggering statistics for the incidence of HIV in newborns, especially in some of the hospitals.

DR. WERDEGAR: Yes.

ASSEMBLYMAN FILANTE: What is the incidence here today? What is it there? And what are the prospects with or without whatever education prevention we can do? Do you have those numbers, Doctor?

DR. WERDEGAR: I don't have them all in front of me. In fact, I think within the next couple of months, Dr. Kizer's office will report on -- you know, they studied all newborns, did blood tests on all newborns throughout the State, and those figures are not yet available. They'll be available statewide and then by areas.

In parts of New York City, there's some staggering numbers where one in every 50 children born is AIDS positive. And of those, perhaps some 50 percent eventually do go on to reach clinical AIDS.

ASSEMBLYMAN FILANTE: That's the horrible number. That, as I recall, was the low number. There were some hospitals that exceeded 2 percent incidence; maybe as high as 5 or 10 percent in some samplings of kids who were going to be AIDS patients and probably die, representing, you know, just a part of that community.

I think that's what we have to look forward to if we don't stop it now, as you described it, with the window of opportunity.

DR. WERDEGAR: I appreciate the question, Dr. Filante, because in looking for ways of explaining to political representatives -- you're a physician and understand it -- but political representatives generally, if they can see that this program is a way of preventing children from being born with AIDS, and is a way of bringing addicts into health care, I think they would be more comfortable in championing the demonstration programs.

CHAIRMAN HART: I should mention that Dr. Grossman is also associated with this Committee and Chairman of San Francisco General Hospital Department of Pediatrics, is also going to be speaking this afternoon. I think he'll probably amplify.

I just might mention, I heard the Attorney General, John Van de Kamp, testify at a budget subcommittee hearing a couple of days ago, and his testimony to our subcommittee was -- and I hesitate a little bit because I can't remember the specifics well enough, but it was a shocking statistic. He said one-quarter of the babies born in Oakland today are born, I believe, with either

a heroin or a cocaine addiction; 25 percent in one of our leading cities of children are being born at that rate with this kind of addiction.

Staff just indicated to me that at the UC Davis Medical Center in Sacramento, they are doing screening of all infants that are born, and that 25 percent of the infants born in Sacramento are, through urine testing, determined to have some kind of a substance abuse in their system.

So, this is not something that is no longer just Newark or New York City. We're seeing it now.

DR. WERDEGAR: It's quite true.

Dr. Grossman is the Dean of Pediatrics in our city, really. At the San Francisco General Hospital, those numbers are similar. Somewhere around 25 or 30 percent of all children born at that hospital are born of mothers who are addicted, themselves have some degree of addiction, acquired in utero. Not only IV drug abuse, of course, but now it's crack cocaine and other forms.

It's why I really regard the substance abuse problem per se as the number one public health problem of the nation.

A final word. I've said most of the things I wanted to say about drug abuse, but back to what you said earlier about general funding of health care.

If we're to help our communities, and help our city as a whole, the Health Department needs the necessary funding. We can't be taking care of those who are uninsured and underinsured just with regard to their substance abuse or potential for AIDS.

There is prenatal care, childhood nutrition, there's general health care. You have to provide general services to the community, otherwise you won't be able to do these more specialized forms of care.

And unless we get the base funding to enable us to do that, then to talk about special funding programs for initiatives in these areas almost becomes pointless.

In any event, thank you very much for this opportunity.

CHAIRMAN HART: Thank you very much, Doctor, for some excellent testimony. We appreciate it greatly.

Our stenographer needs a five-minute break, and perhaps the rest of us do as well.

(Thereupon a brief recess was taken.)

CHAIRMAN HART: We want to reconvene. We're running a little bit late, as normally happens at these hearings.

We have two other witnesses that we want to hear before breaking for lunch. Our next witness is Mr. Peter Carpenter, who's a member of the Executive Committee that did the work on this report, and he's Chairman of the Strategic Planning Committee with the ALZA Corporation.

MR. CARPENTER: Thank you, Senator, and thank you and the staff for allowing me to testify before you this morning.

Let me first introduce myself. I am, unlike my predecessors, I am in the private sector: a philosopher, businessman, concerned citizen. I was formerly the Executive Director of the Stanford University Medical Center, and prior to that was in the federal Office of Management and Budget and served as the Deputy Director of the federal Price Commission.

I also spent two years as Chairman of the American Foundation for AIDS Research, in addition to my service on the Leadership Committee here in California.

Fortunately, I am an officer of a publicly-held corporation which is more than supportive of my efforts in this area, for which I'm deeply appreciative.

However, I'm here today to speak primarily for myself, which in many respects is liberating because I'm not constrained by other individuals in who I report to or who, of necessity, might constrain my views.

What I'd like to do this morning is to give you a broad philosophical view of the epidemic from the standpoint of someone who's watched it closely over the years; to try to give you some facts regarding the magnitude of the epidemic, an issue about which I think there's great lack of knowledge in the public in general; to speak to the financial implications of the epidemic. What's it going to cost Californians this year, next year, the year after? Talk about some of the issues that we see in the workplace, and then perhaps make some recommendations, if I may be so bold.

The first point, a philosophical view of the epidemic. This is truly a crisis. The AIDS epidemic in California is, in my opinion, equivalent to having an 8.5 earthquake. The only difference is, it's taking place much more slowly, and as a consequence, I think the public's reaction to it, and certainly the reaction of the leadership of this State, has in fact been, perhaps, very, very slow in coming, and is still, in my opinion, inappropriate.

How we deal with this epidemic is the true test of our humanity, our wisdom, and our compassion as a society. It is a reminder to us that science and medicine are not all-powerful.

Had this disease occurred 30 years ago, it would have been even more devastating because our ability to understand it would have been dramatically limited in comparison to what it is today. But even our understanding of this disease has not given us very effective tools in stopping it.

The good news is that it's not transmitted by casual contact. The bad news is that it is transmitted by sex and by IV drug abuse, two habits which we know are very difficult to change.

The long incubation period means that we are looking -- we are trying to fight a fire by looking at where the fire was six or seven years ago. We can't see the fire as it truly exists today. And the absence of good epidemiological data with respect to the incidence of and the prevalence of this infection in our society is a crucial problem for all policy makers.

It's important that we be aware of the HIV epidemic, and here, the people gathered in this room, we're preaching to the converted. It's even more important that we do something about it.

We begin with a health care system which is under great strain, and which is already failing to meet the needs of many non-HIV patients, and with governments at all levels which perceive themselves as being out of money.

Now, let's look at some of the facts. And I apologize to you, because many of the things that I would like to be able to tell you, literally we don't know.

There are about 9,000 patients who will be alive with CDC-defined AIDS at the end of 1989 in California. We predict about 12,000 in 1990, and about 15,000 in 1991.

How many are there with mildly symptomatic disease? Having talked to a number of experts, looked at lots of different data, I would estimate for each AIDS patient, there would be at least 5 patients who are mildly symptomatic.

How many will be HIV positive and asymptomatic? Here again, my estimate is based on the consensus of discussion with experts. For each AIDS patient, there will be 10 individuals who are HIV positive but asymptomatic.

What does this add up to? That says by the end of this year in 1989, there will be 144,000 people in the State of California in one of those three categories; 200,000 by 1990; and 240,000 by 1991.

CHAIRMAN HART: Mr. Carpenter, just on that point.

Somehow I had in my head that there were 250,000 to 300,000 people, the projections were, that are HIV infected in California as of today.

As I understood you, I thought you were saying it was about half that number.

MR. CARPENTER: Well, given my assumptions, which are for every -- see, the thing that we do know with a relatively high degree of accuracy is how many CDC-defined AIDS patients

there are. Beyond that, there have literally been no studies that have been done on the population at large that can tell us how many patients -- how many people have this infection. And we've all seen the figures at the national level of a million and a million-and-a-half, and then those were estimates that were made a few years ago and for which we still don't have good scientific data.

The CDC has yet to do a totally random sample of the U.S. population. And as a consequence, we don't have, as policy makers and as concerned citizens, the information that we need.

I was about to go on to say that some of the people with whom I've consulted feel that the ratios which I've used are in fact conservative, and that for each AIDS patient, we're more likely to have 7 mildly symptomatic patients, and 15 who are HIV positive and asymptomatic. That would say that by the end of this year, we would have approximately 200,000 patients in California; 275,000 in 1990; and about 345,000 in 1991.

Now, these numbers have lots of limitations with them. My gut feeling is, as your question suggests, that even these figures may well be on the low side, because I think they're looking at -- again, my analogy of looking at the fire, where it was seven years ago, and trying to tell where the fire is today -- an awful lot of what we know today is based on infections that took place seven, eight years ago.

As we see it here today, lots of different things are happening which bear very little relationship to that. You've talked with your previous speakers about infants being born with

a very high incidence of HIV infection. We know that the rate of sexually transmitted diseases in this State continues to rise. And there's every good reason to believe that that's a very good marker for what's going to happen with HIV infection.

So, this is very much the tip of the iceberg. I think these figures are going to continue to rise. I think the figures that I've given you are conservative, even perhaps the higher ones that I've given you.

As we look into the future, I'm very pessimistic as to where we're going to end up.

Moving from what I think is happening, and I think you've heard this from some of the previous speakers, it clearly began in the gay population, moved very quickly on the East Coast and a little more slowly on the West Coast to the IV drug population. The next big group that's going to be hit hard by this is minority teenagers. And right behind the minority teenagers, in my opinion, it will move into the White teenage population. And at the same time, it's going to be moving sideways from each one of these groups into partners and babies.

And so, we are seeing an epidemic which, in my opinion, is exploding. We're looking at the results of what happened seven or eight years ago. We have gotten a little bit blase about it, because we've heard so much about it, and yet it hasn't visibly exploded it yet. But I think the data that each of you were speaking about indicates that that explosion is, in fact, taking place. Perhaps we simply aren't looking at it as carefully as we should.

ASSEMBLYMAN FILANTE: Mr. Chairman, if I may.

When you talk about the spread, as we're seeing already, from the IV community into the people of color, minorities, the teenagers, is that separate from the drug abuse?

MR. CARPENTER: No, I think --

ASSEMBLYMAN FILANTE: As I understand it, it's just a part of that.

MR. CARPENTER: I think what we're seeing primarily in the teenaged community is, we have three factors which make that community an ideal place for this disease to move rapidly.

First, there is sufficient drug abuse to provide a vector into the population.

Second, it is a sexually active group of individuals.

And third, as we all were when we were that age, they're convinced they're invulnerable.

And these three things come together to create an incredible basically petri dish, if you will, for this disease.

ASSEMBLYMAN FILANTE: The reason I asked the question is, to me it's logical, as you've made these different characteristics, it started with the drug abuse.

But I have problems thinking about it in the future because I'm thinking about some of the studies the federal government has done in the Armed Forces in terms of inductees, and these are not, for the most part, homosexuals vis-a-vis the gay community. These are heterosexuals and young people. And the incidence in these people, although it's low as the national population, is still rising today. And I'm not looking at the future; this is the past.

MR. CARPENTER: Yes, I agree entirely.

ASSEMBLYMAN FILANTE: So, I wonder how you look upon this as something that's going to happen. Or, do you mean it's happening, but it's going to explode?

MR. CARPENTER: I think it's happened, and it will continue to happen if we don't yet really fully appreciate the magnitude of this problem.

The preliminary data from the CDC survey of 20 colleges indicates that 1 out of every 300 students is HIV positive. Now again, that's not a random sampling, so you can't generalize that that's the population as a whole. They predictably used students who were presenting to infirmaries for other reasons, so there's still some bias.

There's a bias in the other direction of the data that you suggested. Clearly, the inductees are a self-selecting population. One would expect that the incidence amongst that population, given the concern that the military is known to have about both homosexual behavior and drug abuse, that that population would be biased on the down side. And yet, those figures are still frightening when you begin to extrapolate them into the country at large.

I would stress, however, so that my remarks not be misunderstood, that this is not a disease of groups. This is a disease of behavior. It happens to be behavior which has been in groups which I've just described.

From a medical standpoint, the question is not whether a particular behavior is right or wrong, but what are its consequences both for the individual and for society?

What are the implications of this for California in financial terms? Again, there's very little data. It's also important to point out that we cannot project simply from the very limited data that we have available, much of which is drawn from the experience here in the City of San Francisco.

San Francisco, in my opinion, is a truly unique city. The sociology, the demography, and the level of volunteerism in this community I don't think is matched any place else in this country.

Even in San Francisco, I think the efforts that we've seen to date cannot be expected to continue as the epidemic grows. We have exhausted to a large degree the base of volunteer support. We have exhausted those few little niches of underutilized medical care resources, and the problem this year is going to be substantially greater than it was last year.

I estimate that on a statewide basis, for each AIDS patient we will spend approximately $50,000 per year. For each AIDS-related complex, or mildly symptomatic patient, I will estimate that it will cost at least $4,000 without continuous drug therapy.

If, as suggested by some of the studies, the provision of drugs such as AZT have a substantial impact in slowing down the onset of a more serious disease and more serious symptoms, then this figure will probably go up to something in the range of $11,000 per year per patient.

For those patients who are asymptomatic, if we simply provide them with counseling, with support, we're talking about

approximately $2,000 a year. If a substantial fraction of those patients receive continuous drug therapy, we're talking about approximately $6,000.

To aggregate this for you, I would estimate that if each of these patients that I've described receives the appropriate level of care, the total cost in California in 1989 would be approximately $800 million. If we add to that continuous drug therapy for many ARC and HIV positive patients, that figure goes to $1.4 billion in 1989. If the higher figures that I gave you earlier in terms of 7 rather 5, and 15 rather 10, ARC and HIV positive patients for AIDS patients are assumed, then we're looking at approximately $2.0 billion in 1989.

Now, I would stress that these are just the dollars that would be required to provide the health care levels that I've described to you. The real issue is health care resources. You've talked earlier about nurses and other types of health care resources.

Those are long leadtime items, and simply providing the money -- and I recognize that simply providing the money is not a simple thing to do -- we also need to realize that providing the resources to provide the health care is something that will take more time: to increase the number of nurses; to increase the number of outpatient facilities; to increase the number of physicians is tough.

So, what's going to happen, as a society we have three choices. We can either fail to care for these patients, which I think has profound implications in terms of our own image as a

society. Or, we can begin -- or we can continue to do something which I think we've already begun to do, we can begin to see these patients displace patients who have other diseases from the health care system, creating tensions within our society which will be profound. Or, finally, we can view this as the crises which it truly is, and find the new resources and new money which are essential for us to solve this problem while we still have an opportunity.

In my opinion, over the course of the next four to five years, education and prevention are the only really important weapons we have to control this disease. Once we have provided appropriate levels of care for the people who are already infected, society's first and most important priority must be education and prevention.

The lifetime costs for somebody who gets the HIV infection will be at least $75,000 and probably significantly higher. The stakes in preventing individuals from getting this infection are, therefore, profound. We can afford as a society to spend a great deal of money on education and prevention if, for each individual that we prevent getting this disease, we save that $75,000.

The difficult question is, who will pay these costs? In looking at the workplace, the health care worker is, in my opinion, a crucial element in this whole process. It is essential that health care workers take appropriate steps to protect themselves, but having done so, if they are exposed, then I think society has a special obligation to them to assist them,

both in monitoring their condition and providing them with whatever care is appropriate.

Casual contact in the work environment, clearly that is not a problem. However, there's a tremendous need for education to eliminate inappropriate fears. The risk to uninfected employees is virtually nonexistent. The paradox is that the risk to the infected employees is, perhaps, substantially greater.

Those of us who walk around each day with minor infections and colds represent a much more significant risk to our colleagues who may have the HIV infection than they do to us.

There are issues with respect to employability, discrimination, confidentiality, and health insurance which will be addressed in the report, and which I think require diligent attention by both the Legislature and the executive branch. Health insurance, in particular, we need to find creative solutions. The current log jam and confrontation regarding the testing issue flies in the face of the whole basis of insurance in terms of trying to group people by risks. We need to take a page out of our booklet with respect to drivers and assigned risks and find ways to properly and appropriately insure people who are infected with this disease.

In conclusion, what are my recommendations? First, do as you're doing here today, but most importantly, try to do it in a way which will reach out to your fellow Legislators. It's crucially important that you, as our elected public officials, be well informed.

It's equally important that you speak up on the importance of dealing with this epidemic. For too long the elected political leaders in this country have chosen to ignore this crisis. This is an epidemic, and it will not wait. It is essential that you take specific actions.

The plan which the California AIDS Leadership Committee is preparing will include a number of recommendations for actions, some of which have been discussed and will be discussed by other speakers here today.

I hope that the plan will serve as the basis for joint executive, legislative, and private sector action. I hope we would find, as a point of departure, for the citizens of this State to say, "Fine. We understand what the problem is. Now, let's go about solving it."

It's important that you as leaders set the tone for public policy making. In dealing with individuals who are infected, it is essential that we put compassion before judgment.

We should never forget the high human and financial costs of delay in taking action. We know enough to do a lot. More studies are not necessary to make the big decisions, just courage and leadership. This is not just a problem for the people with the disease; this is a problem for all of us, and your leadership is essential.

