ORIGINAL

TRANSCRIPT OF PROCEEDINGS

NATIONAL COMMISSION ON

ACQUIRED IMMUNE DEFICIENCY SYDROME

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NATIONAL COMMISSION ON

ACQUIRED IMMUNE DEFICIENCY SYNDROME

HEARING

HOLLYWOOD, CALIFORNIA

WEDNESDAY, JANUARY 25, 1990

9:00 A.M.

Hollywood Roosevelt Hotel

Hollywood, California

COMMISSIONERS

June Osborn, Chairperson

Diane Ahrens

Reverend Scott Allen

Harlon L. Dalton

Don DesJarlais, Ph.D.

Eunice Diaz

Donald S. Goldman

Larry Kessler

Charles Konisberg, Jr., M.D., M.P.H.

Belinda Mason

James O. Mason, M.D., Dr.P.H.

Honorable J. Roy Rowland

David E. Rogers, M.D.

Irwin Pernick

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CHAIRWOMAN OSBORN: Let me ask these people to sit down quickly so that we can proceed.

We have many important people with important messages that we want to listen to carefully today and so I'm going to start now and wish you all good morning. Very happy that we're able to be here and very grateful for the cordiality we've already experienced and for your hard work in southern California in preparing -- we're playing between the balance between this feedback and you not hearing me and I apologize for both.

With a comprehensive agenda this morning, I want to take just a couple of minutes and first I want to thank Commissioner Eunice Diaz for the very hard work that she has done in order to help us in such a rich agenda. Eunice, many thanks from the entire Commission.

I'm going to have to be quite strict about time and I hope that everybody will bear with me. We've -- I don't particularly like the fancy electronic devices, so we're going to have an unfancy mechanical device here in the form of a kitchen timer with which we will try to prompt you as time begins to run out in schedule. I hope nobody will be offended, but otherwise others will be offended by running out of time to talk, so we're going to need to do something like that.

We -- Dr. Rogers and I and in fact the whole Commission much prefer, especially with people who have written testimony, that they trust us to be willing to read it. We do. We will try to take that as a very serious responsibility and if one -- if we can save some time by asking people to summarize -- if we can save time by asking people to summarize written testimony so that we can interact with the people talking to us, we will appreciate that. We find the interaction to be particularly valuable use of time and we will read what you have written for us.

Is the sound level better? Good.

We have sign language interpreters. If there is anyone in need of this service, please let us know.

We're very pleased this morning to have Mayor Tom Bradley with us and we are also joined by Supervisor Ed Edelman and Judge Rand Schrader, Chairman of the Los Angeles County AIDS Commission.

Mr. Mayor, could I ask you to take a place at the table so that we can begin.

MAYOR BRADLEY: Dr. Osborn, members of the National Commission on AIDS, thank you for coming to Los Angeles. We extend to you our welcome, our cooperation, in the tremendous job that you and this whole nation are now undertaking.

I'm pleased to say that Supervisor Ed Edelman and I have been in the forefront of this effort here in the Los

Angeles County area to extend better knowledge, to communicate better to everyone the dangers and the implications of AIDS and what we must do, not only to remove the myths and the misunderstandings about AIDS and also to promote those alternatives that we think are going to be helpful in fighting this battle.

About a week ago, I testified before a House Budget Committee chaired by Congresswoman Barbara Boxer, and in that testimony, a copy of which is being made available to you, I pointed out that Los Angeles has been one of the leading cities in the nation in terms of innovation, in terms of our efforts to adopt steps that we think will be helpful, and I called upon the Congress to take certain actions.

One of them was to follow our lead in establishing an AIDS anti-discrimination act which we were the first city in the nation to adopt such an ordinance. We think it's important. There's a need for alternatives to hospitalization and, again, we've tried to be in the forefront of that effort. The hospice approach, which we think is helpful, sometimes generates opposition in the community because of a lack of understanding and we need your help in promoting a wider understanding of the importance of these kinds of alternatives.

There needs to be an equal access to health care and to early intervention treatment programs and such,

especially in minority communities where, as you well know, the problem is growing and yet the lack of adequate supportive facilities and programs is just not there.

There needs to be a comprehensive AIDS education program. Now, I know this Commission and its members agree with that approach. There needs to be increased funding for AIDS research. We have put on a number of fund-raising efforts in this community to try to help the local efforts in that regard, but certainly more must be coming from the Federal Government.

I announced a week ago that we were going to propose a program to distribute in five of our community-based agencies AIDS information and intervention kits. These kits would contain bleach and condoms. They would be distributed to those who are interviewed as drug users because we think that's the community that's most at risk. Our Council will be taking up that matter.

This morning, I sent a letter to the County Board of Supervisors asking that they reconsider that recommendation which had been made by them and which about 18 months ago they turned down. Supervisor Ed Edelman again is in the forefront of that fight. I believe that we've got to take every action we can, whether it's proven or purely a speculative approach, to fighting this battle. We can't turn down one possibility that offers some hope for relief or for cure.

And I commit to you that I and other members of our city family are going to do everything within our power to help the Commission in its work and we again thank you for coming to Los Angeles for your first such public hearing. I hope that you find here not only gracious hospitality but a number of agencies and individuals who are at the forefront of this battle and we are determined to win this war. Thank you very much.

CHAIRWOMAN OSBORN: Supervisor Ed Edelman, would you join us, too?

SUPERVISOR EDELMAN: Good morning. Thank you, Dr. Osborn. Members of the Commission, we welcome you to Los Angeles on behalf of the County. We know the work that you are undertaking is of great importance, not only to Los Angeles but to this country and we salute Congressman Rowland for the legislation that created this Commission. It is not just serving the Executive Branch. It is serving this nation, Congress and the Executive Branch, to develop a consensus.

It is difficult in this country with the various viewpoints that exist to develop this consensus, but it must be developed based upon fact, not fiction, based upon reality, not myth, based upon the best information that's available, not simply to develop what we hope might be a cure but we know that that is some years away but what

alternatives exist, and to make those recommendations on the national level. We need to raise the education level of this country in terms of fighting AIDS in a constructive and non-discriminatory way. We know the Commission will listen very carefully to the testimony today. You have many excellent speakers. They're covering an enormous area. But I'm impressed with the Commission because you're not just limiting yourself to hearing public testimony, as important as that is, but you're taking site visits quietly and effectively to different parts of this county, to the black community, to the Hispanic community, to the various communities that have this problem as well as to the general community which has this problem.

And so I salute you. I salute your coming to Los Angeles. This is a historic time for the Commission and for the people of Los Angeles County to have this very prestigious Commission visit our community to hear testimony from experts covering very important subjects. So I wish you well from the County of Los Angeles. I particularly stand ready to help you and provide you whatever information you need. Thank you.

CHAIRWOMAN OSBORN: Thank you. Judge Schrader.

JUDGE SCHRADER: On behalf of the Los Angeles County Commission on AIDS, I want to welcome you and thank you for coming to Los Angeles to meet with us, see us, be

with us in our fight against AIDS.

Let me say first of all to Congressman Rowland, to Dr. Osborn, and Dr. Rogers, to our special friend Eunice Diaz who is one of us, to my new friend, Commissioner Ahrens from Ramsey County, Minnesota who I got to take on a tour yesterday, that we know -- we know that you are our allies. We know that you are our friends. And we know that you have the interest and concern that we are talking about today. And our need from you is not to convince you that there should be a fight against AIDS. Our need as citizens, as people of the United States, is that you be our messenger to the people of our country to explain to them and to our Congress and to our President that our fight is happening now and needs response now.

I want to thank Supervisor Edelman, our mayor, Tom Bradley, who have been with us for many years in our struggle, but I must ask, as we ask you to be our messenger, I must ask more broadly where is America in the fight against AIDS? Where is our President in directing and leading in our struggle? Please take that message. Please ask that question for us.

I hope you will be understanding of the anger that you will hear expressed today by people who are unable to comprehend how life is being taken away at 30 years of age. We need your wisdom as well as your intellectual

understanding as you listen to and hear from people so filled with dismay and hurt.

Now, I am from the majority group in Los Angeles which is diagnosed with AIDS, gay white men. We need treatment. We need support in our fight to stay alive. And, in addition to that, in addition to our own needs, we also have cares and concern about our friends and neighbors in the largest and fastest -- in the next largest and fastest growing group of persons affected by HIV in Los Angeles and by AIDS, gay and bisexual men from the black and Hispanic communities. We ask you to carry the message of our fate as we are trying to do to wake up the leaders, the spokespersons in black and Hispanic Los Angeles, to the spreading infection among persons in their community. We ask that you carry this message and tell them that, although it is our fate to be infected, let at least you learn from what has happened to us so that you might avert the spread of infection in your community. Here truly in the minority communities among gay and bisexual men truly silence equals death.

Now, speakers today will inform you better than I could of specific issues, but I ask that you will remember our plea. Some generations in history confront a fate more harsh than others. Although gay, I did not expect to be part of such a group or live in such a time. However, we are facing our fate and our battle with courage and toughness and

a tremendous willingness to help others benefit from our struggle. Help us make our struggle meaningful by working to awaken others to the true risks and to provide resources to us so that we may have a fighting chance to beat death. Our fate allows us no other request. Thank you, Dr. Osborn.

CHAIRWOMAN OSBORN: Thank you very much. I want to read to you only a bit of a longer letter that was sent to us by Senator Cranston and let you know and let the Commissioners know of the letter, that they can examine at their leisure. His letter says, "Although I cannot be here today, I want to welcome you to California. I'm delighted that you have chosen Los Angeles for two days of hearings and site visits." He highlights some of the points that we have scheduled to learn about and highlights his concern and finishes by saying, "I look forward to learning more about what you have learned in Los Angeles and your visits throughout the country. I also look forward to working closely with you in the months ahead as we forge a national AIDS policy for the 1990's. Sincerely, Alan Cranston."

And before we turn to the formal agenda, I would also like to tell the rest of the Commission and acknowledge receipt of many, many letters from people living with AIDS who wanted to tell us in person or through their efforts at correspondence some of the poignant and important aspects of their lives and their needs in the area. I received this

last night and I read everything that I was able to. I don't know Braille and I don't speak Spanish and so I was -- fell a little bit short of my goal which was to at least one Commissioner having read them, but I will try to make them available to all the rest of the Commission and let people know that we are trying to here from you as well as from the people that are on the schedule. We are aware that there are many people who would like to talk to us where the program time constraints simply didn't allow it, but thank you very much for wanting to talk to us and please the sending us letters we will try and read and hear you as best we can.

With that, I'd like to start with the formal agenda which initially is intended to give us an overview of southern California and with that the first panel to come to the table if you will. Viviane Doche-Boulos from the Southern California Association of Governments, Martin Finn, Dr. Martin Finn from Los Angeles County Department of Health Services talking about epidemiology, and Tom Prendergast from Orange County Health Care Agency.

Let me say one more time with a little better amplification, we're going to try to be informal but tough about the time constraints, and so we will be hoping that you can condense your remarks so that we can interact with you and if we get close to the outer boundaries of time available for your remarks, you'll hear a little beep like something

was cooked in the oven.

DR. BOULOS: Good morning. I'm Dr. Viviane Doche-Boulos. I'm principally in charge of growth management --

DR. ROGERS: Viviane, I would suggest that you move a little closer to that other microphone. I'm not sure people can hear you. Thank you.

DR. BOULOS: I'm with the Southern California Association of Governments. I'm in charge of the growth management plan and demographics for the Agency. I would like to present this morning a very brief overview of past and present demographics in what we commonly call the Los Angeles Basin. This region comprises all counties south of Kern and Santa Barbara, not counting San Diego County which is not in our planning service area.

The counties are Los Angeles, Orange, Riverside, San Bernardino, Ventura, and Imperial. Almost half of the California state population lives in this region. This region with a latest estimate of 14.2 million as of July, 1989 is one of the largest in the country, second only to the New York metropolitan region.

The region has experienced very fast growth in the past, especially in the 50's and 60's and although the rate of growth in the future will slow down compared to what it was in the past, we can expect four more million people in this region between now and the year 2010. By the year 2010,

we could very easily reach 18.3 million, if not more.

What are the factors behind this growth? First, we have to look at the characteristics of the region itself. We are blessed with a very clement climate. This region has been always experiencing, especially in the recent past, very strong economic growth and diverse economic growth. Those act as pull factors, plus in this region we have large concentrations of ethnic and immigrant populations that act as magnets for more newcomers to enter the region. We should not forget also that this region is very well strategically located along the Pacific rim and this is another factor that leads to its continued growth and vibrant demographic development.

Second, we have to look at the characteristics of the population itself. A lot of the growth in California and specifically in southern California has been due to migration in the past. Therefore, our population is young, younger than the national population. The median age in southern California both for males and females is lower than the median age for the U. S. in general and, although our population will be aging with time, it will still remain younger than the U. S. population.

The other factors of growth are of course net migration, which is the balance between in-migration and out-migration from the region and natural increase, which is the

-- in our case the excess of birth over death. Those are the two basic components of population growth.

In the past, migration played the most important role in population growth but, with the passing of time, natural increase will take over because of the characteristics of our population, its age composition, and higher than average birth rates among especially our Hispanic and Asian communities. This is not uniform around the region in Los Angeles County. Already natural increase birth is the leading factor behind growth.

What is as important as the volume of growth in this region is the changing ethnic composition of the population. In 1970, according to the census, three quarters of our population was what we call non-Hispanic white. By the 1980 census, this proportion had dropped to 61 percent of our population. By the year 2010, 20 years from now, this proportion could go down as low as 41 percent and by then we won't have any predominant ethnic group in that region. This is due to the fact that the white population has lower than average birth rates and a greater propensity to out-migrate from this region, whereas the reverse is true for the Hispanic population. We have a large influx of migrants from Mexico and other Latin American countries. Those migrants are young. They come in their reproductive age groups and have a tendency toward families plus they have also higher

than average birth rates.

CHAIRWOMAN OSBORN: I need to remind you of our schedule and if you could complete your comments so we can interact a bit.

DR. BOULOS: Rounding up, the third important point that I would like to mention is that not only we have a growing population, very diverse ethnically, but also very mobile. There are a lot of people leaving the region and a lot of people entering the region. Between '80 and 2010, almost nine million people would have left the region and been replaced by as many people entering the region from other parts of the U. S. So what we have now as far as population composition is not what we can expect 20 years from now. And this concludes my comments. Thank you.

CHAIRWOMAN OSBORN: Thank you very much. Dr. Finn?

DR. FINN: Is this -- this is not off?

DR. ROGERS: Dr. Finn, that other microphone may --

DR. FINN: Is this one working?

DR. ROGERS: Yes.

CHAIRWOMAN OSBORN: Yes.

DR. ROGERS: Fine.

DR. FINN: Dr. Osborn, members of the National Commission, thank you for this opportunity. A brief review of the epidemiology of HIV infection in Los Angeles County,

which includes the independent cities in terms of health of Long Beach and Pasadena, shows in excess of eight thousand cases of AIDS diagnosed to this time. Approximately three percent of the cases are women and less than one percent are children under the age of 13.

At this point in time, 89 percent of our cases are in gay or bisexual males and of that number, nine percent also have a history of intravenous drug usage.

If we look at adults in the heterosexual or unknown category in terms of their risk, 4.1 percent of them have a history of use of intravenous drugs. Overall, without questions in sexuality, looking at adults, 11 percent at this time have used intravenous drugs. In terms of ethnicity, the black population at this time has 16 percent of the cases, the Latino community 18 percent, and the Asian-Pacific islanders less than one percent.

Two facts really stand out and that is that the primary risk group for this community is gay and bisexual males and that we do see increasing involvement of persons of color.

If we look at the question of infection in Los Angeles County, the estimates of the Planning Council and also combining that with the Epidemiology Unit, we believe that we have somewhere between 55,000 and 112,000 individuals who are infected with the virus. For planning purposes, we

are using the higher number but, as was said this morning at the breakfast by Dr. Osborn, 55,000 is far too many.

The natural -- there is a natural increase in heterosexuals but it's very, very slow in this community. Our military recruit data shows a very low percentage, 0.19 percent of those being infected by the virus. A core blood study done on infants in our hospitals in 1988 showed a rate of 3.6 infants per 10,000. If we look at the cases, however, of those that were positive, 31 percent were Latino, 28 percent were black, showing that of pediatric cases, and this demonstrates the problem for women and children both, 59 percent were people of color in that category.

We anticipate that our increase in cases will continue through 1991 and at this time we would see that that could be the peak year.

What does this say for Los Angeles? We really must use our epidemiology to our benefit. It has been the foundation for many important decisions for us through the 1980's.

First of all, we really, and it's been said before, we must have a national policy which will allow support for the many needs of a community such as this, the need for anti-discrimination, and this reaches down to every issue that we deal with in an epidemiological sense. We must listen to the epidemiology. It shows us that we have a

sizeable number of individuals already infected in this community. At this point in time, the funding for early intervention services is less than one percent of the anticipated need for 1990-91 based on the numbers that we have at this time. This is the major hope for those who are infected in terms of avoiding pathology, human pathology, and for leading a normal life.

We have to be honest in dealing with the fact that our 89 percent -- that 89 percent of our cases are in the gay community and realize that this will be the service need delivery -- these will be those patients who will have that service need delivery through the 1990's.

We must also acknowledge honestly that even as we look at people of color, that the majority risk is that of sexuality with a large number being gay and bisexual males.

We must look at the increase that is anticipated in terms of people of color and also just in terms of poverty. We see the illness slowly moving. It will crest in the gay community, but it will then become a smoldering illness in that area.

We must keep up at the same time our preventive activities. We do not wish to become another East Coast. We are probably in an enviable position at this time because of our low intravenous drug abuse statistics, but we would want to keep it that way.

I think we have to acknowledge also that in a mental health sense, the mental health system really does not at this time allow for actual real care of those who are HIV infected.

And finally I present you with one major concern that I have. Recently Dr. Richard MacKenzie, who heads up the Adolescent Unit at Childrens Hospital was discussing the 12 adolescents he is following who are HIV positive. Of those 12, ten are children living at home in rather good family situations. Only two are the street children that we are always concerned about. And to me this says that we must be very honest as we deal with issues of schooling, issues of education for the children who are coming to be the citizens in the future with the hope that they will not also have this serious and terrible infection.

I am in awe of your responsibility. I appreciate your caring. I thank you for this opportunity.

CHAIRWOMAN OSBORN: Thank you very much. I gather that Dr. Prendergast is not able to be with us, which gives us a chance to interact a little bit and I wonder if any of the Commissioners have comments or questions that they would like to bring forward.

DR. ROGERS: Might I ask, Dr. Finn, did I hear you correctly that less than one percent of the funds necessary to treat your HIV positive asymptomatic bulk; is that --

DR. FINN: That is correct. We've looked at the number that we consider to be the county or the public responsibility for 1990-91 and the estimated cost there could range from 159 to $166 million. Committed funds for this type of service now are not much more than $1 million.

DR. ROGERS: Would you -- does it put you at political risk? Could you tell me why there's miserable funding for this program?

DR. FINN: Well, this county in terms of its health needs is in serious straits at this time as you heard at the breakfast if you were there. We are barely meeting our prenatal needs. We have family planning needs. We have a hospital system that needs considerable care just to keep it functioning. So I'm afraid, as I look at these issues, that if there is to be resource developed, it will have to be at other levels of Government. I just don't myself see a lot of discretional funding available in Los Angeles.

DR. ROGERS: Anybody have the guts to ask for more taxes?

DR. FINN: I'm not sure about guts. I'm sure there's a lot of thoughts about it, but --

CHAIRWOMAN OSBORN: Dr. Rowland?

HON. ROWLAND: I have just one question I would like to ask you. The principal group now that's infected is homosexual and bisexual men I believe that you stated. Can

you make some comment about heterosexual spread at this time in this particular area?

DR. FINN: It has been very, very slow, probably less than we anticipated if we look back three years ago, certainly nothing in terms of the blossoming as it did within the gay community. As I had said, we look at military record data. We look at various studies in family planning clinics. We still do not see more than three to four percent of our cases actually being heterosexual and that's been the case for several years. We anticipate that it will occur. It occurs I think mainly now because of sexual spread, but if we were unfortunate and we're not able to control our intravenous drug abuse, this would only compound the fact and of course it would immediately begin spreading further.

CHAIRWOMAN OSBORN: Dr. Mason?

DR. MASON: In your written testimony, you indicate that the epidemic in this area will peak in terms of number of reported cases in 1991. Could you very briefly give us the data upon which that is based?

DR. FINN: That's based on our AIDS epi units look at four different methods of predicting numbers infected and of course using retrospective data on the epidemic to this time. It also includes an estimate of the point in time when most of the people were becoming infected and of course it uses the expected latent period between the point of

infection and the development of cases of AIDS.

CHAIRWOMAN OSBORN: Dr. Finn, one thing that, as you know from earlier conversations we've had that continues to concern me about this area, is the potential for spread in the intravenous drug-using community. I think -- I assume that the estimates that you're giving us are predicated on the continued failure to spread in that community since there are so many people who could quickly become involved were that to change. I wonder if you could comment about the degree of comfort at the -- sustaining that very low -- relatively low infection rate with what I think in the written documents suggest is a fairly high rate of needle-sharing.

DR. FINN: I can't say I have any great comfort at all. I believe a factor is the availability of drug treatment programs. They're very low at this time as compared with the need. I think we probably -- the people that we measured are those who are in programs and that is a great concern, that those we have not measured, those that are still on the streets, not in either outpatient or inpatient programs with respect to drug control, that they might have a higher prevalence at this time of infection.

So I can't say that -- it's a constant concern. All we need is for the virus to be introduced more globally into the families of drug users and I fear that we would have

the rapidity of increase that we've seen in the East Coast.

CHAIRWOMAN OSBORN: And around the world.

DR. FINN: Around the world, yes.

CHAIRWOMAN OSBORN: I think that's a point that we probably need to underscore again with the recent events in Thailand where two years ago there was a degree of comfort that turned out to be quite unwarranted. They've gone from a few hundred to a few hundred thousand infected people over just a two-year period so as I look at Los Angeles and southern California demographics, I see that very large number of potentially infected people and then an explosive result.

DR. FINN: We are also -- if I may add just a point -- of immigration, both nationally and internationally, so there's always the potential of this to come into Los Angeles from the outside very swiftly.

CHAIRWOMAN OSBORN: Yes, Don DesJarlais.

DR. DESJARLAIS: On the East Coast, we are seeing the spread of -- on the East Coast, we are seeing spread of HIV not just from drug users through their sexual partners and children, but from people injecting drugs to people who smoke crack through heterosexual transmission. I know that you have a significant number of people smoking crack and engaging in unsafe sex here in Los Angeles. Are you monitoring possible spread from drug injectors to crack users and

then from crack users to other crack users?

DR. FINN: The answer I believe is in the inquiries made as patients develop AIDS as to what their history has been. I'm not aware of a specific program that looks at that issue at this time, Doctor.

CHAIRWOMAN OSBORN: Don Goldman?

MR. GOLDMAN: I have two -- you just mentioned something and I just wanted to ask whether you suggested -- you mentioned immigration. This commission has looked at some of the issues involved in immigration and has concluded that the United States is in fact more likely to be the reservoir and the source of HIV infection for the rest of the world than vice versa, and we don't know of any data that suggests that there's been any influx of HIV infection coming into the United States through immigration in any way. In fact, probably people from here have exported HIV infection to the rest of the world and I'm wondering whether or not your mentioning that was suggesting that there's some new data available to contradict what we have previously found?

DR. FINN: No, I was really speaking of it as a potential. We are aware that our exporting capability by our discussions, particularly with Mexico at this time here in Los Angeles.

MR. GOLDMAN: The second question that I have is that you talked in your written documentation as I read it,

I thought what you said was that if in fact there should be the kind of increase in the drug-abusing population that some people that suggested may take place and that may be taking place without your knowing about it in terms of the data, that the cresting phenomena that you refer to is really a temporary crest and merely represents the time period between the time of infection and the time of onset of symptoms qualifying for epidemiological definition of AIDS and that it's not really a cresting in the sense of a cresting of the problem or a cresting of the need for the response to the problem. Am I correct?

DR. FINN: Yes. The cresting that I spoke of I think was a retrospective -- is based on retrospective documentation that we've had sort of a natural history of this infection in Los Angeles to this time. That certainly can change if any of these other factors get out of control.

CHAIRWOMAN OSBORN: Dr. Rogers?

DR. ROGERS: Just a quickie. What's your estimate of the number of I.V. drug users you have and how many treatment slots do you have available for them?

DR. FINN: I can say that we usually deal with a figure of a hundred to a hundred and twenty thousand. I'm afraid I don't have the exact number of slots, but I think that Dr. Strantz will be presenting this afternoon and she can give you that information.

CHAIRWOMAN OSBORN: Let me thank you both on behalf of the Commission for your important opening testimony which gives us a good background for our subsequent discussions. We'll move on now to a panel of people talking to us about systems of care, including Alex Taylor from the San Bernardino County AIDS/STD Programs, Dave Johnson from the City of Los Angeles AIDS Coordinator, Dr. Penny Weismuller from the Orange County Health Care Agency, and Dale Fleishman from the San Diego County Department of Health Services. I hope you can sort of move the microphones around. We get the sense that a couple of them work and a couple of them work less well, so we'll look forward and I hope you will also not mind if we continue our kitchen timer routine here to give you a sense of the limits of our schedule.

If you can summarize so that we can get a chance to ask questions as you gather, we like to ask questions and if you can be brief, that will give us a better opportunity.

MR. TAYLOR: Okay. I'm Alex Taylor, San Bernardino County Department of Public Health. I would point out that my background is in --

DR. ROGERS: Again, you might pull that a little bit closer to you.

MR. TAYLOR: Is that better?

DR. ROGERS: Yes.

MR. TAYLOR: Okay. Alex Taylor, San Bernardino

County Department of Public Health. My training is in epidemiology, so much of my testimony will be flavored that way.

The greatest problem in San Bernardino and Riverside Counties, which I would point out that San Bernardino is the largest county in the country geographically. Between the two counties, we embrace 27,360 square miles and have a combined population of 2.2 million.

We do estimate that there are 7200 to 10,900 infections based on national estimates and local data. The important thing, though, to recognize is that in San Bernardino County, we have no outpatient care whatever. We have applied for HRSA funding and have been denied that. We think that the Federal Government really needs to re-examine their priorities as far as funding for service, but it's important in our case to look at the type of outpatient care that we truly need. It cannot be what L.A.'s is and it cannot be what Riverside County's is.