Thank you.

CHAIRMAN HART: Mr. Carpenter, thank you very much for a particularly clear and eloquent statement.

I wanted to ask you two questions. One, in going through these costs, you were talking about $800 million per year, up to, maybe, $2 billion, depending on how you judge the number of people that are infected.

Now, this is if we do the right thing, as I understand it?

MR. CARPENTER: That's correct.

CHAIRMAN HART: Did your committee, or do you personally, have an assessment of how much we are actually spending here in California today?

MR. CARPENTER: It's an exceedingly small fraction of those figures. I don't have a good estimate for you today, because to a large degree, it isn't kept track of by disease category.

I would estimate that for each AIDS patient, where I said that $50,000 a year would be the appropriate level -- let me stress that I think that San Francisco, for example, is providing very good care to those patients at significantly lower figures, but they're doing it with a very high level of volunteerism in the city. They're doing it with -- by stretching resources that can't continue to be stretched.

I think that probably of the 9,000 patients that we would anticipate being alive at the end of the year, I would expect that a substantial fraction of them are not receiving anywhere near the quality of care that we as a society think they should be receiving.

CHAIRMAN HART: Can you give me a seat-of-the-pants estimate as to what you think we are spending?

In the State budget, we've got like $100 million plus for AIDS, and a lot of that's in research, which I'm not sure is factored into your figures.

MR. CARPENTER: It's all to patient care. I didn't speak to research at all. I think that my own --

CHAIRMAN HART: You're just talking patient care.

MR. CARPENTER: -- personal opinion, with respect to research in both the federal and other levels, is that we have probably ramped up the investment in research to about the right level, and further investments in research, in my opinion, are much less important in terms of providing value than investments in patient care and in education and in prevention.

My own guess in the patient care area is that with respect to AIDS patients, we're probably spending about half of what we should be spending. And with respect to ARC and HIV positive and asymptomatic patients, we're probably spending maybe a tenth of what we ought to be spending.

And what bothers me the most about that is that you can only get this disease from somebody who's already got it. And if we developed a program that could reach out to every single infected person, provide them with good care and with good counseling, we would maximize our chances of preventing those people from giving this disease to other people.

There are lots of complex issues there in terms of confidentiality and all sorts of other things, but that, to me,

is where the greatest challenge is: make sure that every person in this State who is HIV positive knows it; and make sure that we have available to each one of those people the right kind of support to help them deal with their situation, and to counsel them in such a way that they don't give this disease to other people. And if we don't do that, the figures that we're going to see in 1995 and the year 2000 will make our heads spin.

CHAIRMAN HART: The other question that I had was on education. You focused on the importance of education.

I think there was a recent study done by the Department of Education here in California that indicated -- and I may have this wrong; I've just thought of a news story, and it's kind of vague, so I wouldn't want to be held to this -- but it was something like 90 percent plus of teenagers are aware of how AIDS is transmitted sexually. Yet, with over half of the teenage population or close to it being sexually active, when asked the question, "Do you practice safe sex? Do you use condoms in heterosexual sex," they answer was like 7 percent, 10 percent, 15 percent, way below that.

So the issue in terms of education, as I understand it, if you believe those figures, is not saying, you know, this can be transmitted this way; use a condom. It's not an informational issue; it's a behavioral issue. And making that kind of jump from information to behavior change is extremely difficult, as you point out, and, I presume, extremely costly.

If you agree with that analysis --

MR. CARPENTER: What should we do?

CHAIRMAN HART: Yes, what do we do, and what are the effective ways to change behavior in a so-called education setting?

MR. CARPENTER: I think the most effective way to change behavior, we know in our society how you change behavior. And all you have to do is look at Coca-Cola, or some other consumer product. Being aware of Coca-Cola doesn't sell Coca-Cola. It's the constant repetition.

We've seen in the United Kingdom, where they had a tremendous blitz on AIDS for about two weeks a year-and-a-half ago, and then there was a long, quiescent period in which nothing happened. We know from educational studies and education research that you don't change behavior from one-time pronouncements. You change behavior from a message which is given consistently and often.

Now, our first problem is that those of you who are leaders and who have been elected to public office have been very reluctant to deal with questions having to do with AIDS, dealing with questions having to do with sex, dealing with questions having to do with condoms, et cetera. And there's tremendous pressure at the local level of, you know, let's not talk about these things.

We pride ourselves as a country of having given the responsibility to local school boards who are dealing with education issues. I can't imagine a more conservative force in our society right now. This is a group of people that just don't want to deal with this kind of issue because it makes us all feel uncomfortable.

We have to realize that either we have the comfort of not dealing with messy issues, or we're going to have a lot of our children die. That's a tough decision, but we as a society have to stand up and say the time has come to put aside our scruples on dealing with these issues.

And we have to be prepared in the schools to deal with this issue up-front and consistently. We have to be prepared to give Dr. Werdegar and his colleagues support when they want to do needle exchange programs and they want to get out there and talk about these things in vivid terms.

We know you can't change people's behavior by talking to them in scientific terms. You have to talk to people in terms that they understand and appreciate. And yet, you as Legislators and people in the executive branch get pretty upset when people start using State money or federal money to give sexually explicit messages. But we can't have it both ways. We can't say we want to change your behavior, but you have to do it in real nice words, because it isn't going to change people's behavior if you do it in real nice words.

CHAIRMAN HART: Dr. Filante.

ASSEMBLYMAN FILANTE: On that last point, I want to follow up immediately because it brings all too clear to many of us who have been fighting for this; that is, the education as you were talking. We were kind of saying, "Here are the messages: dollars and death."

You have to be very explicit, granted; you're right. But in terms of education, I totally agree it's got to be Coca-Cola.

Do you see -- and I'm looking for cost effective, I'm looking for the big fight, you know, because you're talking about sex and other things, pregnancy prevention; it's the same thing: pregnancy and HIV prevention.

But as I see it, being someone who has to vote on dollar, and being a physician I've got to get the message out, I see it with teenagers as requiring the family, because you can't afford to be telling the teenager or the student this every day, but maybe if we got the family hooked up in it, that would help.

Is there some possibility that you see, or some technique that you see, where we could do that, because it is Coca-Cola. In other words, it's a message that needs to be repeated, but we don't have the dollar resources that Coca-Cola does, because we've got to do other things, where you can bring in the community, individuals, and what have you.

We were lucky, you know, with our misfortune here in San Francisco. We had a humane, tight, related society in our gay community here that could do a job for us and help. That won't be here, I don't think, for the drug community.

But in the school community, where maybe you've got families or something, and PTAs, and what have you, is there some way that you can see the way through to what you're talking about, or what I'm describing: death and dollars.

MR. CARPENTER: The solution from my standpoint is that I think the people that we have in leadership positions simply have to put this at the top of their agenda. And if you're a superintendent of a school district, if you're on a school board,

if you're involved in local decisions with respect to education, you have to just simply say, as the Surgeon General said, he said, "I'm the Surgeon General of the United States. I'm not the chaplain of the Public Health Service." He said, "My job is to help this country deal with the health care crisis."

And I think that we're going to have to ask the people at all levels who are in leadership positions, in the private sector and in the public sector, to just simply say this is an issue we've got to talk about. This is an issue that has to be on the agenda. And we do it in our families. We do it in our schools. We do it at the State level.

I don't think there's a simple answer to this, but the simple answer if we don't do it is that it's going to destroy our health care system, and, I think, in the process it's going to do a lot to destroy our society.

CHAIRMAN HART: Senator Marks.

SENATOR MARKS: I think that I agree with what you just said, the leadership has to do this.

But unfortunately, the leadership of the Legislature basically is in this Committee. Those who believe in trying to do something about AIDS are on this Committee. Unfortunately, there are a lot of Members of the Legislature who don't want to do anything. That's the basic problem we have. It's very tragic.

Unfortunately, we have to do an awful lot more, those of us who want to do something in our State are here on this Committee, and Assemblyman Filante also.

MR. CARPENTER: Well, my sense is that perhaps what we can do is, when the document from the Leadership Committee is delivered, that we can use that as a rallying point and bring together the people from the executive branch, the legislative branch, and the private sector, and recognize that we have a full-scale crisis on our hands, and commit ourselves to doing something about it because it cannot be business as usual.

If it's business as usual, in three to four years this problem will be so severe that we will have no hope of catching up with it, and all you have to do to see what that looks like is look at New York City today. That's where we're going to be in four and five years if we don't make the intellectual, the emotional, and financial investment in fighting this disease.

ASSEMBLYMAN FILANTE: And if your report doesn't say dollars and death, headlined on every page, we're not going to be able to avoid New York City, Newark, and whatever else.

MR. CARPENTER: I'm certainly not going to be hesitant to speak out, both in the report and on my own in conjunction with the report. In that respect I welcomed the opportunity of chatting with you this morning, and I will work with you to carry this message to your colleagues.

ASSEMBLYMAN FILANTE: Thank you.

CHAIRMAN HART: Thank you very much, Mr. Carpenter.

I think we should break now. It's the intention of the Chair to return and begin our afternoon testimony promptly at 1:30. So, let's take an hour and seven minutes break, and we will be back at 1:30.

(Thereupon the luncheon recess was taken.)

AFTERNOON PROCEEDINGS

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CHAIRMAN HART: I said we were going to start at 1:30. It's 1:35. That's pretty close by politicians' standards; isn't it?

We have a full agenda this afternoon, so I want to begin.

Is Pat Franks here? Thank you.

Ms. Franks is the Coordinator for the AIDS Resource Program with the UCSF Institute for Health Policy Studies.

We really appreciate you joining us this afternoon.

MS. FRANKS: Thank you for having me, Mr. Chairman, Senator Marks.

I'm a health policy analyst, and for the past 13 years, I've worked at the Institute for Health Policy Studies at UCSF and in the community on a number of health issues. My interests are in health promotion and disease prevention, primary care, and community-based health services, also intergovernmental health issues, and public-private partnerships in health. I've always had a special interest in the health of special populations: refugees and immigrants, minority populations, elders, and the medically indigent.

For the past three years, I have had a special interest in people affected by the HIV epidemic. And through the AIDS Resource Program, I have worked daily with communities, and counties, and states across the country to help them plan and implement a continuum of HIV prevention, treatment, and support services.

Today I want to speak to five questions: first, what is the purpose of planning? We talked about planning this morning. I would like to talk a little bit more about it and lend some context.

What are other states doing related to HIV planning? What are counties and communities doing, especially in California, related to HIV planning?

What is my perspective on California's draft HIV plan: the process of developing the plan and the plan itself; its structure and content?

What in my view are the next steps for California with the planning process and with its HIV plan?

I will not address another major question -- what is the federal government doing related to developing a comprehensive HIV plan -- because I do not know the answer to that question. Our administration has not yet made clear its course of action related to developing a plan to respond to the HIV epidemic. The Congress, to the best of my knowledge, has not yet required this administration or the previous administration to develop a comprehensive plan.

What is the purpose of planning? For me, planning is a way for people to think things through, to work things through, and to get things done.

Different types of planning serve different purposes. First, there's policy planning. And the purpose of this type of planning is to answer the question: what should we do?

At this level, planning is goal-oriented. People are trying to figure out in a broad sense how to respond to a problem. Often, they are trying to create a new system in response to a new problem. And here, technological information -- demographic data, epidemiologic data, health systems data, health manpower data, and cost data -- is helpful in describing the nature and the extent of the problem, as well as some of the potential solutions. So is information about how the current system is organized to respond, and how the system works and doesn't work, and who does what. It helps, too, to know what other people are doing to solve the problem, people in other states and people working at the community level. The outcome of this type of planning is often a statement of goals or priorities and recommendations about how they should be met.

Second, there's strategic planning, and the purpose of this type of planning is to answer the question: what can we do?

At this level, planning is objective-oriented. People are trying to develop objectives related to their goals and to explore different strategies for achieving them. Here, information about opportunities and constraints, costs and benefits, efficiency and effectiveness, including cost effectiveness, of different strategies is helpful.

Third, there is what we might call tactical, or operational, or implementational planning. The purpose of this type of planning is to answer the question: what will we do?

At this level, planning is action-oriented. People decide not only what they will do, but also how they will do it;

it; who will do it; when it will be done; and how much it will cost; how to measure, monitor and evaluate the results. Here tasks, methods and procedures, responsibilities, timelines, costs, anticipated effects or outcomes, and monitoring and evaluation are laid out.

The planning process helps to build consensus. One of the major challenges of planning at all levels is to build as broad a consensus as possible. Without some degree of consensus about the nature and the extent of the problem, and what to do about it, we can't have a plan.

To build consensus, we must invite and involve, at some point in the planning process, all the people who are touched by the problem, and who will have responsibility for solving it, carrying out the plan, getting things done. If we don't invite or involve them in the planning process, when the plan is done and we want them to act on it, they'll just say, "No."

The planning process helps fill gaps in knowledge. A plan is as good as what we know about what's happening in the present, and what we think will happen in the future. Again, one way to fill these gaps is to ask a broad range of people to contribute their knowledge and expertise to the planning process.

What are other states doing related to HIV planning? We know the HIV epidemic now touches all states and U.S. territories. Five areas are now being hardest hit. These areas have the highest incidence rates from March, '88 through February, '89, or the greatest number of new cases, new AIDS cases, reported per 100,000 people. These hardest hit areas are:

the District of Columbia, Puerto Rico, The Virgin Islands, New York, New Jersey.

The next hardest hit are: Florida, California, Georgia, Texas, Maryland, Connecticut, Massachusetts, Nevada, Delaware. California follows only New York in the total number of AIDS cases reported since 1981, another way to gauge the impact of the epidemic.

How are states and U.S. territories responding? In terms of planning, only New York and Georgia, among the high incidence states, have five-year plans. New Jersey is working on a plan. The State of Washington is implementing its regional system of planning and delivering services. Other states are reorganizing their AIDS efforts, either by elevating them to a higher level, or creating new divisions in their health departments.

The great majority of states do not yet have five-year plans, nor are the plans that exist implementation plans. However, a large number of high incidence and low incidence states, approximately 35, have begun a planning process, and they have produced policy documents and other special reports. These reports often have been mandated by state legislatures or by governors, and they are often the work of governors' advisory councils, legislative task forces, or departments of health and human services.

With or without the guidance of state HIV plans, more and more states are taking an active role in establishing policies, passing laws, and appropriating more state dollars to respond to the HIV epidemic.

What are counties and communities doing related to HIV planning, especially in California? The HIV epidemic now touches all of California's counties. If we look at the cumulative incidence -- the number of AIDS cases reported per 100,000 people over the course of the epidemic -- clearly, the City and County of San Francisco has been hardest hit. Here, cumulative incidence now stands at 717 AIDS cases per 100,000 people.

Among other hardest hit counties and jurisdictions are: Long Beach, Berkeley, Sonoma, Marin, Los Angeles, Pasadena, Alameda, San Diego, Mendocino, San Luis Obispo, San Mateo, Contra Costa, Sacramento, Riverside, Orange, Santa Cruz, Napa, Monterey, Santa Clara, Santa Barbara.

More and more California counties are falling into the hard hit category. In fact, only about 20 counties now have a cumulative incidence lower than 12 AIDS cases per 100,000 people. The rest have more.

Local response has been a key factor in response to the HIV epidemic. The epidemic has been handled from the start as if it were a series of local health problems. We might describe the situation as bottoms-up health policy. The response of cities first impacted by the epidemic -- San Francisco, Los Angeles, and New York City -- is being recapitulated by communities impacted later in the epidemic.

Municipalities and counties in California and in other high incidence states have taken the lead in developing and testing policies and programs. In reality, communities, and communities within these communities, were the first to respond

to the epidemic. Why? People do not live at the federal level or at the state level; they live at home in their communities, and the epidemic has hit at the heart of homes in these communities.

Mayors' HIV task forces and advisory groups, special HIV commissions mandated by boards of supervisors or city councils, interagency task forces, advisory groups to departments of public health, AIDS offices and planning departments within departments of health, and ad hoc groups of community activists -- this is the way that planning related to the HIV epidemic has gotten started and continues in California and other states.

HIV planning in California counties is proceeding at various levels and paces. When my colleague, Carl Lester, surveyed the 12 California counties with the most AIDS cases as a project of the Center of AIDS Prevention Studies at UCSF last year, he looked at county plans, and he also visited these counties and talked with lots of folks.

In all 12 counties, we know that the chief health officer, or designated local health officer, has overall responsibility for administrating AIDS activities. Seven of the 12 counties at that time had established a formal AIDS planning process and had written AIDS response plans. The AIDS response plans varied from plan-to-plan documents, to detailed comprehensive five-year plans.

Again, these plans were not in any case operational plans, but more policy plans or policy statements. Some of the plans were prepared by consultants hired by the county. The rest

were developed under the direction of public agencies or public bodies with varying degrees of input from the rest of the community.

Nine of the 12 counties had established permanent, multidisciplinary advisory bodies to assist the county in planning, coordinating, and developing HIV policies. Of course, the composition of these bodies varied greatly. In some cases, the advisory group members were appointed by the board or the mayor; in others, the health director had requested a great number of people to serve on a great number of advisory bodies.