For instance, when we talk about AIDS being a largely white gay male disease in California, that's not the case in San Bernardino County. Ten percent of our cases are female. When we look at our zero prevalence data, if you look at AIDS, it's nine to one male to female. If you look at zero prevalence data, the infections are three to one male to female. Women are rapidly catching up so we will need

women's services critically.

Pediatric cases, we have six times the number of cases that Riverside County has, so clearly outpatient services in San Bernardino County will require some pediatric component.

We feel that the influx of funds for outpatient services and some integrated system of care will ultimately save money. It will afford hospitals to discharge their patients to us, to provide care that doesn't really require hospitalization and, further, it will allow us the opportunity to provide early intervention for those individuals infected with the virus.

Clearly, we see the success with the use of zidovudine and aerosolized pentamidine. It is clear to us that there will be further improvements in care available to the HIV infected individual. The point is we need to establish those services now and to set up those systems of care now, not in a retroactive fashion, which is what we're doing, but more in a proactive model such that we can meet the demand as it arises.

I would, though, like to say at least on behalf of San Bernardino County, that we cannot do it the way everybody else does it because clearly our patients -- oh, I forgot one other point about our patients.

When we looked at the ethnicity of our cases and

our infections, if you're black and live in San Bernardino County, you're three times as likely to develop HIV infection as if you are not black and live in San Bernardino County. When people talk about increases in infection rates among people of color, we're already there and so we have to have -- our focus these days is not necessarily ignoring the white gay male because clearly there are services available, but we have to develop services for women, children, and blacks. That is our biggest concern at this time based on the epidemiology of our cases. Thank you.

MR. JOHNSON: I'm Dave Johnson, AIDS coordinator for the City of Los Angeles. It's a pleasure to be speaking with you again. We met in Washington in September.

As the AIDS coordinator for the city, I have to tell you a story of a system of care literally at the edge of a precipice. And as a person with AIDS-related complex, I need to tell you that I am part of a community which has reached the limits of its patience. And I want to acknowledge the substantial number of people from the audience, within the audience, from the PWA community and from Act Up and to reiterate to you what Judge Schrader said, that there is anger, and I think we need to be aware that the anger is more than justified and that indeed in response to what has not happened about AIDS, that outrage is the only morally credible response and that I share that outrage.

I went into substantial detail about the system of care in the written testimony which you have, and I certainly don't want to go over that ground. I just want to summarize by saying that out of a history of quite understandable divisiveness and reactiveness and crisis mode and panic, this community has been able to pull together an extraordinary array of services. The communities affected by AIDS in Los Angeles County have learned to work together, have learned to work with Governments, have learned to work with each other. We have pulled together a remarkable blueprint. We have overcome the hurdle of our difficulties locally with one another. What we face now is that we have a terrific blueprint and no resources with which to implement it. And the existing system of care is beyond -- it has already cracked to the seams. It's falling apart. There are six to eight-week waits for outpatient services. There is no effective prevention program for intravenous drug users. There's only one AIDS ward in the entire county with a daily patient census of four times the number of people who will fit in that ward. We are nowhere near preparing -- we're already behind and we're nowhere near prepared for the onslaught that's likely to come.

The good news is that we've pulled together and we have the blueprint. The bad news is we can't fund it. And that's where the Federal Government has got to begin to play

a responsible role.

I want to talk briefly about the concept of the epidemic peaking and the concept of fewer people being diagnosed with AIDS. There is a dangerous and deceptive mythology that is being created primarily by the fact that AZT is stretching out the amount of time it takes and PCP prophylaxis is stretching out the amount of time it takes for people with HIV disease to acquire the AIDS label. That has nothing to do with doing anything about the fact that we have 112,000 people in this county whose mean T cell level is declining.

People are going to get sick. Unless treatments improve radically, people are going to continue to get sick and if we don't prepare for that, if we pretend the epidemic is ending because AZT is slowing it down, that is an extremely dangerous assumption. And also I would like to point out, as was pointed out by Dr. Osborn, the entire assumption rests in the fact that there are no new infections and that is so preposterous in this county that words fail me to describe my reaction.

There are three key areas we have to focus on -- prevention, intervention, and care. Around prevention, our key need is to finally de-politicize prevention and make it honest. We've got to tell people about safe sex and we've got to tell people about clean needles. If we don't, we're

going to have a lot of dead people around. That's the pure, simple fact. You can help us here. We really only have one major remaining local problem and that's the County Board of Supervisors. And you're in a position to help us there.

Every -- the County Health Department believes, the City believes, that we ought to have effective prevention for intravenous drug users that includes distribution of bleach kits and condoms. This Board of Supervisors is being sued for its efforts to exclude people of color from the Board of Supervisors and we see the consequence of that racist exclusion in the failure of the Board of Supervisors to pursue an effective policy on intravenous drug use and you can help us by challenging the Board of Supervisors while you are here to get in sync with the rest of the nation and begin to effectively work toward seeing to it that we don't have an East Coast style explosion in the I.V. drug-using community.

In the area of intervention, we have months, we have months to get everybody into treatment. Treatment is not a cure yet, but it can slow down the infection. It can prevent some of the most serious infections. The vast majority of people with HIV in this community don't even know about the treatment, let alone have access to it. We need a massive effort, a massive capital investment in early intervention and we need it by yesterday.

We need an investment in distributing information

about treatment, in particular in communities of color, and we need to address the disparity of access for the poor to early intervention programs.

In the area of care, because of the lack and scarcity of resources, we've come up with a remarkable system of alternatives to inpatient care. We need a massive capital investment today to fund that system of care so we will be ready for the onslaught of AIDS cases that is just around the corner.

We have got to address issues of access and care. We have got to create a system that gets people into treatment early, that prevents the spread of infection without political judgment, and that builds care systems that are ready for the onslaught that's coming. And you have shown tremendous leadership in the past in helping to make that happen. I've attached at the end of my written testimony some very concrete specific suggestions around what HCFA, FDA, other agencies of the Federal Government can do, and it's our hope that you will support those initiatives. Thank you.

CHAIRWOMAN OSBORN: Dr. Weismuller.

DR. WEISMULLER: I'm Penny Weismuller. I'm the AIDS coordinator in Orange County Health Care Agency working in the area of public health. I'd like to talk to you a little bit about two components of Orange County's local

response -- coordination at the community and institutional level and case management services which provide coordination at the level of the individual person that has been affected by AIDS.

In selected jurisdictions across the United States, HRSA has provided funding to support the development of coordinated and integrated systems of care. Unfortunately, it is only in selected jurisdictions and unfortunately this funding is not going to be continuing to fund projects at an operational level.

Chief to the development of an integrated system of care is the development of an AIDS coalition that participates actively in planning and implementing various components of that system of care. I think that the citizens of Orange County have benefited from the activities of the county's HIV Advisory Committee because there has been adequate staffing to work with community groups, to work with key leaders in the community to allow us to participate effectively together and to compete successfully for alternative sources of funding from private foundations, from state government, and not to be at loggerheads with one another but to work together to identify what's needed in our community and then to set forth a plan together and work together to put those pieces into place.

One of the things that happens with allowing

adequate staffing for coordinating activities is that we've had some real success in working with other agencies within county government, and I will say that three and four years ago there was community outcry about the lack of response from some of the agencies within Orange County from the community, lack of response from Social Services Agency, lack of response from the Public Guardian, difficulties with law enforcement, and I think that coordinating activities have helped to address many of the concerns of the community and have moved us forward in terms of developing adequate services.

For example, we've developed a very successful partnership with drug abuse services. We have had a detox coupon program funded, public health and drug abuse work together and work with community groups to allow access early into drug treatment, to provide outreach information. No, we're not distributing bleach but we are talking to people, giving them information on the streets, getting them into detoxification and treatment programs when we identify a need, and we've been effective there. We also have established a shelter for HIV positive drug abusers that has proved very successful in getting people to break into that cycle of drug abuse when they're living on the edge.

Right now, there are plans, and you'll hear more about them from Bill Edelman this afternoon, regarding

residential drug treatment options that would include the use of methadone.

With Social Services, we have a foster care program for HIV infected children that includes education for the foster families and medical case management for the zero positive children and I'm happy to report we have more beds than we currently need and I think that's a real success of coordination efforts.

Another success, and not because there is a significant amount of transmission from individuals with behavioral difficulties, but when there are complaints about certain individuals in the community and concern about them transmitting HIV, if we don't respond effectively, we can immobilize the efforts of government, immobilize the efforts of several agencies, and really impune the public trust. I'm happy to report you have an algorithm there of our -- how we will handle difficult patients in the community. I'm happy to say that we have not had to proceed very long -- very far along that path to restrictive interventions because by getting people in the room, getting agencies working effectively together and deciding how can we best intervene, how can we all bring our resources to bear, not only the -- not only public agencies but private community groups, we have been able to deal with very difficult patient situations in a very least restrictive way.

I would -- you all know the value of case management services. I'd like to draw your attention to our patient placement survey and show you that there have been -- there has been success. Now, case management is not the only reason that there's been a reduction in the need for hospital beds for persons with AIDS over the past four years from 16 percent four years ago to five percent today, but case management does play a part.

I'd just like to say in conclusion that HRSA -- I believe that part of the activities that HRSA funds and the demonstration projects, the coordinating activities and case management services, are critical functions. They're not adequately funded by any other source of funding. These are activities that are needed in every community that's affected by the HIV epidemic and we need to provide ongoing and adequate funding for these functions so we can develop integrated systems of care and deal effectively with the epidemic.

CHAIRWOMAN OSBORN: Thank you very much. Dale Fleishman.

MR. FLEISHMAN: Madame Chairman, members of the Commission, I welcome the opportunity to speak to you briefly about the situations in San Diego that make it unique, different than other locales. If you all think of San Diego as that sleepy little Navy town that some of your relatives

passed through after World War II or whatever, let me bring you up to date. This year San Diego passed Detroit. It is now the sixth largest city in the country, the second largest city after Los Angeles west of the Rockies, and San Diego is very isolated from -- is not part of the Los Angeles metroplex. It's cut off in the northern part of the county by a 20-mile wide strip of Camp Pendleton, on the east by mountains, deserts, national forests, and on the west obviously by the Pacific Ocean. The only place we're not isolated is on the south, where we share a common border with the city of Tijuana, a city with an official population of 1.1 million, actually a much larger population than that, and a significant AIDS population and virtually no care for AIDS in Tijuana.

And notwithstanding what the INS might have you believe, there is basically an open border and a lot of people come across from Tijuana into San Diego for care and treatment.

Another thing that makes us unique, I wanted to have the graphics folks also draw an aircraft carrier out there in the ocean but I couldn't get them to do it, but the idea is that we also have a very large military population in San Diego, significant especially relative to AIDS because Balboa Naval Hospital in San Diego is one of the four military hospitals in the country where HIV infected are sent

for care and treatment and a fair number of then who ultimately process out of the military choose to stay in San Diego because they've already established treatment and support arrangements for the disease there.

San Diego has a very high -- continually high incidence rate of newly diagnosed cases of AIDS, approximately 500 new cases in each of the last two years and not showing any decline at this point.

According to the State of California AIDS plan, the region described as south urban California, the counties outlined in purple, will by 1992 have more people living with AIDS than either Los Angeles or San Francisco or any of the other areas of California that you think of in terms of large numbers of AIDS cases.

At this point in time, 89 percent of our cases, as in L.A., are still homosexual and bisexual males and only about five percent I.V. drug users. However, according to a NIDA, National Institute of Drug Abuse, survey completed recently in major metropolitan areas around the country, San Diego is the highest of all areas in poly drug use, highest of all areas in use of methamphetamine, and in a survey of persons incarcerated, we are tied with New York City highest in the numbers testing positive for heroin. All of that suggests that we may very well be in line for a very serious second wave of AIDS among I.V. drug abusers in San Diego.

Let's touch very briefly on service delivery systems. San Diego is unique in that we have no county hospital, no county operated primary care clinics. We are dependent on the University of California San Diego Medical Center and private sector clinics and physicians for care for virtually all AIDS services. Some of them are dealing with the case load problem by putting caps on the number of AIDS cases that they are willing to see. And because they are private sector, they can do that up to the point of running afoul of anti-discrimination laws.

San Diego, like most other areas, has very little dental care, virtually no skilled nursing facilities that will take AIDS patients. We have -- we know we have in San Diego persons with AIDS not quite sick enough to be in a hospital that are now living in Balboa Park because there are no 24-hour facilities for them. We, like everyone else, also have inadequate drug rehab slots.

A key element that assists San Diego right now in meeting AIDS needs is the HRSA demonstration program, similar to Orange County. Two thirds of all AIDS case management in San Diego is provided under HRSA funding, which ends in September. Most of the mental health counseling in San Diego is also HRSA funded and a number of other key services.

Continuation in funding from HRSA or from some other federal source is going to be critical to just

maintaining the services we currently have in place. It's especially a problem in San Diego, and I'm not going to go into all of the reasons why we ended up in this mess, but San Diego County post Prop. 13 has been just about the most short-changed county in California for a number of historic reasons.

In terms of our per capita share of the state revenues that come back to the county, San Diego is 57th out of 58 counties in California. The one county that is 58th, the very small county, is the one you may have heard in California that looked into filing bankruptcy a year or two ago.

We -- if we got the statewide average per capita of state revenues back to the county, we would have $146 million additional in San Diego discretionary revenues to spend on needs such as AIDS programs. We don't have it. We're not going to get it. That's just a reality.

Without some ongoing federal help, our ability to meet the AIDS crisis is going to be diminished at a time that the case loads continue to grow rapidly. We look to your Commission for some assistance to keep this from happening. Thank you.

CHAIRWOMAN OSBORN: Thank you very much for -- in fact, thank the panel for some very powerful testimony. We have such a tight schedule that it is painful to have to

condense things so much. I think that it would be important to add at least a couple of questions and opportunity if we can, even though it will run us a little bit late. Congressman Rowland and then Don DesJarlais.

HON. ROWLAND: I just want to ask Mr. Fleishman, you say there are a good many retirees in the San Diego area. You have some military that is retiring there that have AIDS?

MR. FLEISHMAN: No, I'm speaking of the persons that were transferred to Balboa Naval Hospital because they were HIV infected and then processed out of the military when their term is up and a number of those remain in San Diego because the support systems are already there that they're hooked into.

HON. ROWLAND: Are they getting any care from the Veterans Administration there?

MR. FLEISHMAN: Yes. Oh, yes, we have a V. A. Hospital in San Diego that's also overloaded with AIDS cases.

HON. ROWLAND: That's playing an important role then in the San Diego area?

MR. FLEISHMAN: Oh, absolutely.

HON. ROWLAND: Thank you.

DR. DESJARLAIS: Again a question for the gentleman from San Diego. Again with reference to San Diego, you present a somewhat grim picture of the possible massive increase in HIV infection among drug users. What are your

current prevention programs for drug users with respect to AIDS in San Diego?

MR. FLEISHMAN: We have one NIDA funded program that's currently doing outreach directly with I.V. drug users. Its funding ends in June and it is not going to be extended.

DR. DESJARLAIS: And are you distributing bleach as part of that?

MR. FLEISHMAN: Yes, we are. The other -- there are additional state and federal funds coming in to San Diego to establish treatment slots, but we have an extremely difficult problem finding places to locate 24-hour drug facilities. We have monies we can't even spend right now because we cannot find a neighborhood that will allow a facility in.

CHAIRWOMAN OSBORN: Larry Kessler.

MR. KESSLER: Dr. Taylor, I would -- you say that San Bernardino has no outpatient services. Is that in every category?

DR. TAYLOR: They have no outpatient services for the HIV infected individual.

MR. KESSLER: But they have outpatient services for people with other diseases?

DR. TAYLOR: Yes, sir.

MR. KESSLER: And other conditions?

DR. TAYLOR: Yes.

MR. KESSLER: Well, then why would you expect that the Federal Government provide only those outpatient services for HIV related cases? I mean, it seems that if you -- from what your testimony, it sounded very clear that you have made a decision that you don't do HIV services for HIV people or infected people, but do provide them with other diseases, and it seems a little discriminatory on that basis.

DR. TAYLOR: It most assuredly is but I, you know, welcome your Commission to come to San Bernardino County and talk to our Board of Supervisors about that. It has been a conscious decision not to put any money into this epidemic. San Bernardino County's AIDS activities are entirely grant-funded. It is a zero net county cost program and that is the decision that was made at the Board level.

MR. KESSLER: Well, I can't speak for the officials at HRSA, but I think that's going to be a problem.

DR. TAYLOR: I recognize that.

MR. KESSLER: When they look at that sort of record. I also have a question for Mr. Fleishman. I'm not particularly familiar with the rules and regulations and the laws in terms of the Republic of California, but if you are only getting -- if you're 57th or 56th out of 57 per capita share of your revenue that's coming back to the county and you claim that you could put that $146 million into things

like AIDS and HIV services, you might want to look at an initiative proposal or some sort of cecession from the Republic because you're clearly getting screwed. And as a result, your elderly and your poor and your people with AIDS --

MR. FLEISHMAN: San Diego County has actually a lawsuit against the State of California that we are pursuing for a fairer share of state revenues, but that will still take several years to wind through the courts, and then may or may not succeed. The reality is that in Sacramento, the Los Angeles, and San Francisco Bay area counties dominate the state legislature. That's just the way it is.

MR. KESSLER: We do have a one person, one vote, one rule, or precedent in this country and I think it includes California.

MR. FLEISHMAN: Establishing a more equitable funding formula would take away from some large, well represented areas.

CHAIRWOMAN OSBORN: I think the Commission would love to keep going on this for quite a while. I'm going to take one last question from Harlon Dalton or comment and then I think we're going to have to proceed in order to stay anywhere near our tight schedule for the day.

MR. DALTON: It's really more in the nature of a comment for David Johnson. You're eloquent as always, which

is important, but my comment really has to do with your written testimony which I really appreciate and which is going to be very helpful to us and I just had a chance to sort of skim through it and particular piece on early intervention, but I --

DR. ROGERS: A little bit louder.

MR. DALTON: I just want to say that Scott Allen at the other end of this long table that, Dave, I think has done a fair amount of the work that we need to do for us and we appreciate it.

MR. JOHNSON: Thank you. I just want to point out also in regards to Los Angeles County when we talk about wouldn't it be nice if we could just reshuffle revenues or if the local health authority would make a commitment to outpatient care. We have a commitment here to outpatient care in Los Angeles County. Dr. Finn pointed out it would cost another $166 million to bring it to the levels we need. That money does not exist in the local tax base. It does not exist. A disaster has occurred in Los Angeles County. When there's an earthquake and bridges fall down, when there's a hurricane and houses blow over, the Federal Government coughs up $5 billion to fix the freeways. We need that kind of investment to save the lives of a million people.

CHAIRWOMAN OSBORN: We are going to take a strictly ten-minute break in order to give people a chance to stand up

and stretch since our next panel is going to be very substantial in terms of numbers of presentations. I will call us back to order with or without order in ten minutes.

(A recess was held.)

CHAIRWOMAN OSBORN: I'm going to start, despite the absence of a few people who will come in. The Commission is very eager to maximize the opportunity here and to talk with people, and so I hope you will be understanding as Commissioners are momentarily away.

We have now quite a complex set of presentations, a total of nine people who will be talking about access to care, and just in terms of the size of the table, I think they will be working in batches, so I will ask you to introduce yourself as you go. I presume you are -- have a sequence that follows our order here, starting with Mr. Gates.

MR. GATES: Good morning. My name is Robert Gates. I'm the director of Health Services for the County of Los Angeles. I have provided written testimony to your Commission which I will not repeat or read to you, but rather I thought I'd give you an overview of the situation and we'll go from there.

The Department of Health Services is an extremely large, complex organization. We operate six different hospitals. Most of those are providing treatment to AIDS

patients. Two of them you will visit tomorrow, L.A. County USC Medical Center and Martin Luther King/Drew Medical Center.

The L.A. County USC Medical Center is a major provider of care to AIDS patients in this county. We also operate a ring of outpatient clinics throughout the county. We operate the AIDS program office which coordinates AIDS activities. And in general, it's a fairly large operation. Our budget is $1.7 billion. We have 24,000 employees.

One of the things I do as director of Health Services is serve as a lightning rod for frustrations in the community. I think people who are not happy that we're not moving as fast as they think we ought to or feel that there isn't enough money for the services they need and they do need money for services tend to focus on me and my department to voice their frustrations. We are local. We're accessible. But as I think you've begun to get an impression, we have funding problems that go far beyond our county borders. As an entity of local government, particularly under what's called Proposition 13, our local funding sources are rather fixed. We cannot increase taxes even if we wanted to. We must get state approval for any tax that we would impose locally.

We are very much a creature of state government and we've been suffering for several years by a lack of adequate

funding from the state level. I think that extends also to the federal level when it comes to funding, particularly in the AIDS area, but we're seeing problems here locally in trauma care, in emergency care, in providing adequate O.B. services and throughout our system we are short of care, and when it comes to increasing funding locally for this particular problem of AIDS, it has been extremely difficult and yet we have increased our budget. Three years ago, it was around $15 million, then it jumped to $40 million. This year it's $60 million total and of that, about $20 million is net county cost, so that's our local contribution and that's been sort of eeked out in an era where the total county funding has been stacked, so whatever we put into AIDS has been at the expense of other programs.

We have had a very extensive planning effort here in the county recently to try and bring as many people as possible into the solution of our problems and I think you've heard earlier some expressions that that planning effort has been successful in formulating what is needed, and the problem at this point is how to pay for it which extends far beyond our ability to deal with it locally.

Several areas we need more money in. One is prevention activities. I think we've done an excellent job of formulating what is needed, but to do it is costing -- would cost money that we don't have. In the area of health

services directly, we do need more funding for our hospital system. We do have an AIDS ward that is mentioned that I think is a model program but it isn't enough. We need more capability in our hospitals, particularly in the outpatient area. We're struggling to put together as fast as we can a new outpatient building, but procedural delays are a frustration to all of us in that process.

We need more outpatient services out in the community. I would particularly stress the point that Martin Finn made earlier. To get the job done in early intervention, massive infusions of money are needed. We have a need we calculate of something above $150 million to really do that job properly here in this county and we can't even approach that magnitude of funding. The total county contribution to our entire health department and all of its operations is about $240 million, so you can imagine the difficulty and in essence impossibility of trying to get $150 million for this one activity. It can't be done locally. We need help from the state and particularly from the Federal Government. We're faced with a national problem, a national disease, and a national crisis and we need national help that goes beyond our own ability to fund the problem.

So I guess that would be the one message I would want to leave with the Commission, that the word has to get out that this is not a problem that can be handled locally.

I think not just here, but everywhere, it needs the kind of capability financially that the Federal Government I would hope could bring to dealing with this crisis.

CHAIRWOMAN OSBORN: Thank you very much. The next -- what I'm going to do is to have the group of four who are already seated at the table each present if they would and then give the Commissioners a chance to interact and then go on to the next group so that we can try and have a -- remember who said what in an orderly way, and so I'll go on to Mr. Jordan. Very nice to see you again.

DR. JORDAN: Thank you. I am Dr. Wilbert Jordan. I am director of AIDS clinic at King Hospital. I also have a private practice and I treat AIDS patients in the south central area. I have treated -- most of the black physicians in the south central area refer their patients to me.

There are two issues that I would really like to address for the Commission. As a provider, one of the problems that we have in terms of trying to get other hospitals to also treat patients is the fact that particularly Medi-Cal, some of its regulations, which are federal, will not pay for a patient if he or she needs to get an investigational drug, even if that's the only drug that will save their life. And to me if the Commission, if the Department of Health Services, Human Health Services, could simply and I would think easily streamline some of the requirements

whereby a patient who needs to get an investigational drug for compassionate use because any other drug would result in his dying, should be allowed to stay in the hospital. We have developed a program in the south central area that work with other physicians so if we at King are basically full, I can refer patients to other doctors that work with me, but I will still remain the I.V. doctor on the case.

The problem comes that the hospitals don't want to take the patients because they are afraid that if the patient needs a compassionate drug, they won't get paid anything. And to me it is totally ironic and stupid to have this as a federal regulation for any patient, whether it's an AIDS patient or any other patient who needs a drug. If it's available, then this person to save his or her life, they should have it and I would hope that the Commission in looking over this could recommend or make a stand that this be alleviated and changed so in those circumstances people could receive those medicines.

Often I am called to go to other places to see patients as well. In terms of the black community and though I think this also pertains to the general community, I will really focus just on the black community and black physicians. I think in terms of the black community and black professions, we have lagged far behind in terms of dealing with AIDS and often I have gone out of state to see

patients.

In one instance, I went to Alabama or to Memphis, Tennessee to see a patient who had come with her son from Alabama. He had AIDS. And interestingly, this lady had -- her left eye was closed. There was an obvious scar, an old scar. And in talking to her, she commented that she got that scar in the 60's marching in the Civil Rights movement when two policemen knocked her down and billyclubbed her. And it just hit me, I thought it was a sensation to think that this lady had marched and one of the consequences of her marching was this scar she has to carry, but it was also the fact that many of us got into medical school and into law school, and it seemed very ironic that this lady now who when she reaches back for help for some of those people whom her marching and the scar she's carrying, they're not there.

In this community, I have three dentists that I can call on, whether the patient has an acute problem or whether it's a general problem. There are three dentists in my area I can call on, two black and one white. I can't get the others.

I would request that the Commission would ask the Secretary of Human Services to in the same way he made a very passionate plea to the tobacco industry to not push a cigarette aimed at blacks, that he would address the black dental and the black medical associations to get them to come

into the 1990's and to become more responsive. In some states, there are still one doctor, black doctor, who will treat AIDS patients. It doesn't matter that all black patients have to be seen by black physicians and vice versa. It is still a tragedy when as professionals we lag that far behind. And that is a reality we must face. And I would ask you to request from Secretary Sullivan to address both the National Dental Association and the National Medical Association to ask them to really do a more comprehensive effort to get more black physicians to treat their own and treat these patients. Thank you.

DR. AKIL: Good morning. My name is Bisher Akil. I'm an assistant professor of medicine at the University of Southern California.

DR. ROGERS: You might bring the mike a little closer to you there. Speak firmly.

DR. AKIL: Okay. I'm an assistant professor at the University of Southern California. I'm a member of the AIDS Service at Los Angeles County University of Southern California Medical Center which is the facility that you're going to visit tomorrow and a staff physician at Kenneth Norris Hospital which is an affiliate with the University, and I appreciate this opportunity to share my thoughts about the access to medical care in our community for people with HIV disease.

There are three chief problems impeding adequate care to people with HIV. First, we're not reaching people who most need to be reached. Second, we are not providing a methodical system of medical care. And, third, we are not utilizing our community-based organizations often.