Lines of authority for planning and coordination are often blurred in counties. It's often not clear whose job it is to plan, and whose job it is to carry out the plans that are developed.

Last week, I had a call from one of Sonoma County's AIDS Commissioners who wanted to know how other counties were responding structurally and with funding. He sent a copy of the Commission's Report on AIDS, issued in July, 1988. The title is telling: "AIDS in Sonoma County: An Internal Assessment of the Scope of the Epidemic, the Immediate and Intermediate Needs, and the Available Services and Resources." The report is an eloquent, almost poignant, statement of the plight of this high incidence California county.

HIV planning in counties and communities outside California is also proceeding at a variable pace. I also received in the mail last week an equally poignant document from the Citizens Commission on AIDS for New York City and Northern

New Jersey. This document was, "A Guide to the Plans." Now six of them have been produced by public agencies, public-private efforts, and private sector efforts. Accompanying that document was an article from The New York Times, saying that New York's plans for AIDS are inadequate.

On the other hand, in a given week, I will hear that Boston or Detroit or Cleveland or St. Paul has had a major breakthrough in developing a consensus report or policy guidelines.

Municipal and county policies and programs are forming state and federal policy decisions and shaping state and federal programming.

What's my perspective on California's draft HIV plan? First of all, what about the HIV planning process in California?

Almost a year ago today -- March 30th, 1988, to be exact -- there was an AIDS policy meeting at the AIDS Office in Sacramento. A number of people from the Department of Health Services, including Dr. Kizer and Ms. Fraziear, legislative staff, and people from California's counties met to discuss the need for a California AIDS Leadership Committee and a State HIV plan. There was a bomb threat in the late morning at the AIDS Office, so we moved the meeting to the Senate Office of Research and spent the rest of the afternoon talking about what the HIV plan might look like.

Today, we have a California AIDS Leadership Committee and a draft HIV plan. And I think that a number of people should be congratulated for their efforts: Dr. Kizer and Dr. Marcus

Conant, UCSF, Co-Chairs of the Leadership Committee; Dr. Don Francis, CDC AIDS Advisor to the State of California; Ms. Fraziear; and Dr. David Werdegar, all members of the Leadership Committee's Executive Committee.

The full membership of the Committee also deserves credit because I know how hard many of them have worked, especially subcommittee co-chairs. Many more people were included as members of these subcommittees.

As I reviewed the State of California's three-year comprehensive HIV Disease Prevention and Treatment Plan, dated March, 1989, I went to my file. I pulled out another document, "Acquired Immune Deficiency Syndrome in California: A Prescription for Meeting the Needs of 1990," dated March, 1986.

Both of California's HIV plans were developed pursuant to legislative budget control language. The California State Legislature required the California Department of Health Services to develop comprehensive AIDS plans so that identified needs could be addressed during the budgetary process.

California's HIV planning process has taken a significant step forward, but we need to go further and, I might add, faster. As you know, we can do top-down planning, or bottoms-up planning, or horizontal planning, or vertical planning. As I reviewed a list of California's AIDS Leadership Committee members, I was impressed with the large number of State public agencies represented, and the significant representation from the private health care sector.

I did not find adequate representation from the Legislature, from county agencies, and not-for-profit agencies -- community agencies that have been in hand-to-hand combat with this epidemic from the start -- or from the religious community, the labor, the business community, minority communities, private and corporate foundations, or the media.

It's my perspective that the nature of the HIV epidemic requires us to be as embracive as we can in enlisting people's help in ending it, in caring for the sick, in assuring the protection of the human rights of all Californians, and in understanding better how to finance HIV prevention, treatment, and support services, and research.

What about the structure or organization of California's draft HIV plan? The structure or organization of the plan needs to reflect the purpose of the plan. Is it a policy plan, a strategic plan, or an operational plan?

I believe that it is now a blend of plans, but mostly a policy plan.

Is the purpose of the plan to provide guidance to the Legislature or to counties? Is the purpose of the plan to lay the groundwork for a strategic plan, and then an operational plan for all California State departments and agencies?

The HIV plan outline developed on November 12th -- I believe it's November 17th -- which I have attached as an appendix to my statement, seems to be a better way to structure the plan than the way the plan is now organized.

What about the content of California's draft HIV plan? I think that the plan represents a significant achievement. It is obviously the product of much collaborative, thoughtful work. The ten priority issues in the Executive Summary are sound. The majority of recommendations are also sound, and they demonstrate a growing or new consensus on a number of important issues about how Californians need to move forward in relation to the HIV epidemic.

However, most of the recommendations are "shoulds." They will need to be translated into action. Some of the recommendations will require legislative action. Some have budgetary implications.

If the plan is to move from a policy plan to a strategic plan to an operational plan, meat needs to be put on the bones. Goals, objectives, methods, procedures, tasks, responsibilities, timelines, costs, and outcome measures will need to be added. We will need to know who is going to do what, when, and how much things will cost. We'll also need to know how to measure our progress, because we can't manage what we can't measure.

There is one omission in the content of the plan that needs to be remedied. There is no information on the present or projected utilization and costs of health care services -- inpatient, outpatient, physician, and community-based -- or social support services. Information from the Institute for Health Policy Studies' "California AIDS Cost of Care Study and Skilled Nursing Facility Study" needs to find its way into California's HIV plan.

What are the next steps for California with the planning process and with the HIV plan? The people of California have already shown an extraordinary commitment in responding to the HIV epidemic. We have shown a commitment to end the HIV epidemic, to care for the sick, to protect the human rights of all Californians, and to finance HIV prevention, education, and information, HIV treatment and support services, and HIV research.

We were the first to develop innovative community-based HIV prevention programs, dedicated AIDS outpatient and inpatient units in our public hospitals, home and hospice care programs for persons with AIDS. We were the first to speak out strongly against discrimination against persons with HIV infection. We were the first to define components of a continuum of HIV prevention, treatment, and support services. We have many firsts in biomedical, clinical, behavioral, epidemiologic, and health services research. We were the first to do studies of the costs of AIDS care.

The people of California have committed more State dollars to responding to the HIV epidemic than any other state and many countries. We also have committed a tremendous amount of local dollars and local effort, especially in cities like San Francisco. The Legislature, the Department of Health Services, local health departments, community-based agencies, and thousands of volunteers deserve great praise. The Governor also deserves credit.

California's HIV plan is a way to lend focus to our commitment, and to tie that commitment to the budgetary process in the form of an operational plan of action. California is a diverse, multicultural State. The face of the HIV epidemic is changing, and we are being challenged with creating and recreating new systems to respond to the epidemic. What is happening is that we are moving from a perception of AIDS as a rapidly fatal catastrophic illness, to the perception of HIV disease as a preventable, communicable, chronic illness. We are now being challenged to blend a public health model, a medical model, a social model, and a self-care model in responding to this disease.

California's HIV planning process must continue as a way to build consensus and focus the efforts of all Californians. State and communities, like people responding to HIV disease, proceed through stages in their responses to the HIV epidemic. These stages include denial, panic, and coping. It's time for us, as a State, to move out of denial and panic -- and divisiveness, and partisanship, and anger, and hostility -- and into a coping mode.

I recommend four next steps in helping California move forward in responding to this epidemic.

First, expand immediately the membership of the California AIDS Leadership Committee, including the Executive Committee and subcommittees.

Second, complete a revised draft of the HIV plan by May 1st, 1989, so the policy plan can be useful to the Legislature during the budget process.

Third, move the HIV plan from a policy plan to a strategic plan by June 30th, 1989, involving the expanded California AIDS Leadership Committee.

And fourth, move the HIV plan from a strategic plan to an operational plan by September 30th, 1989, involving the expanded California AIDS Leadership Committee.

Thank you very much.

CHAIRMAN HART: Thank you very much.

I must say that I usually find people who read testimony deadly boring.

MS. FRANKS: I'm sorry.

CHAIRMAN HART: And I also find discussions of plans usually deadly boring.

I was captivated by your presentation. It was compelling, and I don't know how to put it. It was compelling to me.

I wanted to ask a couple of specific questions. On Page Five in your identification of the various jurisdictions that have been impacted, I guess I need to understand if you're sort of mixing cities and counties in here a little bit?

MS. FRANKS: Yes, we were.

CHAIRMAN HART: Like Los Angeles, which I've always thought of as bearing the brunt with San Francisco, and places like West Hollywood. Los Angeles ranks farther down than a place like Long Beach, which I've not usually associated with a heavy impact.

MS. FRANKS: Do you know why? Los Angeles is so big. In this case, when we looked --

CHAIRMAN HART: You're talking about the city or the county?

MS. FRANKS: The county -- both the county and the city.

The other thing that happens, Senator, is that the Department of Health Services reports -- we have special health jurisdictions. Some of our municipalities -- Berkeley, and Long Beach, and San Joaquin has a special health district, too. Let's see if there are other cities: Pasadena. And that's how that happens.

CHAIRMAN HART: I also wanted to ask, you mentioned other jurisdictions, other states that have these plans. You mentioned Georgia and New York that have five-year plans; you made reference to Washington.

MS. FRANKS: Yes.

CHAIRMAN HART: Are any of these plans ones that we ought to be looking at --

MS. FRANKS: I don't think so.

CHAIRMAN HART: -- as a model?

MS. FRANKS: No, I do not think so.

I think that each state is unique, as each community is unique in responding. I think we could learn. You know, there was kind of an irony about New York City. They took San Francisco as a model and made it a state model. Maybe we could look back at New York's model and bring it back home.

I'll be happy to send it to you, but the plan itself, actually I think -- because I'm very chauvinistic as a Californian, used to live in New York -- I think we did a better job. I think we're on the way of doing a better job with our plan.

CHAIRMAN HART: Any other questions?

ASSEMBLYMAN FILANTE: A comment on the District of Columbia.

MS. FRANKS: Yes.

ASSEMBLYMAN FILANTE: If you will, this far away, the high incidence here is obviously tied to drug abuse, and we have D.C. in the news for all their murders, and what have you.

Is that only another seat of drug crimes, or is there something else?

MS. FRANKS: It just seems to me that the nation's Capitol seems to be kind of out of control.

ASSEMBLYMAN FILANTE: That's our response; just one more example.

(Laughter.)

CHAIRMAN HART: In more ways than one.

MS. FRANKS: I'm sorry, I didn't address your question.

ASSEMBLYMAN FILANTE: I thought it was well addressed. Thank you.

(Laughter.)

ASSEMBLYMAN FILANTE: But it is essentially that?

MS. FRANKS: Yes, it is.

Thank you very much.

CHAIRMAN HART: Thank you very much.

Our next witness is Dr. Marcus Conant. Dr. Conant is Co-Chair of the AIDS Leadership Committee and Professor at the UCSF School of Medicine.

DR. CONANT: Senator Hart, Senator Marks, Dr. Filante.

Let me join Dr. Kizer in thanking you for the opportunity of addressing you today to tell you what we've been about for the last nine months, and give you at least our insights into why we think this plan may be of assistance to you as you form legislation this year and in the future.

We, or at least I, come to you with a degree of urgency that I have had for a long time. My first public AIDS lecture was a little more than half a mile from here at Moscone Center in 1981. At that time there were 91 -- 91 -- known cases of AIDS in the world. We were pleading for intervention. We were pleading for education. We were pleading for help in stopping the epidemic. Unfortunately, those pleas fell on deaf ears.

One of the things that has characterized this epidemic as we've gone from 91 cases to today 91,000 cases of AIDS, that thing that has characterized it is the lack of leadership, particularly in the executive, both nationally and in the local level.

This plan is not a plan created de novo. There were outstanding models on which we based many of our considerations and which would have, themselves, served as adequate plans to lead the nation and the State in the past. The first was prepared by the National Academy of Science, entitled

"Confronting AIDS", and it was published four years ago. Unfortunately, it was largely ignored by the administration. The next was the Surgeon General's Report, which was received by the President but unfortunately never endorsed. And finally was the Presidential AIDS Commission Report, which lays down precisely how the nation has to respond to this epidemic. Unfortunately, it was received by the President but again not endorsed.

In the State, this is the third plan. The first was a plan which Dr. Filante and I helped draft at a meeting in Los Angeles in 1985. That plan never saw the light of day. Two years later, we had California's War on AIDS, which was an extensive plan, budgeted, placed on the Governor's desk, and unfortunately it was never heard of again.

This plan, the current AIDS Leadership plan, derived most of its impetus last year when we realized we were working in a vacuum of leadership. There were over 100 AIDS bills introduced into the Legislature last year, and I've just been told there have been 83 introduced this year. And it was clear that we did not have a comprehensive plan on which to base appropriate legislation. We were seeing inappropriate legislation introduced; legislation, for example, that would require mandatory testing of all people to find out who was positive or not. Unfortunately, we felt -- the health experts felt -- that that type of legislation would do nothing more than drive the people who were afraid they were infected underground, and in fact increase the magnitude of the epidemic.

Often when people are frightened, they find security in codifying what they consider traditional wisdom. For those of us who have tried to study epidemics, you find that what happens usually as the last step in the epidemic is the passing of laws to codify behavior or to persecute certain groups. The most classic example is the Great Plague of 1348, when everyone knew that it was the Jews poisoning the wells that killed a quarter of the population of Europe in a two-year period. And so, laws were passed to prevent Jews from traveling throughout Europe, and those laws, in many locals, persisted for another 150 years.

People rush in, and they pass laws that satisfy their prejudice, even though the Great Plague was not caused by Jews poisoning wells. It was caused by the typhoid -- by the plague bacillus.

We saw legislation introduced to round up and test prostitutes, even though we had ample evidence from the syphilis epidemic of World War I that closing down the Barbary Coast and testing prostitutes was of little or no public health benefit in stopping an epidemic.

We had legislation introduced for mandatory testing before marriage, and yet health care experts were pointing out that that would not stop the epidemic and would, in fact, drive people underground. And I remind you that in the State of Illinois, where it was passed, marriage in some areas was down 40 percent within a year. People were going out of the State of Illinois to be married. Why should that be? These were heterosexual people who were at low risk for AIDS. They were

fleeing the state because they were afraid if they had a false positive test, they would experience discrimination.

This plan was written by a group of over 200 individuals, all of whom are expert in various aspects of AIDS and public policy, and it was written quickly because many of the public health ideas, the policy ideas, had been developed over the last seven years from the previous plans I've enunciated and from innumerable local plans that have been implemented.

We stress that this is a plan for the people of California. We hope through it to inform the Governor, to provide information for the Legislature on which they can base legislation, and to bring in the private sector, which we will need desperately as the cost of this epidemic escalates. We hope that it will help in legislative endeavors, but we do not see it solving the problems that the Legislature faces with this epidemic.

I think that one of the problems is that we often think that we can find societal solutions with medical intervention. Medicine cannot solve the IV drug use problem, the homeless problem, the teenage pregnancy problem, the sexually transmitted disease problem, or AIDS. These are societal problems which medicine plays only a small role in solving.

Working together, we may find solutions, but we cannot rely on a group of experts to stop the AIDS epidemic any more than a group of experts can stop the IV drug epidemic.

I would remind you that we have also produced through this process a group of over 200 experts who have deliberated

many of the contentious issues around AIDS that you can use in legislative hearings as you begin to formulate legislation to respond to some of the issues raised in the plan.

As Dr. Kizer pointed out earlier, we have structured the plan to give ten major recommendations which we feel are the major things that the Legislature, the Governor and the people of California need to hear. We stress education; we stress the fact that this is spreading to the IV drug using community; we stress the fact that counties must work closely with the State.

And then, for each of the major issues -- for education, for prevention, children, for IV drug problems, for treatment -- we have made a number of specific recommendations, many of which will require legislation for implementation. My guess is that the plan will end up with approximately 100 such recommendations which will need implementation by someone.

It is my hope that in the final draft of the plan, it will be quite clear who we feel should be the person that should implement those various 100 recommendations.

Let me take five examples from the prevention, treatment and testing area to give you the kind of verbiage that the plan will contain and where I think that it will help the Legislature. Education, we acknowledged, was the most important tool we have in terms of preventing the further spread of the epidemic. And as you heard this morning from Mr. Carpenter and others, we cannot be shy in telling children what they need to know.

Now, we've been through that. We know what happens when you don't tell people what they need to know. Victorians,

uncomfortable talking to their children about sex, talked about birds and bees, so that they wouldn't be embarrassed or embarrass their children. And of course what happens is, the children never understood what the parents were trying to tell them.

We have to explicitly tell children that are ready to hear the kind of information they need to know about their bodies, about the instincts that they will develop as they mature, and about the strategies they need to use to prevent disease transmission.

The wording in the plan is something to the effect that we recommend that the State should mandate all public schools to provide age-appropriate HIV disease education, beginning -- and this is underlined -- no later than the fifth grade. This education should be provided unless a parent requests that the pupil not attend this instruction.

Senator Hart, we are mindful that you have introduced similar legislation in the past. Hopefully, when you do so again in the future, you can point to the State plan provided by a group of AIDS experts which endorsed your idea of two years ago, that we need this kind of education to stop the transmission of AIDS in this State.