I propose a three-point plan in an attempt to solve these problems. The first step of the plan is expand the outreach to people at greatest risk for HIV infection, especially those who traditionally have been hard to reach, such as people of color, women, Hispanics, and other minorities. This reach -- this is best accomplished by members of the affected communities themselves.

The second step of the plan is establish a third-tiered -- a three-tiered system of care for those who test positive. The first level would provide counseling and zero markers, such as CD-4 cam (phonetic). Based on this preliminary evaluation, an individual would either remain at this level receiving periodic monitoring or be referred to the second or third level. The second level is designed to provide care for those with minimal symptoms and moderate immune impairment. This level features early intervention with anti-HIV therapy and primary prophylaxis against other infections as well as the usual monitoring. The third level is reserved for those with active disease who require advanced medical services. Hospital-based facilities are the

most appropriate sites for this level of care.

However, in order for this three-layer model to be effective, there must be a free flow of information between the levels.

The first step of the plan is to improve the outreach. The second step of the plan is to establish a three-level system. And the third step is to strengthen the role of the community-based organizations. Community-based organizations should be involved in the community outreach. They should also be involved in all level of care in the three-layered health care system proposed. Community-based organizations should be particularly involved in supporting people as they move through the system and in acting as patient advocates.

Although the County of Los Angeles has enacted parts of the plan, implementing it in its entirety requires allocation of resources and those resources should not be at the expense of other health care programs and we need your help in that matter.

I believe that with adequate resources, this plan of expanded outreach, three-layer medical service, and strong community-based organizations would in short improve access to health care for all people with HIV. Thank you for your attention.

MR. SOLIS-MARICH: Good morning. Thank you -- I'd

like to thank the National Commission on AIDS for providing me with this opportunity to testify. My name is Mario Solis-Marich. I'm an openly gay Latino man and I'm an activist. I was -- I participated on the working group for Parallel Track and I'm currently on a national working group that is designed to make the ACTG process community-accessible.

When I think about the work that I have been able to do in the past few months on the Parallel Track working group that is designed to make experimental therapies more accessible to people of color that currently only comprise 11 percent of all the people in experimental drug trials, 11 percent of all people in experimental drug trials are people of color. I think that in many ways it's like stepping -- it's a quantum leap for the community in that many people of color and gay and bisexual people of color who here in L.A. County comprise 80 percent of the people of color who are HIV infected aren't even aware of the benefits of AZT or -- and also are not aware of the benefits of aerosolized pentamidine.

I think that before we move into making -- or as -- hopefully, as we move towards making treatments more accessible, we also make the information about those treatments more accessible.

Currently, the focus of -- the media focus that DDI has brought about and that has put pressure on the FDA and

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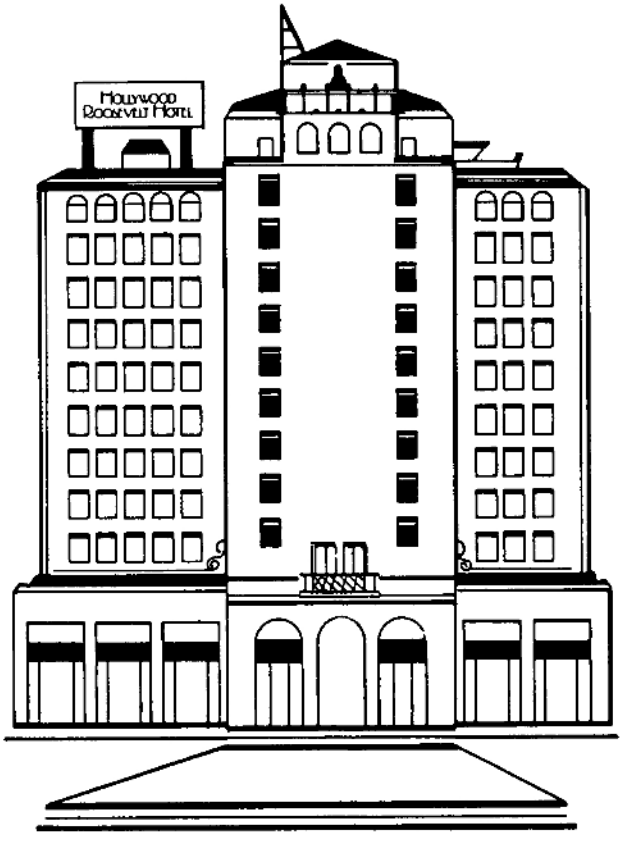

the National Institute for Allergies and Infectious Diseases to create Parallel Track, that pressure has died down and that's very unfortunate. I was told earlier today that that Parallel Track document which is currently on its second or third final draft, is almost completed. However, I have to say as a community activist and as an openly gay man who has suffered many losses through this epidemic, that I am disappointed with the outcome.

The public health service has not seen it as its responsibility to put strong language into that document and to work with the FDA to put strong language into that document that would make Parallel Track accessible to all people, including the medically disenfranchised. I'm asking this National Commission on AIDS to carefully review that document that will be produced and notice that logistical access to people who don't have private physicians is not strongly called for. I'm not saying that I am completely disappointed with the input that we put in. There were -- there is some access language that we were able to insert successfully and that we were able to encourage. However, the work has just begun. I also -- in ending, though, I would like to commend the FDA and the -- especially the National Institute for Allergies and Infectious Diseases for continuing to look for community input.

As we found here with the county planning process,

that is always the first step, is to take community input. However, the second step is accepting that input as expertise and implementing that input. Thank you very much.

CHAIRWOMAN OSBORN: Thank you all for your important statements. I would like to give -- take this chance for the Commissioners to interact with this subset of the group that will be talking to us about access. Scott Allen.

REV. ALLEN: I have some questions for Mr. Gates. One of the -- well, the first issue of our working group --

DR. ROGERS: Scott, pull that a little closer to you.

REV. ALLEN: All right. The first issue of our working group, the human social issues, the concerns there is going to be testing and early intervention, and from what we've heard in Los Angeles, would you recommend a person that may have been involved in high risk behavior to get tested and to access the system at this point, considering the lack of early intervention of Los Angeles County?

MR. GATES: Run that question by one more time.

REV. ALLEN: Well, I'm concerned that we are -- we are perpetuating the potential hoax that you get tested and there's stuff out there, that there's help available, and the person that does get tested finds that they may lose their job, lose their insurance, and still be -- have a great potential of functioning in our society, contributing to our

society, and the early intervention isn't there. The drugs are not there. The places are not available. And I'm just curious on -- as we move into this looking at early intervention and advertising, this is the way we should go as a country.

Would you recommend a person in Los Angeles get tested and access the system and is the system there?

MR. GATES: I think it depends somewhat on their financial status. Unfortunately at this point, someone who has ability to pay probably is somehow going to be able to get care. I happen to believe it's important for people to know what their status is, irrespective of the care that might be available, so I would personally endorse people becoming aware of testing in any event. I don't know quite how to respond to the issue of unavailability of services. They need to be developed. We need help and we don't have the resources to get that job done.

REV. ALLEN: Well, this is along the same lines. I did meet -- one of my site visits was to Act Up L.A. and we talked about some of the issues and some of the frustrations and talking about the West Hollywood Model Clinic, and if you could elaborate on what is this clinic going to do and what is the status, and I talked to some of the folks from the county as to where this is going. Why is this under the auspices of the AIDS program and the shift in looking at

should it be under the hospital district. What's happening with this West Hollywood?

MR. GATES: It is set up as a model clinic. It is operated at the moment by the AIDS Program, Los -- excuse me -- our AIDS Program office. The idea of it is to deal with people who are HIV positive but are not yet showing any significant symptoms, so it's -- the whole idea of it is early intervention and something we've been pursuing for the last couple of years. It is not moving along as rapidly as some people would like in its capability of providing services, and it is not the complete answer, as you've heard, to the kinds of problems we're faced with. There are those who feel that it should be organizationally placed under the L.A. County USC Medical Center in order to enhance the clinical expertise of that clinic and there are other points of view, and at this moment we are reanalyzing where it ought to be located organizationally.

REV. ALLEN: Where do you think it should be?

MR. GATES: I don't have a conclusion right now. Maybe under the medical center. We have a very large outpatient operation in our department that consists of comprehensive health centers and health centers. That's separate from the hospitals and that's another possible organizational location. I think in any event we're going to want to have closer clinical affiliations between that clinic

and the medical center, whether they run it per se or whether they don't. I think that's a desirable direction.

REV. ALLEN: May I ask another question? One of the concerns that the group had was the six to eight-week wait in the outpatient clinic of the county hospital, and is that going to be expanded; are the services going to be expanded there? It just seems like from what we've heard, everything is very fragile at this point and we're moving towards that early intervention, and is that going to break the system? If we are going to keep up with this, what type of expansion is necessary in the county level to diminish or dissolve that type of waiting list? What is the status of that?

MR. GATES: The plan at the L. A. County USC Medical Center, where we do have a six to eight-week backlog, we do have a problem there. The immediate plan is to take space in an adjoining clinic and make that available which will help some. The better solution that will take more time is an entire new outpatient building just for AIDS and that is under way as fast as we can get it together and up and running. And some people are frustrated, including myself, that that is not happening more rapidly, but that's a much larger building that will be much more satisfactory. Some of these things just take time. You cannot move things --

AUDIENCE SPEAKER: Ten years.

REV. ALLEN: Another question is when you're talking about it's going to be labor intensive, and is there some type of program that -- intentional steps to expand the physician care and the nursing care and so forth, some type of recruitment? You know, I deal in Texas with burnout level of those that have been on the front lines and those that are just tired, and their case load is so high right now they can't take on any others, and we see that across the country. In L.A., what's happening there?

MR. GATES: I don't think we have the answer to that either. We had an extremely difficult time staffing our 20-bed AIDS ward. In fact, we went through national advertising, national recruitment, local recruitment. We did everything we could think of and still were able to only hire initially one or two nurses out of a couple of dozen we needed. We ended up bringing people in through registries and other really not very satisfactory mechanisms. Getting these things staffed is a major problem and that's getting them staffed initially. Keeping them staffed with the burnout factor is -- I agree with you that it's a major problem and I don't think we have the answer.

REV. ALLEN: The final question I have is I've heard several comments about the Board of Supervisors and we've heard testimony earlier. What type of -- what can be done basically is -- what can be done in the relationship of

the Board of Supervisors, the County Health, and the community when we find that there is such a resistance to care and do you have any suggestions? Is there something that can take place in that whole dynamic that could be helpful? Because this is not an isolated event. We find this in counties all over the country, and I'm appalled at my own state of the lack of compassion. I'm surprised at the lack of compassion here. And I'm just -- it just hurts and it hurts over and over and over again, and I'm -- I've dealt with political systems for a while and I know the timetables and I know how long it takes, but it just doesn't seem like it would take that long. And some of the frustration that I sense here, that I sense in my own community and I sense across the nation, it's -- what can be done?

MR. GATES: I couldn't even -- I don't know that I can answer that question quite honestly.

DR. ROGERS: Let me escalate it a little bit. The thread that's run through the morning, and I'm just building on what Reverend Allen has said, is a shocking absence of funding programs for sick and dying people in the State of California. If you'll let me finish, I may get worse. I would have thought that one of the first duties of Government is to take care of its ill, of its have-nots, to find that California is permitting this to go on and that there seems to be such a passivity about it. We on this Commission are

clearly going to be asking for more federal funds and I've heard this from everyone, but here is one of the country's wealthiest states and we can -- it seems to me as an outsider, we're watching what was a once proud health system be absolutely disassembled. What the hell is the matter with Californians? Why don't they pay for the care that is needed? And this means everyone in this room, too. I think you are in part responsible for demanding. If it takes more taxes, fine. I think -- but you simply must develop the funding that all these individuals need for their care and I'm surprised at the passivity of simply asking for federal funds when the state has clearly got to do its job sometime. What can we do to be helpful to all of you in that respect?

MR. GATES: I think getting that message across is extremely important. We've been very frustrated by the lack of adequate support from the state and people focus on L. A. County, but I think the -- I've heard earlier that the San Bernardino County Board is not willing to put in one penny of local money. I've heard about problems in Orange County and elsewhere. This is not just an L. A. County situation. It is statewide and in my view reflects a systematic underfunding of our health program by the state for a number of years. What's the answer? Maybe focusing on the problem is part of it.

DR. ROGERS: I would suggest develop an adequate

funding of your health care system and then I think we will ask for more at the federal level to try and bail out your areas of particular concern.

CHAIRWOMAN OSBORN: Don Goldman?

MR. GOLDMAN: Yeah. I just had a -- I believe that some number has been given that in terms of the early intervention arena that the county is only providing one percent of the funding that would be necessary based upon an estimate. I think the number was something in the area of $150, $160 million to provide those funds and there apparently one percent of that, about one and a half million dollars in terms of early intervention. Is that one percent figure -- in other words, is the county of Los Angeles typically not funding 99 percent of its health needs or is that something peculiar to AIDS and HIV infection that it only funds -- that it only funds -- that it fails to fund 99 percent of its health needs?

MR. GATES: No. I think it focuses on early intervention. In terms of inpatient care, we are providing care in our system and elsewhere in the county for patients who need it, I believe. We are short of alternatives to inpatient care, but those are being developed, so I think it would not be accurate to say that we're not meeting 99 percent of the needs. In this one area, which is an emerging one, and these estimates you're hearing are very new

estimates that result from very, very recent planning, we're just beginning to see the magnitude of what would be required to do a proper job in that area.

MR. GOLDMAN: And isn't there an understanding that to do so would in fact likely -- good early intervention would likely reduce the cost of the in-hospital care and the other kinds of care that in fact you tell me the county is paying for and whether, assuming that it is. I mean, I don't understand how you can -- how you can acknowledge a responsibility and a need of that kind of magnitude for this kind of problem where you're not only dealing with the safety of people -- with the safety and the well-being of people's lives, but you're dealing with the safety and lives of the entire community as well and you're simply saying that it's perfectly appropriate to fund it at a level of one percent of its estimated need. Just -- I don't -- it just seems to me to be incredible.

MR. GATES: I just think you're making the comment to the wrong person. We don't have the funding capability to begin to cope with $150 million and maybe the State does, maybe the Federal Government does, but I can assure you that the county does not and we need help.

MR. GOLDMAN: I had thought and maybe I'm mistaken that Dr. Kaiser, at least when he spoke to us last night at a reception, indicated that the State of California had

obtained certain waivers from HCFA for its medical program in terms of providing coverage for certain kinds of outpatient activities, so there is -- so there should be coverage, shouldn't there?

MR. GATES: In order to get on medical you have to have AIDS. Now, we're talking about a group that by definition does not have clinical AIDS, so that's of no help in this case.

MR. GOLDMAN: That's a Medi-Cal rule.

MR. GATES: Medi-Cal -- you have to have AIDS before you can be eligible for Medi-Cal.

AUDIENCE PARTICIPANTS: "That's not true."

CHAIRWOMAN OSBORN: Let me take one last question from Larry Kessler and I think we'll want to hear from the rest of the people who were talking about access to care so that we don't run out of time. Larry, why don't you go ahead.

MR. KESSLER: Mr. Gates, has there been any thought of a strategy of declaring a state of emergency or an emergency condition in the county that will enable you to move a little faster? It just seems so obvious that when you look at the numbers that are currently existing and the people involved in those numbers, and the numbers of people coming down the pipe, that you have a situation that's equivalent to earthquake planning or earthquake response. And

if we had an earthquake here, there's no doubt in my mind we could drop a few modules on the campus of east L.A. and put them up overnight.

I know how difficult it is to build buildings and get permits and so on, but with your climate, with the kind of need that you have, there ought to be an interim solution to providing that kind of outpatient service and clinic space using modules, using eminent domain if necessary to get some buildings and to set up the systems. People are not going to be able to wait two, three, or four years until architects get done designing --

MR. GATES: A couple comments. Number one, that's exactly what we did in creating the AIDS ward. There was great skepticism that we could get that done by September by a lot of people and it was done and that's because we declared it an emergency and we did the work with our own forces. Unfortunately, the kind of building we're talking about just takes time. We are trying to do it in the fastest possible way. It will be done far faster than conventional construction. It will not be three or four years I would assure you. But it does take some time.

AUDIENCE PARTICIPANT: "That's 22 beds."

MR. KESSLER: The numbers just don't add up. That's -- I'm just stunned beyond belief in terms of how much effort it's taking to get one unit of 22 beds when we're

talking about 8,000 people currently.

MR. GATES: We could spend a lot of time on that. They are receiving treatment at the medical center and there are some patients at the hospital who aren't appropriately located in the kind of a general ward that we're talking about.

CHAIRWOMAN OSBORN: I think I want to move us along, if I may, to the other five participants on our panel that basically includes nine people but with fewer chairs than that. Thank you very much for your --

AUDIENCE PARTICIPANTS: Thank you, Commissioner.

CHAIRWOMAN OSBORN: Again, I think everybody has heard me say this, but we're using our low tech kitchen timer to try and make sure that we have a chance to interact with witnesses as they -- after everybody has had a chance to complete their statements so you'll hear the little bell go off and we appreciate any way you can make your initial presentation, so we have time for what has been very valuable interaction. I'll ask you to introduce yourselves as you start, please. We are finding that leaning into the microphones and only some of those microphones works -- is it Mr. Wilson who will be the first witness from the Black Gay and Lesbian Leadership Forum?

DR. ROGERS: Mr. Wilson, pull that mike right in front -- good.

MR. WILSON: Good morning. My name is Phil Wilson. I am the education director of the National Task Force and AIDS Prevention. I'm also the co-chair of the Black Gay and Lesbian Leadership Forum. But most importantly, I'm here today as a person living with HIV disease addressing the issues to access to care. I've debated as to whether or not I should tell you about some of the men that I deal with everyday. If I should tell you about a patient of mine who attempted to jump out the window last week, not because of the pain or discomfort of his illness but because of his shame, because of the stigma of being black and gay and HIV infected, or should I tell you about the black gay man who lives in his mother's garage because his mother's afraid to have him live in the house. Or maybe I should tell you about the young man who I picked up from the county jail not too long ago who had lesions all over his body. He weighed only 85 pounds and he could not walk. He had been arrested for stealing a melon because he was hungry and homeless.

These stories are not new. They are the same stories told nearly ten years ago when the horror of AIDS first began to be revealed. What makes these stories special is the fact that it is ten years later and still among black people with AIDS, the nightmare continues.

Two weeks ago the L. A. Weekly ran an article about local heros. This honor made me consider the reality of the

war against AIDS in this country. What honor can there be in being a hero in a losing battle. History teaches us that those who exhibit valor on behalf of the conquered become the forgotten. There's an increasingly large body of evidence that suggest that those of us who advocate on behalf of people with AIDS and those of us who are ourselves infected with the HIV virus are already forgotten, especially if we are black and gay or bisexual.

According to the most recent AIDS surveillance statistics from the L.A. County Department of Health Services, there have been approximately 8,409 cases of AIDS reported as of November 30th of 1989. Blacks and Hispanics represent 16 to 18 percent respectively of these cases. By 1991 it is projected that the number of AIDS cases in L.A. County will increase to the range of 19,000 to 44,000. Of these individuals, an estimated 16 to 23,000 will have died leaving from three to 21,000 seeking medical, psychological, social, and other services in the county. To date, there are seven residential care facilities and one hospice providing a total of 89 beds. The availability of 89 beds in this county that currently has over 8,000 cases of AIDS with a fatality rate of 86 percent will in no way adequately address the needs.

In Los Angeles County, black gay or bisexual men represent less than one half of one percent of the general

population. Yet 13 percent of all people with AIDS in this county are black gay or bisexual men. The same group represents 23 percent of the gay and bisexual cases and 77 percent of all black cases in this county. If you consider those men who are both, gay or bisexual and I.V. drug users, the percentage of black people with AIDS who are gay or bisexual rises to 81 percent. Yet until November of 1989 the county of Los Angeles spent not one dime specifically targeting black gay or bisexual men through autonomous gay or bisexual organizations.

There is a relationship between sexual transmission between men, between I.V. drug users, and the infection of black women in the progeny. Here HIV positive women are overwhelmingly infected by sexual contact with HIV positive men, many of whom are bisexual. In short, if we do not address the issues of AIDS among black gay and bisexual men, then we cannot address the issues among black women and their children.

The current daily census at County USC Hospital is approximately 60 to 80 people and steadily rising. Yet the current AIDS unit is designed to hold only 20 beds. It is simple to see that even though the unit is state of the art, it is woefully inadequate. The county outpatient clinic, 5P21, has been overcrowded for as long as it has existed. They have too many examining rooms. They offer no comfort

for the patients who wait two, three, or four hours for their chance to see the overworked and unbelievably dedicated nurses and doctors who are forced to work under horrendous conditions.

Is it right that a patient has to get I.V. chemotherapy with vomit-inducing medications in full view of 20 or 30 fellow patients? Is it right that the patient has to strip to the waist in the hallways so their lesions can be measured and check all in full view of anyone else who happens to be around? So why are we losing the war? Because ten years into this epidemic, we still are not taking measures to repair or replace a collapsing health care delivery system. Ten years into this epidemic, we still cloud the medical reality of AIDS and HIV disease with destructive dialogue about moral judgments and blame. Ten years into this epidemic, we are still slow to empower and fund those of most at risk to HIV infection to defend ourselves against this deadly virus. Ten years into this epidemic, policymakers want to believe that all people of color are I.V. drug users and non-gay people of color institutions want to pretend that we, gay people of color, do not exist. Ten years into this epidemic, if you are poor or black or Latino or Asian or native American or a gay person of color, often you are still uninformed. You still do not know about aerosol pentamidine, AZT substitutes, the promise

of DDI or DDC or the possibilities of clinical trials and early intervention. And even when you do know of these things, often you don't have the means or the financial wherewithal or connections to access them.

DR. ROGERS: Mr. Wilson, I'm sorry. You're going to have to finish up very soon. My apologies, but we will read your statement. Could you conclude there?

MR. WILSON: Yes. We speak about the second wave of the HIV infection. We say we know that people color-infected at this proportionate rate but our health care delivery systems still are not designed to reflect these new populations.

As I speak to you this morning, I come with ambivalence. I wonder if the meeting with you will be different from other meetings that we've had. I debated whether it was more important for me to spend this time talking to black teenagers in south central who may not be infected and who as a result of our meeting might be spared HIV infection. Do I spend this morning discussing early intervention with an asymptomatic HIV positive gay man who as a result of our interaction may delay the symptoms. Do I spend this morning advocating to get a PWA into a hospice and assure that you will not be forced to die alone and on the streets or do I spend this morning talking with you and hoping and praying that you will understand the world we live

in and attempt to help make a difference? I'm here and only you can decide whether or not I made the right choice.

DR. ROGERS: Mr. Wilson, we thank you for making that particular choice.

CHAIRWOMAN OSBORN: J. Craig Fong of Nation Pacific Legal Center of Southern California.

MR. FONG: My name is J. Craig Fong. I am the director of the Immigration Project at the Asian-Pacific American Legal Center of Southern California.

I am here today on the panel discussing access to care. I have been put here primarily because they didn't know where else to put me. I am not going to be talking to you today about access to care in a strict sense. And surprising to some of you, I will not be asking for money. I want to talk with you a little about the effects of a regulation and a law that has been passed by the Federal Government on immigrants to the United States. Immigrants are in some senses a forgotten group; they're very easy to forget about -- pushed around. Perhaps many of you do not know that, at least as far as I know, on a national level the issue of universal testing that has been one that is very controversial. And yet immigrants are subject to universal testing in the United States. What I would like to do is explain how this program has affected this group of individuals.

This testing began about two years ago. All immigrants to the United States are required, all permanent immigrants let's say who want to get Green Cards, are required to be tested for the HIV virus. Without boring you with the arcane immigration law, let me just tell you they have to go to a specific kind of doctor, a designated civil surgeon that is designated by the Immigration and Naturalization Service. I could tell you countless stories who have come to be, not just here in Los Angeles but nationwide. What they tell me is when they go in to the designated civil surgeon, the blood is drawn, the exam is given. They go back two or three days later to get the results. Anyone who is HIV positive is often told in the middle of a very crowded waiting room, "Here's your medical report. It's sealed. You are not permitted to open it, only the Immigration Service. Take this to them. By the way, you have AIDS." Now you have to understand, as I'm sure that most of you do, that the impact of a statement like that is devastating. Most especially on a population of people who are not that well informed about AIDS. They understand that AIDS is deadly. They understand that it's fatal. That's about all they know. And in the middle of a crowded waiting room they're told that they have AIDS. Designated civil surgeons are under instructions by the Immigration and Naturalization Service to provide counseling. They do not do that. They are required

to, by California law, to maintain records in privacy regarding HIV. They do not do this. What I'm suggesting is that if this program of universal testing on the part of the Immigration Service for immigrants cannot be administered in a sensitive and humane way, they shouldn't be doing it at all because all it's doing is driving these individuals underground. All it's doing is encouraging fraud, which there is a great deal.

DR. ROGERS: Mr. Fong.

MR. FONG: Yes.

DR. ROGERS: It might be of interest to you to know that the Commission completely shares your view and has spent a great deal of time on this issue under the leadership of Mr. Goldman and has put a strong statement forward to the Immigration authorities so you could -- you don't need to persuade us of the -- of this particular --

MR. FONG: What I would like to do then is to jump into it very briefly. The last thing I'd like to talk about is the availability of a waiver. The Immigration Service and the Congress has instituted a program whereby people who have applied for amnesty, so called legalization, and those who have applied for refugee status. If they are HIV positive, there is a complex document about 15 to 25 pages long called an HIV waiver available to them. If I decide in my judgment that they deserve this waiver, it will be granted to them and

that person will be allowed to come into the United States. This waiver is not available to immediate relatives of U.S. citizens and people who come through the more regular channels of immigration of which there are approximately 600,000 people per year. The Immigration Service is fairly automat about not extending the availability of this waiver to regular immigrants and I would urge the Commission to recommend to the Congress and to others that this waiver be extended. Thank you.

CHAIRWOMAN OSBORN: Thank you. Think you would take some heart from seeing some of the material that the Commission has already put forward on this topic and we don't intend to stop with a simple statement. We will be working with people in Congress who are looking at the reasonably complexed business of altering the law with respect to immigrants and we've already asked for a much different approach to the short-term situation that now pertains. So perhaps that will be something that we can give to you to make you -- encourage you a bit in your important statement. Thank you.

Donald Hagan. Dr. Donald Hagan from Orange County.

DR. HAGAN: I am Donald Hagan. I'm a family physician from Orange County and I will try to speak for a few minutes from my heart regarding issues that I think are pertinent to access to care.