ASSEMBLYMAN FILANTE: Mr. Chairman.

CHAIRMAN HART: Dr. Filante.

ASSEMBLYMAN FILANTE: On that point -- I hate to interrupt you, Dr. Conant -- it was thoroughly debated. It was a problem, and there's an obvious need both at that time and today for a wider section of the population, namely parents, to be involved.

Can you or the Committee suggest a way to implement that education goal with the involvement of many more parents? Far more than just parents saying you can't have it. That's the last thing we want to see, is that little note. Any suggestions?

DR. CONANT: But you won't -- that little note, that parent has to approve it. There's another little note that people like to pin --

ASSEMBLYMAN FILANTE: My plan would say that you've got to give it to all parents and their kids, or the kid can't pass if the parent -- something Draconian, or whatever, because I have the fear, and you come up with some weird ideas.

But, you know, anything that might make sense that could be done to at least move in that direction. For example, my suggestion in terms of getting -- let the parents decide, the parents had to know what the plan was and be aware of it before they could reject it, so at least they'd have a little education.

Anyway, were there any thoughts in the development of that?

DR. CONANT: I wasn't present at the deliberations, but it might be useful to get the subcommittee chair who conducted those to help you as you formulate the bill again.

ASSEMBLYMAN FILANTE: All right, thank you.

DR. CONANT: But I think, Dr. Filante, that what we're going to have to do is, the Legislature is going to have to speak directly for what most parents want. Certainly, the parents of the children that I'm seeing, as a physician here, want their kids to be educated. So, while I understand your concerns, this

large body of people who do not wish their kids educated, many of us don't see them. So, I think that need to speak for what the majority seem to want their kids to have.

And clearly, if the kids are not informed, we are negligent, and we're going to be watching our kids die. I think it's just unconscionable that we would have a situation where a child was not told how to protect himself.

ASSEMBLYMAN FILANTE: Let me reword my statement or question.

Given that no parent precluded their children from this education process, a large number won't be educated. In the current state of our schools, whether it be funding, or mix, or illiteracy, or drugs, or violence, or anything else, the fact is, a tremendous percentage are not going to get the message.

That's why I'm so concerned.

DR. CONANT: Why is that?

ASSEMBLYMAN FILANTE: Why is it? Because they're either zonked on drugs, absent, doing something else during class, out to detention, or whatever, or it's smart not to pay attention, whatever it might be. They're not going to get the message. There is no homework, and so on and so forth.

Just pragmatically, even if I could get 100 percent okay, and no parent ever said no, that's where I have the problem.

DR. CONANT: Of course, your question goes to a greater issue than we have.

ASSEMBLYMAN FILANTE: Obviously, yes.

That's why I was trying to drag in parents, or homework, or anything that would -- because this is not like history or math; this is life and death.

DR. CONANT: But to go to a point that Senator Hart mentioned earlier, as to how do we go from education to behavior change, one of the ways you do it is, you get the entire cohorts to start behaving in a certain way.

We were educating the gay community in 1982, and telling them they should use condoms, and we had documentation that they were not. What happened was, when people started seeing their friends and neighbors die, they became frightened. They started using the information that had been given them, and now we've seen the entire consensus change in the community where everyone is behaving in the same way.

Even if you reach 80 percent of the children, it becomes the norm to behave in a certain way. Those that were asleep, or zonked, or didn't listen might be positively impacted.

One of the other concerns that we have had is that we are seeing people with indeterminate tests for AIDS with those tests reported out. This, too, can be fixed by legislation. An individual is told that the test is indeterminate -- it may be reported as positive when it's not positive, and the person is frightened to death, or even worse if it's reported as negative.

The subcommittee that dealt with that -- and Dr. Smith is here and can answer questions about it on that specific issues later if they come up -- suggested, quote:

"Legislation should be written to require that all indeterminate test results should be confirmed by a designated State lab ..."

which has greater expertise in doing the test, and hopefully, we could reduce to an acceptable minimum the number of tests that were indeterminate. There is --

CHAIRMAN HART: On that point, what percentage are indeterminate? Less than one percent?

DR. CONANT: I don't know.

Carl, do you know?

DR. SMITH: Less than one percent in a thousand, I think. [Ed. Note: Recent figures indicate 1 in 2,000.]

CHAIRMAN HART: I would assume that if you had an indeterminate test, you'd do the test again.

DR. CONANT: Sometimes they'll be indeterminate if you do them again. You need more refined testing mechanisms than many commercial labs have.

CHAIRMAN HART: And now, when there is an indeterminate test, the test giver doesn't suggest or automatically send it to a more sophisticated test?

DR. CONANT: No. That's what this is asking for.

CHAIRMAN HART: Why not? Why wouldn't they do that? Cost?

DR. CONANT: I don't know.

They are a private lab. They do it and report it the way they have it, and they stop there.

What we think needs redressing there is that, with that small number of tests, they should be sent to a reference facility for a final arbitration and determination.

And this is a real issue. I have a surgeon friend who stuck his finger with a needle and went back two months later, tested himself to make sure he had not seroconverted so he did not expose his wife, and got an indeterminate test result. While it's rare, it ruined his life for about six months while he tried to figure out if he had seroconverted from the needle stick or not.

So, it's a real issue. A small issue, but one that could be quickly remedied with legislation.

CHAIRMAN HART: I don't want to take too much time, but why did it take six months? A surgeon, knowledgeable about medical procedures, wouldn't he immediately, upon finding out that it was indeterminate, get this other test done right away?

DR. CONANT: We did the other test right away, and then he didn't know which one to believe, so we had to wait and redo it.

If it had gone to the reference lab initially and come out negative to start off with, I think he would have avoided a lot of it. At the point that it was indeterminate, he saw me, and then we started the process.

The Legislature has passed laws which have said that while people can test for life insurance for HIV, they cannot test for health insurance. Unfortunately, what we are now seeing is that companies writing legislation -- writing health insurance

policies are requiring life insurance policies that have the health insurance policy, a way of getting around the intent of the Legislature.

The plan addresses this by suggesting that we need legislation to close that loophole.

And, of course, there's the whole issue of surrogate testing, whether you can use a helper or suppressor T-cell ratio to determine whether someone qualifies for health insurance or not. You can say that, yes, you can't do an HIV test, but perhaps the insurance company would like to do a surrogate test.

The plan suggests that that's inappropriate and calls for legislation which would prohibit the use of surrogate tests in the case of someone applying for health insurance.

Another contentious issue is the recalcitrant patient. There's be a lot made in the press, and there have been a number of bills introduced to try to deal with the individual who continues to have sex, perhaps unprotected sex, after he or she finds that they are antibody positive. In my experience as a physician who treats large numbers of HIV patients, this is exceedingly rare, but when it does occur, it tends to get public attention.

The plan points out that such individuals are generally terribly disturbed. What they are doing is notifying society and their physician that they need help, and the first approach should be an attempt to intervene and find some acceptable way of diffusing their anxiety rather than letting them act out in public.

The plan goes on to acknowledge, though, that the public needs to be protected, and that if attempts at intervention have failed that there are existing statutes that can be used for health officials to intervene and control the behavior of such an individual.

Finally, there's an area that we have not addressed in the plan, and the plan is notably deficient in not yet having a solution for this problem. This is the whole issue of antidiscrimination legislation. There are many experts in the State who feel that there are already existing laws which adequately protect people against discrimination in the workplace, from discrimination by losing their job, their insurance, their home. There are others who point out -- and I believe you will have the opportunity this afternoon of talking to some HIV infected patients who have experienced it -- this kind of discrimination is occurring. That even though the laws may exist to protect people, the discrimination occurs.

These people who are experiencing the discrimination point out that they are often too ill to fight in the courts; their health is often so poor that they will not live long enough for the issue to be adjudicated. And even if they do fight it, the stress of the litigation in fact is detrimental to their health.

There have been a number of proposals, and we have had testimony at the Committee, but no definitive language has yet been written. As you know, John Vasconcellos has introduced Assembly Bill 65 that addresses this issue. Many of us on the Committee would urge that you support that bill this year.

In an attempt to try and further shed light on this issue, there will be a public forum on the issue of antidiscrimination in AIDS in the Capitol, Room 447, on April 13th, sponsored by John Vasconcellos and the International Bioethics Institute, to try to get further dialogue on this issue. So, that's one of the major deficiencies in the plan as it stands today.

We join you in hoping that we can get you a final draft of this plan within the next six weeks. Copies of the plan are available to Legislators to use as you begin to formulate plans for legislation this year. And I and other members of the Committee would welcome an opportunity to help you formulate those plans for legislation.

Thank you.

CHAIRMAN HART: Dr. Conant, thank you for both a cogent statement and also for your involvement in this issue over the years. You've been a great contributor, and we are all very appreciative for your contributions.

ASSEMBLYMAN FILANTE: A couple of things, and I'll ask later on testing, but in the area of counseling, there's obviously tremendous need for counseling, and that gets buffeted around in the legislative process, almost ridiculed. Those of us who are involved in this, like you, know that it is a tremendous need and cost.

Do you have, or does the plan have some rational way of reaching that goal, because it is tremendously expensive in terms of dollars today, although it may serve to help a lot to defray costs later. What is the suggestion here?

DR. CONANT: I don't recall specific language in the plan about how much it would cost, Bill.

I think what you could do is, experimental test programs in different communities. You see, the counseling will depend directly on the community in which you're involved. Counseling in San Francisco, where there's already this data base in the general population, is going to be quite different from counseling in, say, Fresno.

As the disease spreads -- as you've heard this morning, the disease is clearly spreading to other risk groups -- counseling among Black and Hispanic kids in the inner city, or intravenous drug users, is an entirely different problem than counseling gay men.

And finally, in my practice, I am now seeing young heterosexual women who have contracted the disease as a consequence of sex with bisexual men, and counseling in that group is an entirely different problem because you're now counseling about pregnancy and continued intimacy in the heterosexual setting.

So, I think that the costs are going to be all over the board. I think you would find, though, that most of the experts on the Committee would second your suggestion that the money spent for that kind of counseling now will save us in total dollars later on.

ASSEMBLYMAN FILANTE: Those figures, that's what I'm going to have to have. I can tell you, and I'm sure our Chairman can confirm it, that without that kind of backup, we haven't got a prayer of getting adequate counseling.

CHAIRMAN HART: Thank you, Doctor.

We need to take a break for our stenographer of five minutes max, and we'll be right back.

(Thereupon a brief recess was taken.)

CHAIRMAN HART: We're ready to reconvene, if everyone could please take your seat.

Our next witness is Michael Hennessey. He's Co-Chair of the CALC Subcommittee on Public Safety and Prison Issues. He's the Sheriff of the City and County of San Francisco.

Sheriff, we appreciate your testimony here today, and we apologize for being about an hour late. You're a busy man, and we've taken more of your valuable time than I wanted to. I'm pleased you were able to stay with us.

SHERIFF HENNESSEY: Thank you, Senator. I'm very happy to be here, and the time is well worth it.

In addition to being a co-chairman of the AIDS Leadership Subcommittee on Prison and Public Safety, I'm also on the National Sheriffs Association Advisory Board Regarding AIDS Issues, and I'm also the California State Sheriffs Association representative to the Red Cross Project on Emergency Employee Safety Issues.

In addition to that, as being Sheriff of San Francisco, we've had a considerable amount of experience with AIDS in the correctional facilities and those issues. We've seen literally thousands of people come through our jail system with AIDS. We've had two inmates die in our custody of AIDS. We've had nine Deputy Sheriffs die from AIDS in the past six years. So, in our

Department, we've seen first-hand how this tragedy can affect a public safety agency.

I'm going to be talking briefly about the Committee recommendations, the Subcommittee recommendations, which are -- can generally broken down into two areas. We do see transmission among -- within the inmate population in State prisons and in county jails; and secondly, what are generically worker safety issues for emergency workers.

I'd like to preface my remarks about the worker safety issue and point out that in the entire life of this epidemic, no correctional officer or deputy sheriff working in a county jail has ever acquired AIDS, or has become HIV positive in the course of their professional duties. Of the nine Deputy Sheriffs who died in my Department, all have been gay men who -- there was no claiming it was incurred during the course of their duties.

So, there is a great deal of concern among public safety workers, police officers, correctional officers, deputy sheriffs who work in jails, but I would like to stress that no jail workers anywhere in the United States, or the world that we know of, has ever acquired AIDS in a jail or prison setting in the course of their professional duties.

There are inherent contradictions in enforcing public safety and addressing the prevention of the disease. The two examples, or the three examples that come most readily to mind are: IV drug use and how to do AIDS prevention with IV drug users at a time when the mere possession without prescription of a needle is a crime itself. That creates a contradiction to a

public safety agency who's interested in helping the community do drug prevention, and at the same time, is mandated by law to take away the very tools of disease prevention.

A second one is condoms in a jail or prison institution. As you know, in the State of California consensual sex at a State institution of a jail or a prison is a felony. Therefore, at this point in California, jails and State prisons do not permit condoms to be distributed, even though we acknowledge, professionally acknowledge, that consensual sex does take place, and that that presents a great risk factor for the transmission of AIDS in prisons and jails.

I think San Francisco will be the first jail in the State of California to begin such a project, but we are doing it with the risk of potentially being prosecuted for aiding and abetting a felony.

A third area is the contradiction of medical confidentiality and criminalization of those who are HIV positive or who have AIDS. We are seeing an alarming trend of criminalizing people who are HIV positive by making sentencing enhancements, turning misdemeanors into felonies, creating new crimes for people who are HIV positive.

And at the same time, through particularly Proposition 96, we have done away entirely, or almost entirely, with any sense of confidentiality for anyone in custody. Therefore, a person who is in custody who may be concerned that they are positive, it is not in their best interest in general to seek assistance or seek help, because any sense of confidentiality

will be out the window, first of all. Second of all, it may in fact jeopardize their status with a pending case, or their status in terms of programs and treatments within the jails or prisons themselves.

Specifically, the Subcommittee on Public Safety on workers in custody issues made recommendations in five separate areas, and there are eight separate recommendations. I will go over them very quickly.

First of all, we recommended that there be mandatory staff education. There is no such requirement under State law now for correctional officers or for deputy sheriffs. As a result, education among peace officers is very spotty and is, in fact, woefully inadequate.

We recommend further that a Red Cross model be used. If you're familiar with the "Public Safety Workers and AIDS" booklet put out by the Red Cross and developed through law enforcement, it is an outstanding publication, easily obtained, and it is one which we highly recommend that correctional officers and deputy sheriffs become familiar with.

We also recommend that in adopting guidelines, that the CDC guidelines for infection control be adopted and adhered to by agencies.

CHAIRMAN HART: May I just take a look at that?

SHERIFF HENNESSEY: I brought this for you. You can have it.

We further recommend, in terms of employee education, that -- believe it or not, we recommend that departments adopt a

policy about AIDS and education, and adopt a policy about how to prevent transmission within the agency, and that that procedure provide for a reporting mechanism if a person feels they've been exposed, and that that reporting mechanism be followed with appropriate medical follow-up.

Secondly, we made a recommendation for inmate or prison education. Senator Watson passed a bill, SB 2854, requiring education, but it carried with it no funds to implement it, nor any teeth to implement. Therefore, it is my belief that that law is, at this point, not being implemented.

It may not be necessary to add additional funds. There may be existing training funds through POST* or through the Board of Corrections training programs. But unless there's any -- unless there's a further mandate or teeth, I don't believe that AIDS education will be implemented statewide merely because of the existence of that law.

We also recommend with regard to inmate education that there be a study regarding -- a long-term study regarding the degree of transmission within the jail or prison setting. There are many myths about this, concerns, hysteria about this, and I believe that while it's acknowledged that jails and prisons have a tremendous pool of at-risk individuals, and the environment is there for considerable transmission, the general feeling among people who've studied it so far is that the level of transmission is fairly low, and indeed, no higher than the general public. This needs to be studied further to determine what other steps must be taken to stem the expansion of transmission within a jail or prison.

* Peace Officers Standards and Training (POST)

CHAIRMAN HART: Sheriff.

SHERIFF HENNESSEY: Yes.

ASSEMBLYMAN FILANTE: Are you suggesting in those words, then, that we continue or repeat the policy that was started in terms of surveying anonymously the incidence in State prisons so that we have a record over time?

SHERIFF HENNESSEY: No, I'm not, Assemblyman.

One of our recommendations is regarding testing. And our recommendation of the Committee is that, because of the change of the confidentiality laws, primarily through Proposition 96, that we do not recommend mandatory testing.

ASSEMBLYMAN FILANTE: I said anonymous screening. It was just a survey of the State prisons, as I recall, to get an incidence.

I thought that you were talking about a follow-up, or an idea of how much spread there would be that that represented, basically serial repetitions of that anonymous survey or sampling.

SHERIFF HENNESSEY: To be truthful, I'm not familiar with the anonymous sampling project that the State of California may have, so I don't know how anonymous it is.