I'm a family physician that had to leave private practice two years ago next month because of an AIDS-related illness. I come from a county that has a real difficulty with this issue. I serve on the HIV County Commission which spent 18 months preparing for an HIV anti-discrimination ordinance laying the groundwork of the staff of our supervisors and discovered at the very last minute that there would be a very strong religious and elected official battle against that proposed ordinance. And the Congressman William Danemeyer spent 12 minutes giving his personal testimony before a board on the hearing for the ordinance and concluded with the following statement, "If you must pass this law, make it applicable only to the innocent victims of this disease".

Some of your questions I think have to do with the spirit of our people and the reasons why our county board of supervisors, the majority in several cases, I think have not addressed this issue as one of spirit, but as one of a lack of understanding of who we are. It's not been easy in a conservative county to be a family physician and to be openly gay. It is not easy to be a family physician in Orange County being openly HIV positive and have an AIDS-related illness. Primary care in Orange County has been hit hard by cases similar to mine. When I left practice, I had over a hundred people who had tested HIV positive under my care and

hundreds of others that I was in the process of arm-twisting to be tested. And to date, I know of seven physicians in Orange County who are either dead or no longer practicing. What happens to all of those people who have great trust in us because they know we practice without passing moral judgment? They are in a system looking for quality care. They're in a system looking for a physician who could practice without prejudice. It's not easy for them to find a place to go.

Early intervention is critical if we're going to help those who are not already sick. It is a problem not only of funding, but it is a problem of knowledge of these primary care physicians and most of them in my county aren't aware enough of the disease process to impress their patients with the fact that they are capable of providing care for them. I get phone calls weekly from people not only from those who have Medi-Cal and for whom there are few avenues of care in Orange County but even those who have the ability to privately pay, they cannot find a doctor who can see them and know as much about the disease as they do.

Tertiary care is also a problem -- we have 50 to 60 hospitals in Orange County. We have only two, three, or maybe four who are capable of providing for care for a person with AIDS who has an opportunistic infection. The problem is, many physicians are tied into prepaid plans

and they must admit their patients at certain hospitals. My own HMO primary care internist has warned me against being admitted to his own hospital because there are not specialist there who are knowledgeable about opportunistic infections but more importantly to me is the fact that he says that they joke in the OR and the doctors lounge about fags with AIDS. I don't want a person like that providing care for me.

Here is a critical problem for us. We have dozens of facilities but none take patients with AIDS. We have a skilled nursing facility that only recently has begun to take a few patients providing there is funding but they are not medically licensed so therefore it is only for those who can afford to pay or those that we could come up with $400 a day cost for. Why is that? Plain and simple, discrimination. It is not against the law. There is no authority that requires the nursing homes in the Orange County to provide care for our people. Hospice. We have no hospice in the Orange County. Our case managers at the AIDS Services Foundation of Orange County spend hours on the phone trying to find a facility in an adjacent county that will take our dying. We find places 50 to a hundred miles away and the extended family and friends of the dying are then faced with two, three, or four-hour drives to visit those people in surrounding counties. When I talk to my fellow persons with AIDS in Orange County, they say when you speak to the

Commission, remind them of the fact that mental health care is an important part of the process at this state of their lives. Ordinary traditional insurance is hard enough to deal with in coming up with funding for mental health care. It has been really difficult to experience the loss of some of our family and the loss of jobs and the loss of insurance and the loss of self-esteem and facing death without some counseling and assistance. We are truly a third world with regards to community-based research and experimental therapy available.

We're a little envious of Los Angeles and the money their county has placed in AIDS. We had no money funded by our County Board of Supervisors. We had one project applied for for a community-based research initiative and it was not granted and when we investigated across the country, we found that very few of those were granted and funding was probably inadequate in many. We have not had one primary HIV therapy experimently provided through the County of Orange. We are expected to come to Los Angeles to seek that kind of care and we have two and a half million population and it is a disgrace. We are no longer a suburb of Los Angeles.

The problem is one of spirit. And I believe that the base of that spirit is homophobia and we must face it head on. And it must come and be addressed by the leadership of our nation. I'm finishing. Only when we address that

issue do we really address why there are problems and why you are sitting here today. Thank you.

CHAIRWOMAN OSBORN: I always feel bad interrupting in such a powerful statement but we want to have a chance to interact with you at the end and I think some of your comments have raised some questions we'll surely want to ask. Next, Fred Wietersen from Being Alive.

MR. WIETERSEN: Good morning. My name is Fred Wietersen. I'm the president of Being Alive/People with AIDS Action Coalition.

Every 30 minutes a person, with AIDS dies in the United States. By the time you've heard today's testimonies, there will be 16 more people who will have died of AIDS.

I would now like to ask the Commission and the audience to participate in a moment of silence to honor those sixteen and the 70,000 men, women, and children who have died before them.

When is all the talking going to stop? Will we convene a new Commission every year to discuss the same problems and tell them every HIV-infected person is dead? Why are we sitting here ten years into the epidemic and 70,000 deaths later talking about access to health care? I am bringing you a message from the 2,500 Being Alive members. We are outraged. Our community is being destroyed by AIDS. Day after day the calls come into our office saying, "I've

lost my friends, I'm the only one left, I've tested positive but I have nowhere to go for treatment. I'm frightened, I know I'm going to die. We want to live. We want our dignity back." We appreciate your presence here today but it's simply not enough.

Please take this message back to Washington. We demand action that guarantees our right to the possibility of life. We demand action that states every life is of value and that includes the lives of lesbians and gay men and the lives of addicts and the lives of people with color. In the name of all those people who have died and all those who are going to die, many needlessly because of bureaucracy, politics, and profit, we implore you to join with us in demanding forceful federal intervention now. Thank you very much.

CHAIRWOMAN OSBORN: Again, thank you for a powerful statement. Dr. Paul Rothman, Pacific Oaks Medical Group.

DR. ROTHMAN: Thank you very much for the opportunity of speaking today. My name is Dr. Paul Rothman. I am a physician in private practice here in Los Angeles with Pacific Oaks Medical Group.

Our practice, unlike many of the people who have spoken today, is composed primarily of white middle class males with HIV disease. And yet in spite of that difference, we share one thing in common and that's a lack of many

important things with health care.

Two areas in lack of access stand out as being most important. First is the inability to get and to keep insurance which will help keep the disease at bay. And the second and just as important is the inability for people with AIDS to get treatment for the disease at any time in their own lifetimes.

The first problem stems from the insurance companies singling out people who are HIV positive and trying to deny them the health care benefits that they have worked so hard to get. The problem is that insurance companies single out these men because they do not want the financial burden of taking care of what they have entered into a contract to provide. Insurance companies cut back on ways of providing health care of these individuals afflicted with HIV by cutting back on benefits which keep them alive. This is a terrible disgrace. They make insurance premiums rise astronomically, forcing people with limited incomes, even with employment, to drop their insurance and then receive benefits as near as they are from the public sector.

The secondary, which I think is more important, is the inability for people who are already affected by HIV disease to get treatments to keep them alive in their own lifetime. Research takes forever and it is responsible for the suffering and the loss of life that we are seeing across

America. It takes nearly ten years and $100 million just to prove just one drug to treat HIV disease. And in a situation where thousands of people die each year, this is really inexcusable. The FDA smugly asserts that it's necessary to do all this research and to take all this time to safeguard the health care of Americans. But they're missing the important part of this equation. More people with AIDS die from lack of drugs than dying from unsafe ones. To the AIDS-afflicted, it appears as if the FDA is more obsessed with preventing anyone from using an unapproved medication than approving effective medications.

Ten years into the epidemic, 100,000 Americans have come down with HIV disease and probably every one of them at some point during their illness has taken some unapproved treatment. Over 50,000 Americans have died of AIDS and not one of them has died from an unapproved drug. The sad truth is that most people with AIDS view the FDA not as an ally in the fight against AIDS but rather as an adversary. The solution to these two problems are pretty straightforward. First of all, all Americans, regardless of income and health status, should be guaranteed access to affordable comprehensive health insurance. And, second, a new government agency should be formed whose mandate is not to protect us from unsafe medication but rather to cure disease. We need a government agency composed not of French poodles but rather

pit bulls. Thank you.

CHAIRWOMAN OSBORN: I'm pleased that we have some time to let the Commissioners interact with this portion of the access to care panel. Don DesJarlais.

DR. DESJARLAIS: A question to Dr. Fong. The AIDS epidemic has clearly shown a lot of more generic problems in our health care system such as lack of universal health care. In your discussion of your immigration problem with respect to HIV testing, do you see this as a particular problem around HIV testing? There are a number of other diseases, such as leprosy, tuberculosis, and syphilis that are written into our immigration laws. Do you feel from your experience with immigration testing for diseases that we should just fix the AIDS problem or is it necessary to attack the whole immigration policy around various communicable diseases?

MR. FONG: I think my answer to that is probably a little bit broader than what you would like to hear. I think generally speaking there's no problem in my mind with screening immigrants for certain types of contagious diseases. The difficulty that I have is the way in which the screening takes place and the availability of the humanitarian and other forms of waivers that would permit those individuals to come to this country, one, to rejoin their family and, two, to receive treatment. So I think the real broad answer to that is that I don't have a real problem with

the testing itself, provided that there are humane ways of permitting people to come here and to stay here. I think that's the answer to your question.

CHAIRWOMAN OSBORN: Don Goldman.

MR. GOLDMAN: Yeah, I have just a few questions. Mr. Wilson, you decried the lack of care and the access to care in the communities that you're familiar with. But isn't it true that black people who suffer from cardiovascular disease, high blood pressure, diabetes, and a whole bunch of others in a disproportionate way, have problems -- just have general problems in access to health care delivery systems? And to what extent -- I suppose my question is to what extent is it -- is it a generalized problem of our health care delivery system and to what extent do you feel that the communities that you're working with are being particularly targeted for lack of access if you want to call it that -- that it's just a generalized problem of just a broken health care system?

MR. WILSON: Well, first let me begin that the health care system is broken and you're absolutely correct that the issue of access to people in color and poor communities is real, regardless of the illness. The complications that arise when we deal with HIV disease are the added versions of not simply dealing with the medical trauma but also dealing with the stigma and emotional trauma

and the hesitancy even to seek treatment. We have a system that even if you are acutely aware of health issues and you attempt to access that system early, it's problematic access to that system. We add on to that the stigma that forces people to resist even seeking treatment. What we end up with is crisis upon our already overburdened system. So that's one of the primary differences.

The other primary difference is that in the HIV environment, that in addition to the person who is infected -- let me look at that in a different way. If we're talking about let's say cancer -- if I am slow to respond, to get information about cancer, in my slowness I do not risk infection to other people that I'm intimately involved with. That's one of the major issues that make HIV a different situation.

MR. KESSLER: Dr. Hagan, I have a question about your practice. My assumption is that you have stopped practicing in your family practice. What is unclear to me is whether you lost your license for some reason or are being forbidden to practice?

DR. HAGAN: No, sir. I had to quit because of health reasons.

MR. KESSLER: Okay. The other seven physicians, were any of those discriminated against by the licensing board that you're aware of?

DR. HAGAN: Not that I know of. I would say three or four of those physicians even died without ever publicly acknowledging their disease. So their patients didn't even know what caused their death.

CHAIRWOMAN OSBORN: Harlon Dalton.

MR. DALTON: I guess this is directed to Mr. Wilson. One of the saddest things I heard this morning was your statement that the infection among black women and children can be traced to gay and bisexual men. I think it's one of the saddest statements because the implication of that was we should care about gay and bisexual men because we care about the women and children. But if there weren't women and children, we wouldn't care about gay and bisexual men. And I understand that that was tactful choice in your part, that you made judgment for the society -- for gay and bisexual men and, therefore, I thought it useful to wrap your concerns in the -- and that's very painful -- and I guess it's a tactful choice you have to make but I encourage you in talking to us and to everyone to take a stronger, clearer, more direct position that we should care about gay and bisexual men because they are people.

MR. WILSON: Definitely I believe that we should care about gay and bisexual men because they are people because we should care for all people -- that we should understand that we are all diminished when we lose those

types of resources. The reality is that the evidence that exists does suggest that we as a society, we as a culture, are not at that place. That in fact we don't care about people who are different. In particular, we do not care about sexual minorities in this country. We have an environment -- we are very easy to talk about innocent victims as if there is some relevancy to that.

MR. DALTON: You're right. You can help us as a society get to that point. What mother wouldn't want you as her son when she gets diseased? Push me.

DR. MASON: This panel has very powerfully focused on I guess two issues -- access and discrimination. I wanted to ask whether the discrimination bill that has passed the Senate and will be considered by the House, whether this will modify any of the problems that you have brought to our attention today and if the answer is no, what other action would have to be taken to assist? Obviously, some of the access problems are money and resources and others are discrimination. What will the discrimination act do to assist you and what other action is needed? That's my question.