With regard to testing, we recommend that prisons and jails do encourage voluntary testing with informed consent; ~~that~~ the results of the test will become -- may become widely known within that jail or prison. Nevertheless, we do feel that voluntary testing for those individuals who want to know should made available.

We also recommended that separate housing for persons who are HIV positive is not necessary. It's not mandatory, in other words. We acknowledge that there is a difference between -- in settings between prisons and jails: jails being more transitory in nature, and prisons being more longer term in nature. Therefore, we said that if separate housing is to be a department policy, that there be concern that there is equal access to programs and services, that staff who are working in the, quote, "noninfected" areas still be educated, because there will be people who are infected there who have just not been identified yet and they are not necessarily free from potential exposure, and that the confidentiality of medical records, to the degree they can be protected, do be protected.

And then finally, we made recommendations with regard to prevention programs, one of which I alluded to at the start, and that is regarding condoms. We recommend that the State should, in some fashion, sanction pilot programs for the distribution of condoms in jails or prisons where necessary. As it is now, there is a great concern that to do such a program would be violating State law, and as a result, no one in the State of California is allowing condoms within a jail or prison. Nevertheless, this is being done in the State of Mississippi; this is being done in the New York City Jail; this is being done in the Philadelphia City Jail; and this is done in the entire State of Vermont in jails and prisons without, at this point, any jeopardizing of safety or security.

In closing, I'd like to say that there are areas for legislation: again, regarding mandatory training through either POST of the Board of Corrections; regarding the funding or further mandating of inmate education; in the area of providing permission -- not to make it mandatory -- but providing permission for limited condom distribution; in the area of ensuring nondiscrimination against people with AIDS or HIV positive within a jail or prisons. And I think there should be provisions for voluntary, anonymous testing, although currently that would take a change in law because Proposition 96 mandates that any knowledge of a positive person be reported.

So, those are areas where I think legislation would be helpful.

CHAIRMAN HART: Thank you very much.

I had a couple of questions, Sheriff, if I could ask. I guess the most fundamental one that I'm interested in, if you could give me some insights, is to the concerns that your officers or officers in general have about exposure, and what those concerns specifically are.

Obviously, they're concerned about becoming infected, and I sort of have this image that if there's some kind of fight or altercation, is that the principal thing that people would be concerned about, or are there other kinds of activities that law enforcement officers are primarily concerned with?

SHERIFF HENNESSEY: Well, at this point, in our Department, because of six years of education, I think the primary areas of concern are exposure to blood or other bodily

fluids, because there still are concerns in that regard, and those would occur at the scene of a crime, or a suicide where there's blood, or in a fight where people are injured and an officer may have an open cut or not. And that is probably the most primary concern.

But then also there's the area of needle sticks, specifically, because deputies, correctional officers, and peace officers who are searching subjects may find needles in the course of their searches, and people are concerned about that type of exposure. That's very hard for them for good searching techniques, and some devices can help.

In other departments, where the education has not been so high, the concern is much greater. There is concern about dirty clothing and laundry; there is concern about the common use of utensils in eating areas; there's a concern about working with coworkers with AIDS. They've not -- other departments have not had the experiences that we've had to learn from, and there is a high level of concern. CPR is a high level of concern; although there now is a State mandate that CPR masks be provided.

I, nevertheless, have been told to my face by peace officers that they would not provide CPR to someone whom they believed had AIDS, even with a mask. So, that still is an area of high concern.

CHAIRMAN HART: So what happens when an officer is the first on the scene in the Castro, you know, or where ever a high AIDS area in San Francisco is today, does that mean that in those instances, some of your officers or most of your officers would not provide CPR?

SHERIFF HENNESSEY: Well, in those situations, Senator, that would be the San Francisco Police Department who would respond, and so I really can't speak on behalf of the San Francisco Police Department, but I do know that many officers in that situation will call for the ambulance rather than provide medical care themselves. And they'll risk the chances of being disciplined or sued for not providing first aid.

CHAIRMAN HART: On the issue of prisoner segregation, we have such a policy here California now. Most other states, as I understand it, do not.

I'm curious as to whether or not in your judgment, with this policy in place, is that likely to trickle down, if you will, to county jails? Is there pressure building? Is there some likelihood that there'll be segregation in county jails as there has been in our State penal institutions?

SHERIFF HENNESSEY: I think the pressure is there, without question. I think that many county jails currently do follow such a practice.

San Francisco does not, and of course, many county jails have had very little -- in the 58 counties, have had very little exposure to the individuals with AIDS at this point, Los Angeles and this county being the two major exceptions.

I don't know exactly what they do in Los Angeles County in that regard. I know in San Francisco, we do not. We simply cannot use our segregated areas, our rare resources, where it's not necessary. We've got to put people in those areas who are predators, or who are escape artists, or who are people who are

vulnerable and present a risk. The mere fact the person's HIV positive does not make them a risk in running a jail or prison.

CHAIRMAN HART: Did you say, though, that you believe there are counties that are segregating currently?

SHERIFF HENNESSEY: Yes, I believe there are.

CHAIRMAN HART: Can you identify those?

SHERIFF HENNESSEY: No, I could find out, but I would not like to say without checking.

CHAIRMAN HART: Getting back to the issue with your officers, do you have any idea, of either the City Police force or your County officers, what percentage have requested and had HIV tests? Is this a fairly rare request that's made by an officer, or in your jurisdiction is it somewhat common?

SHERIFF HENNESSEY: It is not uncommon in San Francisco to have a person file an exposure report. In other words, a report -- either a formal report saying they believe they may have been exposed to HIV in the course of their employment. However, any testing they would request is anonymous. That's between them and their doctor, and the Department would not know unless they volunteered the information. We would not know if they requested the test or not.

CHAIRMAN HART: The last question I had was on Proposition 96. You made a number of references to Proposition 96 in terms of testing programs.

I'm not sure I really understand what you're saying. The implication was that because of Proposition 96, one who was a prisoner would not want to be tested because that would somehow harm them.

SHERIFF HENNESSEY: Yes.

Under Proposition 96, if a medical person or a jail custody person finds out -- and of course, if you're going to your medical person for a test, they find out -- that you're HIV positive, the law says that that medical person is obliged to tell the commander of the facility; and the commander of the facility is obliged in some fashion to let anyone who may be working with this individual know of the person's status.

So, obviously, there is no confidentiality.

The law also, in a backwards fashion, exempts any peace officer from telling -- from any liability of telling any other peace officer the HIV status of anyone who's been in their custody. Under Health and Safety Code 199.99(e), it says that it is a misdemeanor to willfully disclose a person's HIV status, except peace officers who are communicating this to other peace officers and health officials who are communicating this to other health officials.

I think what we will see in the near future is computerized AIDS lists being circulated in the criminal justice system, because it's currently permitted under Proposition 96, and that will be an easy way to communicate from one jurisdiction to another, just like we communicate about outstanding arrest warrants.

CHAIRMAN HART: Thank you very much for your testimony.

Our next witness is Dr. Moses Grossman, who chaired the Subcommittee on Pediatric Issues of CALC, and is Chairman of the San Francisco General Hospital Department of Pediatrics.

Dr. Grossman, I don't know if you were here this morning, but we had some questions about incidence of newborns and AIDS, and the general consensus was that in many of our public facilities in California now, particularly in urban settings, that as many as 25 percent of babies are born with some drug-related problems. When we asked one of the witnesses to go on a little bit in greater detail, he suggested that you might be the person to amplify or comment on that.

I just throw that out to you if you care to say anything about that particular issue. I think the Members of the Committee would be particularly interested.

DR. GROSSMAN: Yes, I was here when Dr. Werdegar testified. It was towards the end of his testimony, and I heard some if not all of the questions that were addressed.

Senator Hart, Dr. Filante, I chaired the Committee on Pediatrics, as you know, which is why I'm here. And the reason I was appointed to chair the Committee was because for the previous five years, I chaired the Committee in San Francisco, devised a plan for perinatal and pediatric AIDS and issued guidelines. So, the Board recommended that I be appointed to the State Committee. We had some meetings and presented recommendations.

What I thought I'd do today is highlight those recommendations concerning children for you, and I will go into the area that you mentioned.

Before I do, I might just give you a few elementary statistics about pediatrics and women in California. We're in a different situation with children than we are with adults.

There's much greater opportunity to exercise prevention because not as many are infected yet as far as we can tell, so prevention is even more important in dealing with pediatric AIDS than it is in adult AIDS, which has spread so much in our State.

The number of women infected in the State is unknown, but the number of AIDS patients is 468 as of January 1, 1989. That's 3 percent of the total reported AIDS patients, which is not very much if you look at the population distribution.

CHAIRMAN HART: Four hundred sixty-eight is what?

DR. GROSSMAN: Number of AIDS women -- not HIV infected; AIDS women.

In terms of positives in pregnant women, there was some question raised about that earlier today. As you know, all states are doing a survey of [umbilical] cord bloods. The first month of the California survey is done. We're doing a three-month sample. When the three months are done, we'll know by ZIP Code the exact distribution of positives.

In the first month's survey, which is 4200 births, I believe, California is 8.3 per 10,000. That's much less than I anticipated. That's compared to 21 per 10,000 in Massachusetts, and 74 per 10,000 in New York.

I think we'll also find that there are pockets when they distribute it by ZIP Code. That's a lesser incidence than I expected.

Not surprisingly, looking at the infections, Black women are disproportionately represented throughout the State. I think that's pretty well known.

A few other facts. If the mother is positive at the present time, the evidence is that 30 or 40 percent of the children she has will become infected. Which 30 or 40 percent is not clear.

Numbers for California of AIDS in the State at the present time, as of January 1, is 108. Of these, 42 percent infected through transfusion, 47 percent perinatally, 8 percent in the fluid. This is different from national data, where 75 percent are perinatal. I think California data will resemble national data very soon because they're no longer getting infected by infected blood. That's been controlled.

Nobody knows the number of HIV positive children in California, and there's no way to find out. A group of particular interest, and some samplings may be done soon, are the adolescents, because the thought is that it's the high-risk adolescents who get infected, who then develop the disease and die. But no data are available on that in our State.

The other fact which underlies many of the issues in pediatrics is that when the baby is born, it is not immediately clear, and often not clear for nine, twelve, sixteen months, whether the child is infected or not. So, during that period of time, the child is in limbo, so to speak, in terms of knowing whether the baby has just been exposed or is infected. It presents a variety of special both medical and social problems in dealing with that baby.

So much for the facts. Now, I broke down the Committee recommendations to three areas, as you see in the small paper I

distributed. Even though a lot has been said about education, I laid a few more things about education because we discussed it a great deal in our committee. It is the most important thing to do. We certainly, as well as every other committee of the Leadership group, recommended that school education be mandated, school education be effective, and it be throughout the State.

Initial comments that were made in our committee is that neither the legislative branch -- the legislative branch attempted to do something, not successfully -- nor the executive branch have really exercised strong leadership in the State on how to do this, that it should be done. We should know how many schools are teaching, how many are not teaching. And you might consider requiring a report to the Legislature on what is happening in our schools, because I don't think that we know.

We also thought that if HIV related items were added to the standardized school tests, it would give us some idea about how much children in fact know about HIV infections, and this is something that could be done through the State Department of Education. We thought it's not enough to talk about children who are in school. What we're doing in this area is not reaching the highest risk group, out-of-school teens and homeless youth. So, I think we need to devise programs for those who are clearly not going to go through school, which are going to be in some way peer-driven, or peer-oriented, to give a message to the children and youth who are not in school.

Finally, one of the highest risk groups is incarcerated. We want to make sure that youth who wind up in juvenile halls,

whether short term or long term, use that time to provide the opportunity to at least start their education. I think much remains to be done to flesh out these recommendations, but we thought that really was a most important issue.

The second issue is prevention of -- the neonate prevention of children being born with HIV infection. We thought there should be risk assessment in prevention in all childbearing women. That's education of all women, essentially, to say that this is one of the problems in our society; if they're thinking about having children, they might think about their own risks, and they might think about getting tested before they become pregnant so they can become informed, give it adequate thought.

Our committee was divided, and I think it's an issue on which our society is divided, on whether we should test all pregnant women routinely. And I don't mean mandated; I mean routinely. If you're pregnant, you come to the doctor. He says, "Now we'll test you for syphilis, or we'll test you for this, and we'll test you for HIV, unless you object, of course." Rather than singling out -- with informed consent, rather than singling out what we do know may be high-risk women. This is done at the present time in women who are perceived to be high risk. Usually the way this is done is to have the woman herself determine whether she thinks she's high risk, and then counsel those women to be tested to make sure that Hepatitis B, where transmission is similar to HIV, testing high-risk groups does not work. You really need to do routine testing.

The committee was not unanimous on this issue. Some wanted to wait for the results of the California cord blood testing to see what the overall risk in the State really was. We thought that all HIV infected pregnant women deserved really thorough reproductive counseling in terms of telling them what is likely to happen, what the risks are, if the baby will be infected, what the future of an infected baby is, and what their own options were with regard to the pregnancy.

We thought we needed standards for breast milk banks. That probably could be done --

ASSEMBLYMAN FILANTE: Dr. Grossman, before you move off testing and counseling, I was discussing this at a recent College of OB/GYN seminar, and the counseling problem is, as we've described before, it's a very large problem, extensive. So, there were no answers.

The problem that came up because of differences was in the routine testing as we described it. It is a good idea to diffuse the issue and so forth.

The question of accuracy, as was alluded to earlier today, and the question of cost. We have very grossly different -- a great spectrum of cost differentials, from as low as a couple of dollars, literally, in the Armed Forces, to $50, $60, $75.

What recommendations does the committee make? Obviously what we need to do is universal availability, however it's done, for routine testing, and reliability, a designated lab, and cost.

What was the response?

DR. GROSSMAN: We had a good deal of discussion. It's based on that, based on cost more than anything else. More cost than philosophy. The committee was divided. Several obstetricians on the committee -- we were both pediatricians and obstetricians -- several obstetricians on the committee said that you just cannot continue raising the cost of pregnancy. And this would be just another addition which is not warranted, in their opinions, except in high-risk women.

I think that the cost did play a part in their thoughts. I think that if it was possible to get it, for example, the way the Armed Forces do it, reliably and cheaply, it would not eliminate but decrease the issue of cost.

ASSEMBLYMAN FILANTE: Actually, it does away with the issue of cost. A $500 item -- I don't know what a pregnancy costs nowadays, but --

DR. GROSSMAN: If it were $10, but it's probably closer to 2,000.

ASSEMBLYMAN FILANTE: It was $150 when I was delivering babies.

But anyway, if it's anything over 500 bucks -- take the Armed Forces mode, or any kind reliability and volume, it's under $10, $8, or what have you. So, it's just negligible; it's nonexistent.

So, the cost question disappears if we have the standards, whether it be a designated -- I hate to mandate a lab, but certainly we could say it should cost no more than that.

That's what I would hope the committee or the Legislature would, you know, kind of look to implement.

DR. GROSSMAN: The other issue, of course, is one of discrimination, because if we really have strong, nondiscrimination laws, people wouldn't be quite as anxious about will this test get out. That goes across everything because of the number of anecdotal things were stated in the committee about small communities with an obstetrician, and his secretary will tell everybody in town those issues on AIDS.

ASSEMBLYMAN FILANTE: The former secretary.

DR. GROSSMAN: I might add before I get off the newborn issue, the question you asked me about crack.

In our own institution, San Francisco General, today 17 percent of all babies are born -- are babies of crack using mothers. They are a particular problem in our society over and above HIV because many of these babies are premature, and the cost of raising them is enormous. Using crack brings on labor in many mothers. In fact, when they're tired of pregnancy, they use crack just to have premature births. Enormous costs not only to the immediate care of the baby, but many of these babies are brain damaged and represent future problems.

The way it relates to HIV is that, as is not surprising, women earn money for crack by prostitution, and in so doing, they expose themselves to the risk of HIV.

I don't think that anybody knows, at least I certainly don't know, what the incidence is in crack using women as opposed to other women. Theoretically at least, that is the connection.

The concern is,with the number of crack babies, there will be an increased number HIV babies among that group. I haven't seen any figures or data in that regard.

CHAIRMAN HART: I'm very ignorant, Doctor, in this area.

If you have a crack mother, does that mean you will have an addicted crack baby?

DR. GROSSMAN: Yes, if you have a crack mother who's been using crack during pregnancy, things are going to happen: (a) the baby only suffers some damage in utero because of the effect of the crack on the cardiovascular system of the mother and the baby; (b) the baby's almost guaranteed to come early, prematurely, and carries -- over and above costs -- carries health risks and neurological risks to the baby in the future.

The baby will be addicted, but that is the least of its problems. If that's all there is, then it's just a seven or nine day cost of caring for the baby, who is a very unhappy, tremulous baby, cries all the time. And if that was all there was, it wouldn't be such a big problem.

CHAIRMAN HART: Meaning that the addiction is eliminated after that seven or nine day period?

DR. GROSSMAN: Yes. Addiction, in and of itself, is eliminated. But the prematurity, a stroke of the baby, and some do suffer stroke that leaves damage.

CHAIRMAN HART: I wanted to also ask as it relates to AIDS babies, is a baby who has AIDS different in terms of the nature and duration of the illness in comparison to an adult who has AIDS?

DR. GROSSMAN: There is a spread, but they are different because the incubation period in a typical baby who was perinatally transmitted is only nine months. The majority of the babies who are infected will begin to have symptoms at nine months.

You realize that that's very different from the six, seven, eight years that adults will have before they become sick. There are exceptions to this because we've seen a baby who went six years, but that's a distinct exception. Most babies who develop symptoms at nine months if they are infected by two, two-and-a-half years.

CHAIRMAN HART: The normal life expectancy of an adult who has full-blown AIDS, as I understand it, is roughly two years, and you're saying that for a baby it's about the same?

DR. GROSSMAN: About the same.

CHAIRMAN HART: Thank you.

DR. GROSSMAN: To go on to other issues concerning with children themselves, one of the steps that's been taken in our State, a forward step, administrative -- rather, legislative, it was a legislative step. One of the Assemblywomen introduced legislation to have California Children's Services to provide -- to include within their service component all children who are HIV positive. That's a distinctly positive step forward because now every child who's HIV positive has the medical coverage for doing the tests and following the baby.

What they do not yet have, either this group or the AIDS group, is for California Children's Services to provide some type

of social services and home support, which is needed for adults also, but it's particularly needed for children because, as you recognize, many mothers are ill, many mothers are nonfunctional, some mothers are dead. So, every child who's infected, almost without exception, needs serious social and psychiatric, developmental support. So, we hope that through budget efforts or otherwise, California Children's Services could provide that component as well.

Some uniform recommendations for the State, and that probably is not a legislative issue, are needed for day care arrangements for these children. There is no consensus yet about how that could be done best. But again, for the same reasons I already mentioned, these children need infant stimulation, they need day care. They're not all going to be infected. Sixty percent are not going to be infected, so in the meantime, we want to be sure that they develop adequately, and yet the home environment is often deficient. So, we need to work out some way in which they could benefit by day care programs and infant stimulation programs.

It's very important for those who are going to foster care to provide the foster homes. San Francisco and Los Angeles both have demonstrated that can be done by special recruiting, by special support for foster parents, and frankly, by incentive payments.

I talked to Jim Brown, who was -- testified before our committee, in fact was part of our committee, was part of social services. He felt that cost-wise, the number of these children

compared to the overall number of foster children in California is so small that the overall fiscal impact is not going to be felt. It's more a policy issue than a true fiscal issue.

Nevertheless, when you're asking somebody to take one of these children in their home, we need to give them something in return, whether it be more support, more money, or both. San Francisco does both. We've been fortunate in being able to get high-class foster parents to take these children on. New York has not been. Of course, they have much greater numbers to deal with than we do.

As the number of adolescents increases in our State, and we don't know how many adolescents there will be -- we had a meeting of people taking care of adolescents in San Francisco, just anecdotally they came up with maybe 14-18 known adolescents, aged around 15-18, 15-16, who are HIV positive, many of them homeless. I think there are probably some residential arrangements in larger areas in the State, like San Francisco or Los Angeles, where some program will be necessary for adolescents with this disease.

One other particular issue, which goes right across all age groups, but I'll highlight pediatric issues because that's the one we dealt with, I'm not sure if you're familiar with the fact that if a child is on a protocol, or an adult for that matter, is on a protocol which includes investigational drugs, Medi-Cal will not pick up the fiscal tab if you're ~~any~~ 2 using any investigational drugs at all.

Children are, essentially, all of them are on investigational drugs. Investigational drugs are drugs not yet completely approved.

CHAIRMAN HART: It's like an experimental drug?

DR. GROSSMAN: Experimental drugs. And because AIDS is so new, and because we're bringing in newer and newer drugs, most drugs are investigational. And Medi-Cal excludes all patients from payment if you're using experimental drugs.

With children there's a particular impact because essentially they're all on experimental drugs or you wouldn't be treating them at all.

CHAIRMAN HART: Don't they --

DR. GROSSMAN: With children, everything's experimental.

CHAIRMAN HART: Again, I don't know much about this, but I would assume that the manufacturer of the drug would pick up the cost because they need to verify that their drug works. If the investigation or experiment proves efficacious, then they're going to make a lot of money. So, don't they underwrite the --

DR. GROSSMAN: That's the way it's been done traditionally, and that's the reason that Medi-Cal excludes them.

Manufacturers, however, will not underwrite hospitalization, will not underwrite expensive tests. They will pay for the drugs, but that's as far as that goes.

So, there is a significant fiscal impact on those providers, particularly hospital providers, who participate in these programs. That's why we highlighted it.

Finally, when I testified to your Committee before, a year or two ago, there was a very serious -- a year-and-a-half ago -- there was a very serious problem in communication between obstetricians and pediatricians, and how to pass information along. The bill that passed allowing health professionals to exchange information has helped a great deal in regard to those communications.

The issue still remains about how we go about testing a baby who's going to foster care so we can let the foster parents know. It's considered proper if foster parents are going to be parents in locum, so to speak, that they should have similar information that parents would have. It's become pretty universal among foster parents, if they're going to take a high-risk baby, to be able to tell them whether the baby is or is not HIV positive. It's confidential to them, but nevertheless, they find out.

The way we can do this today is by going to the judge of the Juvenile Court, and then -- the procedure was devised in San Francisco by my committee, of going to the judge of the Juvenile Court, who then reviews the evidence, and then orders -- issues an order that such testing could be done, and would be confidential, and who would be allowed to see the result. In San Francisco, it's become pretty routine; it is not a burden.

Nevertheless, there are many juvenile court justices all around the State; they change all the time. If you look at it statewide, there's a considerable amount. Last year, a bill was introduced, which didn't pass and which I testified in favor of,

allowing any two physicians who feel that this test is medically indicated, if the indication here is the one I told you, to order the test to be done. But that bill didn't pass. It was controversial, and I understand why it was controversial.

Nevertheless, I still think we need some mechanism, which is probably legislative, which wouldn't be quite as burdensome as the one we have now.

Those are our principle recommendations that we submitted to the Leadership Committee. Thank you for the opportunity to tell you about them.

CHAIRMAN HART: Thank you, Dr. Grossman, very much.

Our next witness is Dr. Carl Smith, who's another Co-Chair -- we've got a lot of co-chairs, just like the Legislature -- of the CALC Subcommittee on HIV Antibody Testing and Reporting Issues. He's the Health Officer of Alameda County Health Systems Agency, and Chairman of the Epidemiology and Disease Control Subcommittee of the Health Officers' Association of California.

DR. SMITH: Thank you, Senator Hart, Dr. Filante.

Dr. Conant touched on some of the issues we covered in our committee, and I hope I won't go much farther on those.

The interesting thing in our committee was that it was a group of quite technical people who were -- laboratories were highly represented on the committee. And the first issue that came up was the issue of discrimination. And I was sort of startled at this. I thought we would quickly get into the esoterics of various kinds of lab testing. But the issue over

rode everything. It was the recognition that before you can talk about testing or reporting, you have to have a system that will guarantee confidentiality. You've heard this several times before, but I thought it was interesting to see it come up in the context of this committee.

Dr. Conant pointed out the problem of the inconclusive test. I think that what became clear in the discussions about this was, there does not need to be an inconclusive test if you do the adequate follow-up of a single test with confirmatory tests and backup tests, and follow a person over time. You can usually -- not usually, but always -- can put that person in -- either classify them as a negative or a positive for HIV. So, there's no need to have people sort of languish in this indeterminate sort of limbo which sometimes happens. So, a lot of emphasis in this committee was to determine ways in which you could really be certain that testing was conducted in such a way to keep people from being left in the indeterminate status.

You asked about some of the problems about this, and one of them is that -- one of the issues is who has the responsibility to really figure out, to take all the steps that are necessary to resolve an indeterminate test. If the tests are performed in a public health laboratory, automatically confirming tests are done. If they're done in a private laboratory, confirming tests may or may not be done.

One of the barriers here is the cost. When the tests are ordered, it may be difficult to return and order backup tests for that person because the follow-up test, then, is more

expensive than the initial screening. So, one of the things we talked a lot about, as a sort of footnote on this, but it's how you begin to develop a fee structure for laboratory tests, which includes as part of it the automatic development of the automatic payment for the follow-up testing.

The other part of it is to be certain that the evaluation is done in an accredited State Department of Health Services' laboratory.

So, this was an issue that took up a lot of the discussion in the group.

A related issue had to do with surrogate testing. That is, testing for signs of HIV disease other than HIV antibodies. And the committee's recommendation was that tests for markers to HIV, other than antibodies, should be restricted to the evaluation of known infected individuals in research studies until these tests are licensed for use by the FDA. So, we tried to make a distinction, tried to limit the use.

We noted that screening tests of infectious diseases are not required for evaluation of tissues, such as organs, semen, bone from living donors, and we wanted to be certain that this hole is plugged.

Another thing that the committee was interested in was in looking back at the current law which requires a 60-day waiting period for blood donors after -- for notification of results after tested. As you recall, this was built in when HIV antibody testing was first initiated, the idea being we didn't want people to go to blood donor sites in order to determine what

their HIV status was, so that there was this pause built in. We have a good anonymous testing test site system now, and really, we should begin to notify people immediately after blood donation if they do have HIV antibodies, or if their tests are indeterminate so that, again, they can be evaluated and placed in either the positive or negative category.

We noted that the impact of HIV disease in racial and ethnic minority communities is growing. I'm sure you've heard this several times before, too. But again, the issue here of making testing readily available to the groups which will be -- we perceive as being at increasing risk in the coming years, and to be certain that testing services are made more available to minority groups.

Dr. Conant mentioned the position he took on the so-called recalcitrant patient.

And the last recommendation was that we noted that there's -- this is a sort of a process thing, but that there's a significant lack of microbiologists in this State. And as the demand for laboratory work, particularly associated with HIV testing increases, we are going to have to implement much better training programs in order to increase the pool of available microbiologists.

So, those were the issues that our committee dealt with. Again, I was interested and rather startled at the breadth of the concern the committee had. We were able to get beyond the issues of just technicalities of testing.

Thank you.

CHAIRMAN HART: I had one question I wanted to ask.

The ongoing controversy, at least in the Legislature among some, is as to the advisability of mandatory reporting for HIV positive results.

Did this subcommittee, or your own work in this, health officers, get involved in this?

DR. SMITH: Actually, the subcommittee felt -- we didn't -- the subcommittee did not take a position on this. Their rationale for this was that testing should be -- reporting, mandatory reporting should be considered in the context of a broader program or broader approach. If you're going to discuss mandatory reporting, what are your goals, and what are your objectives, and what is the breadth of the particular strategy that you're working on?

The Conference of Local Health Officers has debated this subject a long time, for several years. And our current position on that is that if -- there is value to reporting HIV antibody positivity to local health officers if three conditions or three things are in place. One is that there's adequate protection against discrimination. The second is that anonymous test sites are as readily and easily available as they are now, and continue to be available. And the third is that there are treatment and education resources available to which you can refer people once they are report to you. And if those three conditions are met, we believe that it would be profitable to make HIV antibody status reportable to local health officers.

CHAIRMAN HART: So, tell me again how that would work as it relates to anonymous testing? Anonymous testing, by definition, is anonymous. Sharing of these results --

DR. SMITH: The way anonymous testing works, there's no way in which those data can be reported to the local health officers, because there's never a name associated with the test results. It's just a numerical match.

CHAIRMAN HART: So, under those conditions, there would be a significant number of people who would be HIV positive, who went through anonymous testing, and that information would not become known.

DR. SMITH: That's correct. The real concern there is, if you make it -- if you make HIV antibody status reportable, people will stop getting tested. And that's an ongoing concern, and that's why we stress the need for antidiscrimination, specific antidiscrimination.

CHAIRMAN HART: But if you had antidiscrimination, and you had support services, once you had that identification you would still want to leave that option because the fear would be that some people would feel that discrimination protections wouldn't prevail.

DR. SMITH: Yes, exactly.

CHAIRMAN HART: Dr. Filante.

ASSEMBLYMAN FILANTE: Back to a question we talked about before from your standpoint on testing, just as you stated it here, because we talked about the need to counsel all the HIV positives, and you mentioned that.

I'm still looking for additional ways to get more people tested. This set of criteria would help; we don't have it yet, but it would help. And I think general public education helps.

One of the things you bring to mind is the problem with time of exposure, and the need to test early, or young, or whatever it might be, particularly with sex partners. And that the incidence of HIV conversion increases every year with the contact with an HIV positive person; it doesn't necessarily take one. So that you've got a year or two years or three years, but if you delay it inordinately, that's when the real problems come on.

I'm always looking for ways to compress this and get down, and what you just talked about for local health officers would help, but can you give me any other suggestions as to how we can diffuse and broaden this?

DR. SMITH: I think that the emphasis on what you want to get from reporting is really people into treatment programs so they can identify the illness early and manage their disease, and take responsible measures to prevent transmission.

I don't think it's going to be the basis for patient -- I mean, educating people about how to break the chain of transmission. I think it'll be helpful.

I think that the primary thing we're going to have to do is continue to educate everyone in the community about AIDS, or how you avoid transmission of the disease.

I think knowing your HIV status is an enhancement, but I think the basic thing is going to have to be the educational message which we direct to the entire community.

I don't think that we're going to get an awful lot of benefit from having -- in terms of educating people and modifying their behavior -- from reporting of the disease.

ASSEMBLYMAN FILANTE: Not so much from the reporting but from the testing, along with the education of the community, along with counseling.

DR. SMITH: I missed your point.

ASSEMBLYMAN FILANTE: My problem as a physician is the increased spread of the disease from HIV positives who don't know it in sexual relationships, because the figures that I've seen show the increasing incidence of the disease in the partner -- one year, two years, three years -- after the person becomes HIV positive. And if I had some better way -- you've touched on part of it; in other words, antidiscrimination -- but some better way to have the testing done, along with counseling and education, and more of these people be tested early, then I could help stop the disease from spreading. That's all.

DR. SMITH: Yes, the other part of that is -- which doesn't really affect you as a practitioner; doesn't help you too much -- but what does help, I think, is the presence of the anonymous test site, where people are encouraged to determine their own status. Hopefully, with the counseling that goes around the anonymous test site, they'll take the steps necessary to avoid transmission.

ASSEMBLYMAN FILANTE: Test sites exist. They've been very helpful here, but they're not enough. I need to do more without mandating testing, which we know doesn't work.

So, that's why I thought perhaps you could --

DR. SMITH: I don't have a bright idea on that.

I think, you know, what I say is lots more anonymous testing and the protections from confidential -- around confidential testing.

ASSEMBLYMAN FILANTE: Do you see the schools or the universities as a place where maybe more could be done? I know that's a select population at the university.

But I think whatever we can do to make it more -- I'm sorry to say this -- matter of fact because now we've gotten to the point where it isn't just one population group; that should help. It's not just one racial group, and that will help.

You know, it just needs to be a part of everybody's knowledge, and that's the job of being a responsible person.

And I think with, for example, the program we've talked about here, of childbearing women, that's important. Because I don't care who you are, as a childbearing woman you care about your infant or your potential infant. That's an automatic selection against irresponsible behavior.

I'm looking for things, like maybe your education groups, like universities, would be a start, the university students.

DR. SMITH: You have to be a little careful when you -- you don't want to make testing -- like, say, take a university. You've got a group of very sexually active people. You don't want to have the cornerstone of your efforts there be testing, because otherwise you give sort of the assumption that if you're HIV negative, it's okay and you don't have to worry about --

ASSEMBLYMAN FILANTE: I think everybody in the room here knows that testing is not the cornerstone. We're talking about the rest of this, so that testing can be a part of, you know, the reasonable behavior in helping to stop the spread of the disease. That's all.

CHAIRMAN HART: Thank you, Dr. Smith.

We're going to take a short break for our stenographer, then we'll return with Delia Alvarez as our next witness.

(Thereupon a brief recess was taken.)

MS. ALVAREZ: I'm Delia Alvarez, Director of the Santa Clara County Health Department. I'm also the Co-Chair of the Ethnic Minority Subcommittee of the California AIDS Leadership Committee.

What I want to do today is just highlight the major problems and recommendations that have come out of the Minority Subcommittee.

First, I just wanted to give some statistical information. I hope I'm not repeating what's been said earlier in the day, but I also want to just show what the alarming impact is on the minority communities throughout the State of California.

[Ms. Alvarez presents first slide]

Clearly, HIV infections have been a very severe problem nationwide within the ethnic minority communities. On a nationwide basis, the statistics do look different because the racial and ethnic minorities, who are approximately about 22 percent of the population, and yet we're about 42 percent of the AIDS cases reported nationwide.

In looking at California statistics, which we did in the subcommittee, the statistics do not reflect the same national trend, but there is an alarming increasing trend to the minorities being a disproportionate share of the number of AIDS cases.

[Second Slide]

I'm going to go through this very quickly because everyone's very tired, and it's been a really long day.

What I really wanted to show here is that as of December of 1988, there were over 17,000 cases reported to the California AIDS Registry. Clearly, that the Whites account for the greatest percentage; however, the data indicates that there is a rapidly increasing problem among the racial ethnic minorities population, particularly the Blacks and Hispanics and Asians. And if you'll look at the far left, you'll see in the column that is in total black there, it shows in the Black population the percentage of AIDS cases is certainly disproportionate according to the percentage of the Black population in the State.

Given the Hispanic community, however, Hispanics really being about 19 percent of the State population, the number of AIDS cases in the Hispanic community is between 11-12 percent.

And then you see in the Asian population, a little over 6 percent of the population, the number of AIDS cases goes about 2 percent.

I should point out that in 1988, Blacks accounted for the highest proportion of new AIDS cases that were reported throughout this State.

[Third Slide]

I just wanted to show this, because again, I wanted to show in graphic form some of the statistics that have come out of the introductory part of Section 6 of the Minority Subcommittee report.

If you really take a look, starting from about '84, you do have variations typical of statistical reporting, but if you take a look, particularly '86, '87, '88, if you run a pencil through there of the percentage of AIDS cases by ethnic groups, you could just see the escalating numbers and the trends, and it's continuing to go up. That's what I indicated earlier, that even though total minority population in the State of California is not a disproportionate amount according to the number of the minorities in the State -- except for the Blacks, this is different -- but we are seeing a tremendous growing trend, particularly among the Hispanic community, where we are certainly going to the point where the total minority population in the State will be a disproportionate number according to the number of AIDS cases.

[Final Slide]

Given some of these statistics, the Minority Subcommittee -- and what I want to say at this point is that it was quite a challenge to bring together the Minority Subcommittee. As a member of the California AIDS Leadership Committee, it was my responsibility to ask someone to be a co-chair, who was Dr. Wilbert Jordon out of Los Angeles, and we put together a subcommittee that represented a number of

minorities, ethnic minorities, throughout the State, and represented not only urban communities but the agricultural communities. And it was really, I think, a very constructive workable group. I've had a long experience working with minority groups, and I was really quite pleased that we were able to work so well together, and for everyone to really make a tremendous effort to really highlight what we thought were the minority issues that should be reflected in the plan.

I should clarify that there are minority issues identified in other elements of the plan. I think Dr. Werdegar talked about it this morning, and some of the other co-chairs have talked about the impact on minority communities.

What this committee tried to do was to make sure that there were not minority issues that were falling through the cracks and were not identified anywhere in the plan. So, as we reviewed the other plan elements, we wanted to avoid a redundancy, but we also wanted to highlight some specific minority issues that needed to be highlighted in the State plan.

The first one, of course -- and I'm really going to be paraphrasing this, because again, I've promised to summarize -- the first one is a problem that -- and I know it's not that clear, or at least my contacts aren't that clear, or I'm just getting older, or whatever -- but it's clear the HIV disease is escalating in the ethnic communities, as I just showed in the chart.

A recommendation that came out of the group was that the public and the private sector -- and as a Director of Public

Health, I think that's very important, that we in local government and State government work very closely with the private agencies, the community agencies, coalitions, et cetera, and work very closely with the ethnic minority communities and their organizations to take the lead in carrying out services, doing the plan, the development, the implementation, getting into research. That minority perspective certainly needs to be brought into the whole AIDS war. Clearly, the minority groups need a lot of help.

Another problem was the difficulty in translating materials. There are a lot of materials that are available, say, in Spanish, Chinese, et cetera. But what was discussed considerably in the committee was that you have so many dialects, so many special community needs, say, from the urban to the agricultural, that there's a constant need by community and groups, along with the health departments, to have relevant, culturally-related materials.

Looking at the Asian community, on which I'll talk more later, there are a lot of dialects that have to be taken into consideration. A lot more work has to be done as far as translating the materials.

The next problem, the health workers and other related workers, need to have greater education regarding the cultural factors in the ethnic and racial populations. We spent a lot of time discussing the fact that, as a Director of Public Health, I see it since I have responsibility working with paramedic services, et cetera. And we constantly have to be aware of doing

the training, the cultural training, of the health workers within the health care system. So, this was a high priority area for those on the committee, that the health people working in the health industry really need to receive a lot more training. It has to be constant, and it has to be constantly increased in order for them to be aware of the cultural differences, et cetera, regarding minority communities.

The next problem, methods of reporting the disease in the Asian-Pacific Islanders, does not allow for adequate planning. A great deal of discussion was centered around the fact that there are so many groups that fall into the category of Asians, and they're put together into one lump sum, and that presents a lot of problems because a lot of the different minority issues are not addressed within the Asian communities: the differences between those who are Filipino, Chinese, et cetera, Japanese. So that the recommendation was made that the State Health Department really improve, greatly improve, their disease surveillance and reporting procedures for these groups.

Next we go on to the AIDS HIV data on the native American Indians is inaccurate. There was very strong feeling on this subject area from those representing the Indian community. The Indian reporting of those who really are native Americans is considered to be quite serious, and the recommendation was made that the State Health Department needs to provide greater training to those who do the reporting to make sure that there is valid reporting. The example was given that you will have some native Americans that really have Spanish surnames, and they

could fall under the Hispanic category and not appropriate fall into the native American category. And there's just a lot of difficulty with self-identification.

Another and the last, again, this is a summary; really a summary of the numbers of issues that were discussed. They're not in priority order, by the way.

The mandatory HIV antibody test requirements for applicants to the Immigration and Naturalization Services has created considerable confusion among the applicants and the civil surgeons. The recommendation coming out of the committee is that the civil surgeons for the INS should follow the California standards for confirming tests, and informing, and counseling applicants. I know within Santa Clara County alone, we've had some horror stories of how applicants for amnesty have gone to a doctor designated as a civil surgeon. They have found out they're HIV positive; they have not received any counseling; there's been no follow up. They ended up at the Health Department being terribly scared, afraid, and these are the very individuals who will really go underground and will not even continue the application procedures.

A lot more training -- a lot of training has to be done with the civil surgeons so they can deal with this issue more appropriately.

That, very briefly, is what's been highlighted under that Section 6 of the State health plan as to what are some of the critical problems identified by the committee and some of the recommendations.

Clearly, a lot has to be done, as was mentioned earlier, about how we're going to address the specific issues. There are many minority and cultural issues that have to be addressed. There are, again, within the other plan elements, a lot more said about the impact on the minority communities. But clearly all of us, and I speak again as the Director of Public Health, those in the public sector have to work with the communities and work in a partnership effort so that we can really decide where we're going to spread our priorities, and our energy, and time, and reallocation of resources so that we can really address this tremendous impact on the minority communities.

If we don't, and we look at it only from my own Department, the prevention efforts are really critical as we work with the minority communities, because as we see the trends, we're clearly going to be having a disproportionate impact on the minority communities, as has happened nationwide.

I promised I was going to be real short, and I think that was short. I left out some things.

Thank you.

CHAIRMAN HART: Thank you.

Let me just ask, the INS testing, is that going on now?

MS. ALVAREZ: It's still going on, not as much as before. But, we're still trying to do some of the follow-up, trying to get to some of the applicants. I don't have the specific numbers.

CHAIRMAN HART: Thank you very much for your presentation and the specificity of your recommendations. It was very helpful.

Our next witness is Brian Dobrow, President of the California Association of AIDS Agencies.

Welcome.

MR. DOBROW: Thank you, Senator Hart. We appreciate this opportunity to provide comments on the draft plan and hope that these will be constructive.

First of all, I'd like to commend the California AIDS Leadership Committee and the Office of AIDS for the development of what we look on as a meaningful policy document. It's a statement of policies, and I hope it will serve as a basis for further implementation, for further allocation of resources in the State.

But I hasten to point out to you that as a community health planner, I have to second the comments that came from Pat Franks earlier. I don't look at this as a strategic or an operational plan. It is a good statement of policies. It lays things out very well. But in terms of having specific objectives, of goals, of an action plan, of even recommendations for -- or referrals as to who will implement activities and what they might cost, and how we might evaluate the progress later on, it doesn't do it. It falls short in that respect, and I hope in latter or later activities in the further development of the plan, these will be elaborated on and added to.

The Association actually had some specific comments on the contents of the plan document. These are not meant to criticize what is currently being stated, but it's to point out some of the omissions and, perhaps, some of the areas that might be considered for further elaboration.

I'm editing these comments as I go along so that we're not going to spend all afternoon listening to them.

First, although we recognize that the document was developed in compliance with a legislative mandate, and will require the Governor's approval in order to be implemented, there are a number of recommendations that appear to have been watered down somewhat, that they have been made politically acceptable in order to obtain gubernatorial approval.

That is understandable, but I think that we have come to a point where we need to say what needs to be said. We need to take the recommendations of experts. We need to take the recommendations of departments, whether it's State departments or local health departments, and get them implemented. If they're controversial, they're controversial. They need to be stated flat out.

We are no longer at the point where we can afford to allow specific recommendations to be referred for further study. There has been study after study after study, and it's time to start implementing.

A second point, although the document does refer to the existence of community-based organizations, at least in some sections, it doesn't truly recognize the fact that there is an essential network of both public and private agencies out in the community working to combat the entire HIV epidemic throughout the State. The State Office of AIDS and other State departments are supported by county health departments and those community-based organizations throughout the State, in both their AIDS education and their service programs.

In reality, much of the innovation in education and prevention is being done by local health departments, is being done by community-based organizations in Los Angeles, San Francisco, Sacramento -- you name the community. A lot of things that are quite innovative are going on in Sonoma County. These don't tend to be recognized.

We believe that the document should, somewhere along the line, credit the effectiveness of those efforts, and should spell out ways and means of strengthening and enhancing them.

In addition, there needs to be a recognition that additional resources need to be provided to support the further development of cooperative arrangements on a local level. From our perspective, the cooperative efforts of a comprehensive network of agencies, public and private agencies, is an essential element in the statewide battle against HIV infection.

Also, if there's going to be successful planning, the State plan has to lay out principles for the development and implementation of local plans in addition to establishing some clear-cut goals that can be addressed in response to requests for proposals from the State Office of AIDS.

Third, the draft document, as Dr. Conant pointed out and we also identified, does not address the issue of AIDS discrimination. We're concerned about this omission and feel that it has to be immediately addressed in order to avoid further instances of discrimination against HIV infected individuals.

The fourth and final point that I will deal with at this point is that we believe the AIDS Leadership Committee plays a

pivotal role in the determination of State policies on AIDS. We find it difficult to accept the fact that the California Association of AIDS Agencies, as one of the principle agencies, functioning on a statewide basis, specifically focused on AIDS, is not involved in those discussions and has not been.

We're urging that specific consideration be given to the appointment of a representative from the California Association of AIDS Agencies, along with a broadening of the composition and the base of the AIDS Leadership Committee.

I think those are the basic points. If you have any questions, or you'd like some additional information, I'd be happy to respond.

CHAIRMAN HART: Thank you. You've been very concise, and we appreciate that.

In terms of your first point about watering down, could you give, or do you care to give a specific example of something that's particularly distressing in that regard where you think the compromise process has gone too far, and that the basic document, indeed, has been compromised?

MR. DOBROW: It's my understanding that there was a specific request or recommendation from one of the State departments that involved the expenditure of funds that was deleted, and it's one of the essential -- it was felt that it was one of the essential points that could have been and should have been included. It was related to the Department of Mental Health.

I don't have any more specifics.

CHAIRMAN HART: We began this hearing with some focus on that, and personally I think you're right on target.

Thank you very much.

MR. DOBROW: Thank you.

CHAIRMAN HART: Keep up your good work.

Our next witness is Alison Hardy, the Staff Attorney, Prison Law Office, Director, AIDS in Prison Project.

MS. HARDY: Good afternoon. I thank you for having me here to speak today.

As you say, I am the Staff Attorney for the Prison Law Office. In that capacity, I represent many of the prisoners who are in the AIDS Units in California. There are approximately 240 State prisoners right now who are known to have tested positive for the AIDS virus and are living in the AIDS Units at Vacaville and at Chino.

I'm here today to address specifically the recommendations that are found in Section 7 of the draft report. Section 7 identifies a number of problem areas for public safety and custody workers, and makes recommendations on policies to address those problems.

The first problem area that's identified that I'd like to speak about is Problem Statement Number 49: the problem of AIDS education in prisons.

The report notes that detainees in custody settings are frequently at high risk for HIV infection, and therefore recommends that Senator Watson's AIDS education bill be implemented, as it was written last year but was not funded.

The AIDS education program in prisons and jails that is aimed specifically toward affecting behavioral change could be the key towards preventing widespread AIDS infection in California, particularly among IV drug users, and so therefore, I would stress that it is very important that such a program be implemented.

AIDS education should be a priority in jails and prisons not simply so that we ensure that all prisoners are aware of what does not spread the virus, but also so that we provide some motivation for these individuals to change their high risk behavior. Most prisoners and inmates will not stay in prison for the rest of their lives; rather, they are going to return to their communities. And if they are not properly educated in prison, they will be a risk to their families and to their lovers.

Senator Watson's education and counseling bill is a very good first step towards the program, and I would reiterate that it should be funded.

I would also stress, however, that the Department of Corrections and many local jails are already providing some sort of AIDS education. Most of their programs are based on an information-based model. That is, they consist of an educator who presents a presentation and then distributes educational materials. While this education model may be appropriate for some subjects, such a program is not likely to affect long term behavioral change among prisoners. The behaviors that put many inmates at risk for contracting and transmitting the virus, i.e.,

sex and drug use, are deeply rooted in biological impulses, and individuals are not likely to change their behaviors simply because they're told their behavior is dangerous.

How many of us here are smokers? And despite the fact that we know conclusively that smoking causes lung cancer, we don't change our behavior.

So, I would urge that the report also recommend that the Department of Corrections work with AIDS education groups who have specifically targeted at-risk communities to come up with a sensible program which is specifically tailored for the prison population and is not just based on distributing educational materials to prisoners.

The next problem area that's discussed that I'd like to address is that of HIV testing. People with AIDS, and ARC, and HIV infection continue to suffer discrimination, as we've talked about earlier today. Without the assurances of anonymity provided at alternative test sites in California, many people would choose to forego taking the antibody test.

Due to legislation in Proposition 96, prisoners and jail inmates cannot be tested anonymously while incarcerated. The test results of prisoners who test positive must, by law, be distributed to correctional employees, volunteers who may come in contact with the prisoners, the chief medical officer of the institution, and also to the inmate's parole officer. Never mind the fact that while you're in State prison, you are also segregated in an isolated ward where everyone knows that you've tested HIV positive. So, prisoners who test positive within the

institution will have their HIV status basically known by everyone.

I believe that prisoners who are in the institution and who want to receive testing should be counseled that should they choose to get tested, probably the people in their communities that they return to are going to know about their HIV status; probably the parole officer will know; probably the police officers who are going to be looking for them once they get back are going to know that this person tested HIV positive. Prisoners who return to their communities will be marked not only as lawbreakers, but also as public health threats.

In the wake of these disclosure laws, some counties have stopped offering HIV testing. I think that this is a sound policy, given that inmates are in county jails for a short period of time, and I think that when they request counseling, they should be told -- or request testing, excuse me, they should be told that alternative test sites are available when they're released, and they can be tested anonymously there, unless, of course, they are symptomatic, at which point they should seek medical care.

The next area that I'd like to address is that of segregation. Recommendation 51 says that should segregation be followed, then certain guidelines should be in place: prisoners should have full access to all of the programs that prisoners have access to on the mainline.

I would like to say that segregation is not an acceptable policy for the California Department of Correction.

California has segregated its prisoners who test positive for about the past four years. It's one of only six states in the nation who does that, and the federal prisons, which have relatively the same rate of HIV seroprevalence in its institutions, have not -- don't follow such policies.

In California presently, when a State prisoner tests positive, they are shipped to one of the AIDS Units at either Vacaville or Chino, and they suffer great deprivation in terms of their access to programming, educational programs, vocational programs. They're not allowed to participate in work furlough programs, and they are isolated with a number -- with all levels of security classifications, so that prisoners with very low security classifications, such as petty thieves, are housed with murderers, creating a very tense environment.

One of the most poignant cases of segregation is in the women's prison. There are currently approximately 10 women prisoners who are segregated in the infirmary at CIW. They are barred from participating in any prison programs at CIW.

And most painfully for some of the women, they are barred from participating in the family visiting program. The family visiting program is a program that allows women to be with their families for an overnight visit on weekends. This is most often used by the women at CIW to spend weekends with their children. There are three women right now who are at the CIW unit who have been denied access to the family visiting program to spend weekends with their children, who are between the ages of 8 to 15. This has been a very painful experience for them.

CHAIRMAN HART: What's the rationale for that? Do you know?

MS. HARDY: Well, the rationale is that no prisoner who tests positive should have access to the family visiting program because it's a hazard to the visitors.

That was developed because most of the prisoners who originally had AIDS were men, and the assumption was that if they had their spouses come, they could infect their wives and the Department of Corrections would be -- could possibly be liable. That's what the Department of Corrections has said.

But it doesn't work that way for women who, most of them want to spend time with their children.

It also bars prisoners from having family visits with their parents. Many of the men, in fact --

CHAIRMAN HART: One can argue about the conjugal visit thing, but if there's no conjugal visit, it seems like the policy doesn't make any sense.

MS. HARDY: Absolutely. It does not, but the Department of Corrections has been very firm in opposing access to family visiting. It's something that we've urged them on, and it's something that we've included in a lawsuit that we have against Vacaville currently.

So, I would like to reiterate that the report should reflect, I believe, that segregation is not viable or reasonable policy for dealing with AIDS in prisons.

Finally, I would like to briefly say that I am encouraged that the report recognizes the necessity of bringing

-- or the possibility of the necessity of bringing condoms and bleach into the prison setting. Sheriff Hennessey noted earlier that the Department is reluctant to do that because, of course, AIDS -- having sex in prison is a felony in California, as is drug use.

However, I don't believe that handing out condoms or bleach in the prison would be aiding and abetting a felony. Rather, it would be recognizing that such activity does occur in the prison, and such activity will occur, regardless of whether or not condoms or bleach are distributed in prison. And the Department has an opportunity to distribute these items and to encourage their use among prisoners should they decide to participate in these activities.

Other states -- Mississippi and Vermont -- have decided to distribute condoms, and other jurisdictions, as well as New York City, and Philadelphia, notably.

I think that any AIDS education program within the prison is severely -- the message of any AIDS education program is severely undercut where an educator emphasizes to the prisoners that they must use these items in order to prevent transmission of the disease, and then refuses to distribute those items.

In conclusion, I applaud the section on public health. I think it makes some very good policy statements, and I hope that they are further elaborated upon with concrete plans.

Thank you.

CHAIRMAN HART: Thank you very much, Ms. Hardy.

Rand Martin, Legislative Advocate, LIFE AIDS Lobby.

MR. MARTIN: Thank you, Senator. Since I'm last, I guess this is the star turn?

CHAIRMAN HART: We have a couple of other people.

MR. MARTIN: Oh, you do. I'll try to be brief.

I don't have a whole lot more to add to what the last few witnesses have indicated.

I will indicate that LIFE does believe that the plan is an excellent policy document, but again, as Mr. Dobrow has said, it is not a plan because it does not have objectives, it is not strategic, it is not operational.

Unfortunately, I think that's what many of us were expecting to come out of the AIDS Leadership Committee in this plan: something that could be implemented instead of discussed and left for future implementation by either the Legislature or by the Leadership Committee, or by a subsequent committee or commission.

If you consider some of the recommendations that are highlighted in the Executive Summary, which are ostensibly a prioritization of recommendations, it indicates that we are about three years behind where we should be in terms of this plan. According to that list of recommendations, the top priority is that the Office of AIDS should continue to be the center of expertise.

While we don't disagree that that is the case, I highly doubt that it should be the top priority in a 100 recommendation plan.

There is a recommendation that there be adequate counseling provided to minority communities to meet their unique needs. Nobody disagrees that that should be done. The plan does not say how it's going to be done. If you talk to people in South Central L.A., and south of Market in San Francisco, these are the places where they need some guidance. They need some specifics on how to get the message out to people in those communities.

One recommendation indicates that the Department of Mental Health should conduct a needs assessment. As I recall -- and I've been doing this for three years now -- the budget contained money for a needs assessment two years ago. The Department of Mental Health was supposed to conduct a needs assessment. If the Department has conducted a needs assessment, why are we conducting another needs assessment?

As I understand the subcommittee's report to the full Leadership Committee, it was very specific. It was very detailed. And it was watered down basically to a needs assessment, again, because it was too specific.

There is a recommendation in the top priority that we do evaluation of education and prevention programs. Last year's budget -- the current year budget -- there was $500,000 appropriated by the Legislature to do evaluations of information and education programs. And it seems odd that the draft plan would contain a recommendation to do something that has been done, or should have been done, over the last at least two years, if not longer.

One recommendation that really underscores the delay and the problems that the delay has caused in terms of developing specifics on a plan is the recommendation that they do a study on licensure of hospices and other residential care facilities. Because there has been no firm policy on that in the State of California, and there is not now until this plan is adopted, it has been real hit and miss in terms of who to provide residential care.

What has resulted is a licensure category that was created by legislation last year for congregate living health facilities that has caused nothing but problems, except for a few, isolated facilities across the State who have benefitted from the licensure category. The others are being forced to either meet the standards in that category or not to provide the kind of care to residents with AIDS that they have been providing and been providing well. Los Angeles County is currently suffering most from that, from those restrictions, and are looking at several residential care facilities, either closing down, or ones that are being planned are not opening up because they cannot meet the stringent requirements.

If there had been a policy in place in 1985, when Dr. Conant and others were attempting to put together a plan in this State, then I believe that by 1988, we would have passed legislation that developed residential care models that were comprehensive and dealt with the needs of the client population at that time.

I do want to be somewhat selfish for a moment and bring up one recommendation that was notably absent from the priorities in the Executive Summary. For over a year now, we have been, LIFE, has been speaking with leaders like Dr. Conant and Dr. [Don] Francis about the issue of early intervention for people who are HIV positive but asymptomatic, and how that is in terms of preventing transmission to other people, and delaying or forestalling the progression to more serious disease.

As a result of those discussions, and as a result of pilot legislation that was passed and implemented last year, LIFE took on sponsorship of a bill this year to establish early intervention projects across the State.

We have been under the impression that this is a top priority from everybody's viewpoint. However, it is clearly missing from those recommendations, and I guess it leaves us with the question: are we missing something?

While we applaud the Department, and while we applaud the Office of AIDS, and we certainly applaud the AIDS Leadership Committee for developing the plan that they did, we are very concerned about what happens now when the plan goes to the Governor's office. Clearly, if you look at some of the subcommittee reports, compare them to what was done -- what was finally distilled down in the draft plan, there was a lot of watering down: mental health, health care financing. Subcommittee reports were clearly watered down.

If that is the case in that step of the process, what happens when it now goes to the Governor's office? Are we going

to see it watered down even more, or, as has happened with other plans in the past, is it going to sit on the Governor's desk and never see the light of day?

We're certainly concerned that this not be an exercise in futility, that something come out of it now.

I heard an anecdote yesterday about the Public Health Director from Massachusetts coming out here and finding out that California did not have a plan, and Massachusetts has had one in place for three years. And he could not believe that California was still without a master plan.

The bottom line is, I think it is up to the Legislature to ensure that there is a plan implemented, a plan with specifics, a plan with objectives that are measurable, concise, time-limited, that gives the assignment to somebody to do in a certain period of time.

I think the AIDS Leadership Committee could do that. I think the Legislature can do that. I'm not sure whether the Department as an arm of the administration can, so -- we defer to those two bodies, the Committee and the Legislature, to implement a plan and quickly.

Thank you.

CHAIRMAN HART: Thank you.

We have a couple other persons who have asked to speak to the Committee: a John Belskus, he's on the Board of the Community Health Coalition of San Francisco.

MR. BELSKUS: I thank you for the opportunity to speak for a couple of minutes.

I'm a little bit overawed by listening to the testimony today. When I hear terms like should this plan be strategical, should it be operational, I must confess that it sounds to me like a lot of -- that kind of discussion sounds like a lot of bureaucratic language that obfuscates some of the human issues involved; the human issues being people receiving the health care and the treatment and the protection that they need at a time of crisis during the AIDS epidemic.

I know that I had a very close friend who, when he was coming down with his first attack of Pneumocystis here in San Francisco, went to San Francisco General, had to wait in the waiting room for six hours because he has no medical insurance. He's not covered by any kind of medical plan whatsoever. After waiting six hours, the overworked medical staff there told him that he had asthma, gave him some kind of asthma inhalant, sent him home, and two weeks later he was calling an ambulance to go back to San Francisco General Hospital with a full-blown Pneumocystis attack.

And I really haven't -- maybe I'm not schooled enough in the language of the terms that have been used -- but I haven't heard much significant testimony today, with some exceptions, that have really even begun to address the problem of my friend, which I think will be a growing problem. There are estimates that there are as many 10,000 asymptomatic people in the City of San Francisco alone, mostly in the Castro District. With the new wave of the epidemic growing among Black and minority teenagers who are involved in the drug epidemic, you'll see even greater numbers of people coming along in the future.

The human issue that that points to, if we take it out of the strictly, you know, emotional terms that it touches upon, is: what are we going to do about our health care system in general; and does the AIDS epidemic pose a crisis for our health care system?

What are we going to -- if San Francisco General is facing cuts of $4½ million because of San Francisco's budget crisis, that means what? That they're going to cut back on X-ray technology at San Francisco General, so that there's going to be a longer line waiting to use the X-ray facilities there.

Well, if you have Pneumocystis, or some kind of lung infection, and you get sent to have X-rays done, you wait in the same line as everybody else who's dependent upon those facilities at San Francisco General.

So, the AIDS epidemic itself becomes a part of the crisis of our health care system that is not being adequately funded, and becomes a part of the crisis of the fact that 5 million Californians are without health care. So we have to -- if we're going to address the issue of how to provide adequate health care for people with AIDS, we have to think about how to provide an adequate health care system for the people of the State of California across the board.

Now, I don't know if I've made myself clear, or if I've gotten the idea across. It's been repeated by a great many more people than myself. I really haven't heard it that clearly expressed here today.

I think that's only one of the larger social issues surrounding the AIDS epidemic that needs to be taken into account in any kind of strategic or operational plan for what to do about the AIDS epidemic.

There's one final issue that I think we can narrow on that I would like to speak to in closing, and that's the issue of needle exchange. It seems to me needle exchange is a simple thing. Unfortunately, I've had a drug abuse problem in my past and limited -- it was a vision of hell that I don't care to go back to -- limited though it was, I never found anyone who developed any kind of drug abuse problems because of exchanging the needle. It's just a fact of life that I never encountered.

It seems to me such a simple thing. The barriers to it, I think, come from people who misunderstand the problem, people who are related to puritanical, unnecessarily puritanical backgrounds, or really want to hide from the problem.

The fact is, it is easier to get any drug that you might want on the streets of San Francisco than it is to get a clean needle. And I think that providing for needle exchange will do absolutely nothing to encourage the spread of drugs. And it's almost ridiculous to talk about encouraging the spread of drugs when drugs are so widespread; it's absurd.

There was a Bayview Hunter's Point group that interviewed several hundred African-American youths, ages 15-19 years old, about their crack and drug habits. They found from the group that they interviewed that 68 percent had engaged in the sale of crack. These are teenagers, 15-19 years old; 68

percent had engaged in the sale. And some 40 or 50 percent had contracted at least one venereal disease at some time in their lives in that four-year age span.

Now, among that group of people, to present something as simple as a needle exchange is not going to encourage an already existing problem. And of course, it's not going to be the only solution that needs to be made. But I think it is definitely something that we can get the political will to do.

And if we can't get the political will to do something so simple as a needle exchange, I don't think we're ever going to be able to address the larger issues of what are we going to do about a comprehensive health care plan in the State of California.

Thank you.

CHAIRMAN HART: Thank you very much.

What appears to be the last person to speak today is Harvey Maurer. Is Mr. Maurer present?

MR. MAURER: Thank you, Senator Hart, for having this hearing and this Committee meeting.

I have to admit to a certain amount of confusion myself. It's a very wide topic, but it's certainly clear to me that there's a lot of controversy surrounding what the effects of this report will be: how the Governor will interpret it; how it will be implemented.

I'm afraid some of that comes from confusion within the report, and that deals with treatment being a priority, but what does treatment mean? Does that mean going into a hospital,

having a bed, having a physician, having a standard of treatment, and then a release? Or, does that mean access to an efficacious treatment that isn't yet approved by the FDA, such as aerosol pentamidine?

It really is a question that's going to come up more and more frequently. We're talking about AIDS going into the IV drug using community, and we're talking about wanting to limit the spread of AIDS, and we're talking about wanting to reach the IV drug user, and have him or her modify their behavior.

Well, it's interesting. Conventional wisdom is that IV drug users are real difficult to reach, don't have much self-respect, certainly don't modify behavior quickly.

I've been involved for now almost three years with the bleach exchange program, which has seen about 20 percent of its weekly allotment being given out to IV drug users, seen the consequence of the return by those users of the empty bottles. Now, these people have embraced the program. They have recognized that it is helpful to themselves, and they are participating.

Now, there are a couple of things. We don't ask for names, and we don't take photographs. We don't keep records. We make it very easily available. They can drop off; they can collect. Very simple, but they participate.

And if you had gone to the literature a couple -- say, five or ten years ago, you would have found that people would say IV drug users won't participate in prevention. They do. The question is whether you're clever enough to provide a basis whereby they can contribute.

I guess the last comment that I'll make deals with the area of the mental health cutbacks. I really think that mental health appropriations or programs as relate to AIDS, we're involved in a learning experience. And we're involved with -- particularly in the IV user population, the substance abusing population in general, whether that includes crack cocaine or whatever -- we're dealing with a different mentality of a lot of people posing multiple problems. And in the end, I would ask, who is going to help these people maintain some stability in their lives? Because I would say from what I understand this Committee's done here that a principle area of interest is that people who are infected act responsibly. To accomplish that, sometimes people have to receive a lot of counseling, a lot of education, and I think the Committee's recognized that.

But I also think that people, when they're under extreme stress, sometimes need some special help. And I would submit that that's not going to come from a nurse. That's not going to come from a doctor who they see once a month. That at some time, they're going to need to be referred to a person with specific competence, psychiatric competence. And if that person isn't there, then I would ask whether society's prepared to pay the cost for that? Because I think we know that the cost of society not providing those services is going to be more infection and, in the end, more expense, and probably more death.

Thank you.

CHAIRMAN HART: Thank you, Mr. Maurer.

I want to bring this hearing to a close. I first want to thank all of the people who testified, as well as others who are here in attendance, for your contributions and for your patience throughout the day.

I also want to mention that with our stenographer here, we'll be producing a transcript of this hearing. If anyone would like a copy of the transcript, I don't know how long it will take for it to be available, but hopefully it won't be in the too distant future, and if anyone would care to receive a copy, please call or write the Select Committee on AIDS office in Sacramento.

In terms of this report, I'm impressed by the number of people who participated in the deliberations, and the expertise that the people who were part of the development of this plan brought to the process, and the degree of specificity in the recommendations, the length of the recommendations in the report, and the consensus that has been developed. I think those are all things that we can be very pleased about.

As I mentioned at the beginning of the hearing in my comments directed toward Dr. Kizer, and it's been repeated by others as well, the fact that there are not dollar figures that in any way are really attributed to this report is troublesome. I understand the sensitivity of that issue, but it seems to me a plan that does not attach any resources or any dollar figures to implementation of the plan is really lacking in credibility.

I think the whole idea behind this, as I see it, is that we are trying to fashion a battle plan. When you're in a war,

need to be specific. You need to be operational, and you need to be dealing with some kind of measure as to whether or not you are succeeding in winning or losing the war.

The degree to which we can have greater specificity and greater implementation of a plan that gives all of us in this process some indication as to how we're doing in effectively implementing the plan seems to me to be extremely important.

I guess I would conclude by saying that although this plan is put forward by many people with expertise in the health and medical fields -- and that's my bias, is that we want to rely upon this expertise; that's what we want to do through this planning process -- but I think it's also important to mention that this plan is not only an expertise document, a health document, it's a political document. And this hearing is a political process, obviously. Where this report goes in terms of its further draft revisions and final execution, it is a political process that we are part of. And the extent to which this plan can be a focal point for a political debate and discussion is extremely important.

So, I would urge those that are involved in sort of the final execution of this report to keep this in mind, that it is a political process. That political process is educational for Members of the Legislature, for the media, for the general public, and certainly for the Governor of this State. And I hope we'll keep that in mind so that we can have a document.

What strikes me is that with this issue and so many other issues, those of us that are involved in the process, it is

so easy to sort of have an informational overload, or to get confused, or to -- there's just too much. A document like this can help focus our understanding, and hopefully our will, to take some decisive action.

That's what my hope is that this plan will be, and what I hope that this Committee hearing is sort of initiating, that process.

So with that, we'll conclude the hearing. We won't conclude the process, because the process, in a sense, is really moving from those that are part of developing this plan to, as someone suggested, to make it more inclusionary, and that inclusionary process will certainly include the Legislature and others as well, so the process is really just under way.

Thank you all for attending, and this hearing stands in adjournment.

(Thereupon this hearing of the Senate Select Committee on AIDS was adjourned at approximately 4:30 P.M.)

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CERTIFICATE OF SHORTHAND REPORTER

I, EVELYN MIZAK, a Shorthand Reporter of the State of California, do hereby certify:

That I am a disinterested person herein; that the foregoing March 31, 1989 hearing of the Senate Select Committee on AIDS was reported verbatim in shorthand by me, Evelyn Mizak, and thereafter transcribed into typewriting.

I further certify that I am not of counsel or attorney for any of the parties to said hearing, nor in any way interested in the outcome of said hearing.

IN WITNESS WHEREOF, I have hereunto set my hand this 11th day of April, 1989.

EVELYN MIZAK
Shorthand Reporter