MR. WIETERSEN: I think the law is definitely needed for very concrete situations but one of the problems people HIV infected face is that there is sort of the pressure from your friends, the pressure from your associates

and the people you work with. If they don't support your right to be out there and to have dignity and self-respect and be treated fairly, it really doesn't matter what the law says. How many laws do we have on discrimination in other areas and how effectively are those applied? It really seems what's needed is leadership at all levels of society, both federal, state, and local where the top people are getting up and saying this is simply unacceptable behavior. We don't discriminate against Jews. We're continuing the fight against discrimination for blacks and women and Hispanics but it's the same types of things. If you don't have particularly federal leadership, when's the President going to speak up forcefully on AIDS and how people with AIDS should be treated? It's incredibly frustrating. My personal answer on this is simply that if the leaders in the society don't stand up and act as role models for the kind of behavior that's appropriate, then you can pass all the laws you want. Those will help to a certain extent in very concrete situations and you can go to court and argue about it but the truth is that the leaders and a society as a whole doesn't create the group -- the idea that this is simply unacceptable. I don't think you make a lot of progress on it. I can just tell you that we see in our organization the people that want to participate, that they're afraid to participate even though they're deeply involved in this because they're

afraid if their HIV status becomes known, their jobs will be lost, their professional status would be compromised. It's an incredibly difficult situation and a lot of these people are top leadership people.

DR. HAGAN: May I respond also? I think it's helpful certainly. It's a trickle-down theory. It starts at the top and people get the message and it's a slow message. I give you an example of part of the problem. President Bush visited some people with AIDS in the last ten days or so and if I didn't get two newspapers -- the major Orange County newspaper -- headlines said, "President Bush visited children with AIDS." I read the whole story and it didn't even say that he had visited some gay men with AIDS. I had to find that out in the Los Angeles Times. That's an example of the problems that we face that certain messages aren't passed on to the public. Because that was clearly an important step for him to take, but a very small one.

DR. MASON: That's exactly what I wanted to talk about too because just before Christmas I was at the National Institute of Health Clinical Center when President Bush, his wife Barbara came to the NIH -- met with not just children but adults and patient support groups marched down into the Masur Auditorium immediately afterwards and gave a talk to five or 600 people with the press there and strongly said how much we need to be compassionate, we need to help and work

with these people. I saw a little of it in the Washington Post and almost no other publicity. But I do want to just mention that I have heard President Bush speak rather strongly of the problems of discrimination and the need for compassion and not to worry about us as we work with persons with AIDS. But how do we even get that message out?

CHAIRWOMAN OSBORN: Dr. Rogers?

DR. ROGERS: Yes. This is -- I guess Dr. Hagan. I guess as a comment, the dreadful lack of health care facilities and life support systems for people with AIDS steadily grows as we hear from people here in Los Angeles. My question -- when you told us of this shocking no nursing home facilities and no hospices. Nursing homes certainly receive federal funding. Can't they be taken to court for failure to admit patient and for discriminating against patients with the HIV infection?

DR. HAGAN: Well, I don't know the answer to that. Penny is that possible?

DR. WEISMULLER: It is possible of the city's skilled nursing facilities of Orange County that are severely underbedded and when we're dealing with persons with AIDS who are on public funding for their care, all patients with public funding for care go to the bottom of the list. Skilled nursing facilities take privately-insured patients first. We hear about the -- we don't have appropriate

inspection control precautions. This is going to raise the cost of care. Currently in California its skilled nursing reimbursement rate is in the neighborhood of $55 a day for that type of patient. Studies here in California indicate that the usual patient at the skilled nursing facilities requires about three hours of nursing contact time. Here in California a pilot, a study was done by the State of California -- skilled nursing contact time to a person with AIDS was unable to put in seven and a half to ten hours a day and the skilled nursing facilities can't do it at that level of reimbursement.

DR. ROGERS: Thank you.

HON. ROWLAND: Let me ask one question.

CHAIRWOMAN OSBORN: Yes. Go ahead.

HON. ROWLAND: Earlier I believe I heard Major Bradley say that the City of Los Angeles has some AIDS discrimination laws. Are any of you familiar with that? If you are, how well does it work?

MR. WILSON: The City of Los Angeles does have an AIDS discrimination law in regards to combinations of housing and employment.

There are two issues. One, currently the process of dealing with persons who call upon the enforcement of that law is one of mediation which can take long. And, secondly, for many people with AIDS to go through the long legal

process often, as we just experienced here, with Hollywood's ordinance that the patient dies before the case ever goes to court. So even in those situations where the law exists, there are problems as far as immediate remedies for the people infected.

HON. ROWLAND: Are you saying that in the case of discrimination, the burden of proof lies with the person who has AIDS, that he or she has been discriminated against rather than the reverse of that?

MR. WILSON: Yes.

HON. ROWLAND: Thank you.

CHAIRWOMAN OSBORN: Thank you very much for your testimony. We appreciate your judgment in coming to talk with us. We hope that we can move the same --

DR. HAGAN: Thank you.

CHAIRWOMAN OSBORN: The next panel will be comprised of discussions of alternative to inpatient care and let's give a minute here to relocate.

I guess Michael Weinstein.

MR. WEINSTEIN: My name is Michael Weinstein. I'm the president of the AIDS Hospice Foundation and we administer Chris Brownlie Hospice, which is a 25-bed hospice, residential hospice facility, which we'll be visiting tomorrow morning. It is the largest such facility in the nation, and from our previous discussion, I might inter-

ject that fewer than 25 percent of our residents are privately insured and that we see at the instate of AIDS the fruits of a lack of access to health care. We see people who might not have arrived at our hospice for a year or two because they did not have care, arriving at that much earlier.

I have to say that I was a little chagrined at the earlier discussion at the county because while the county is certainly worthy of criticism and while it certainly has gotten its share, I think that the federal lack of participation in programs related to care of a person with AIDS, as opposed to research and education, has been absolutely shocking. The amount of money that goes directly into care from the Federal Government outside the Medi-Caid program has been almost nonexistent. In 1988, the Federal Government put into place -- the authorization was put into place for a subacute demonstration project, $30 million. That appropriation was never made. What we see is that really the PWA, in terms of federal policy, has become a forgotten person in this whole AIDS epidemic.

Federal reimbursement policy encourages more expensive inpatient programs as opposed to encouraging less expensive outpatient or residential settings. We have a situation now that's of great importance here in California because in 1988 we passed, for the first time, a licensing

category for residential hospice facilities called Congugate Living Health Facilities for the terminally ill and that program is dependent upon federal participation on the medicated for that reimbursement to go into effect. I hope that all things that can be done to speed up the process of that approval, whether through administrative or legislative means will be done.

And then to talk for a minute about -- we talk about a continuum of care and really we haven't seen that continual care in any type of any reasonable form anywhere outside of the San Francisco. And that continuum of care as I see it starts with diagnosis of HIV infection and ends with death. And actually the sense extends beyond that because we have to deal with the bereavement needs of the survivors which would go for one year after the death. But that continuum care includes testing, monitoring, early intervention, outpatient care, home care, shelter programs, nursing homes, and finally residential hospice facilities.

The other thing I would like to say about federal policy is that it has been very detrimental -- that there -- despite the fact that the Federal Government has been aware for quite some time of the fact that the county has been derelict in its responsibilities in addressing the care and needs for persons with AIDS, it continues to put its funding through the county as a fiscal agent. I really cannot

understand for the life of me why that continues. Anyone who is active in AIDS in Los Angeles knows that the entire continuum of care that exists here exists because of the community-based organizations who have not only built it but fought with the county in order to be able to have built it.

I strongly urge the Commission to go back to Washington and to instruct HRSA and would recommend to HRSA and to CDC that these grants -- that the county no longer be the fiscal agent and that these grants be made directly to community-based organizations.

And finally what I would like to close on is simply to say that you cannot deal with AIDS strictly as a medical condition. The crisis of AIDS is as much a crisis of psychosocial questions as is the medical questions. When you are dealing with, for example, with a facility like ours, with the lover of a person who is dying of AIDS who is imagining himself in that bed, or the friends who have lost the third person that year or a family who's learning for the first time that the person is gay as well as having AIDS, you're dealing with the multi-cultural death rituals of so many people. So when we go to funding sources and we say that while we have -- what about a cessation of heroic measures to save a person's life, we are substituting that with social workers and case managers and other people and we're told that there's no funding for that. Even though the cost of

the care at our facility is $150 to $200 a day as against $800 a day for Medi-Caid in a county hospital, we need to have an understanding that that is the key part of the care of a persons with AIDS.

CHAIRWOMAN OSBORN: Thank you.

MS. ANDERSON: Hi. First of all let me find a mike that works. Thank you for this opportunity to come and speak with you today.

In September of 1988 AIDS Project Los Angeles opened the Our House Facility as a transitional shelter for homeless individuals symptomatically affected by the AIDS virus. During the first year of operating Our House as a transitional shelter, it was determined that the clients needing such a facility presented more significant issues than expected. Approximately 80 percent of the individuals admitted had significant psychiatric and/or substance abuse issues in addition to symptomatic HIV infection. This population was found to need more supervision, structure and treatment than the existing staff could provide. The search for appropriate referrals indicated that residential substance abuse programs, mental health programs and even the board and care system were not set up to deal adequately with the special needs of HIV infected individuals.

In June of '88, APLA convened a task force drawing from experts across the country to explore and make

recommendations about carriers to residential treatment for HIV infected individuals. The task force identified several barriers -- no existing licensing category, no program models, lack of fiscal resources. Mental health, substance abuse, and AIDS agencies were not working in conjunction to resolve the growing problem.

APLA's response to the information gathered by the task force was to convert the fourteen bed transitional facility into a long-term treatment program for dual and multiple diagnosed individuals. We hired an LCSW to develop and structure a treatment program. We upgraded paid staff by hiring individuals possessing either a background in either substance abuse or psychiatric treatment. Our intent was to structure a model program for this specific population. Our long-term treatment program has been in existence since September of 1988. The issues of licensing and reimbursement continue to be problematic.

The model has demonstrated that it is possible to successfully provide residential treatment services to multiply diagnosed symptomatic HIV infected individuals.

The overall goal of the program is empowerment of the individual. This has been accomplished by structuring the program based on the theory that given adequate support, program flexibility, and recognizing the extensive worth of each individual, they can improve the quality of their life

independently and successfully.

I feel the best way to illustrate this is to tell you about a client that we'll call Joey. Joey is 27 years old. He has been on the streets since age 12 supporting himself through prostitution. Joey spent the two and a half years prior to coming to Our House living in a state park. Joey came to Our House diagnosed with ARC substance abuse and psychiatric diagnosis of severe depression. Today Joey has been at Our House for approximately ten months. He has successfully applied for public benefits. He is currently enrolled in cosmetology school and plans to graduate in March. He has been setting aside money to make the move into an independent living situation and perhaps most importantly Joey has maintained his clean and sober status throughout his residency at Our House. Without the services he received at Our House, this new lease on life would not have been possible for him. Joey is extremely proud of his accomplishments and is looking forward to achievement of a successful career for whatever amount of time remains in his life. It is on behalf of the thousands of people like Joey that I respectfully request that you recognize a critical need for funding models such as Our House. I encourage you to become the needed advocates for these individuals to President Bush and the legislators, for if this does not happen within the next cycle of funding, we can honestly predict increased

transmission of HIV infection and the resulting inhumanity of American men, women, and children dying alone on our city streets. Thank you.

CHAIRWOMAN OSBORN: Sharon.

MS. GRIGSBY: Thank you. My name is Sharon Grigsby and I am president of the Visiting Nurse Association of Los Angeles. Like my sister organizations, VNAs across the country and in small towns and large towns, we share a 100 year old history of commitment to public health based care in the community inpatient homes. When the AIDS epidemic surfaced in Los Angeles, our organization reacted much as it had years ago when tuberculosis or polio were presenting a similar threat to the community. We knew little about the disease when we received our first patients. And in the intervening six years we have learned more probably than we want to know.

We've seen over 600 patients during that period of time and we feel we've learned a lot of lessons and built a care system that we wanted to share with your Commission and some of the lessons we've learned along the way we feel could be helpful elsewhere perhaps saving others some of the costly and painfully hard-earned experience that we've collected.

The model that we built in Los Angeles, initially under contract with AIDS Project Los Angeles, and subsequently with contract with some of our referring hospitals

with the County of Los Angeles, was an integrated program of home based care which combined intermittent nursing services, visiting nurse services, and I.V. support services along with extended care for patients who needed more than visit-based support, services from a nurse or a nursing attendant from four to 24 hours a day in the home. We added visiting nurse home pharmacy support because many of our patients were on experimental protocols and receiving the medications that they needed was difficult for them because most of them only had Medi-Cal as a source of support. Hospice in the home -- our Visiting Nurse Association certified hospice in the home program, those four services combined created the spectrum of care that we were able to offer to patients in their home.

As Mr. Weinstein has pointed out, a true system of care -- community-based care, has a wide range of services which must be provided if patient choice and patient acuity are truly to be matched up which must be provided if patient choice and patient acuity are truly to be matched up. And certainly the residential and inpatient models of hospice are choices for many of those patients who have no home or no caregiver to go to. But for a very substantial number of patients -- county hospital and private hospital patients as well -- they do have an option to remain in their home because they have family members or caregivers who can look after them. And our program was directed towards that group

of patients.

Last year 300 patients were seen under the contract with the County of Los Angeles. Their average length of stay on the program was three months. Their average cost for the period -- the entire period of care that they were enrolled in our program was approximately $9,000. And that total would have supported them in the hospital for approximately ten days. They were offered the option to live at home in the community with a level of support that they needed to stay there and 85 percent of them did accomplish their goal of dying at home with the support of the program.

Along the way, we warned that it's a very expensive program to provide. The AIDS patients and case load made up approximately three percent of our total case load. They were responsible for more than 50 percent of our losses on free and subsidized care. For our agency, that added up to over half a million dollars in the last year. And we're not a large agency. That's a major commitment to supporting the community. We were fortunate to have some United Way money. We had funds that we raised in the community, but it is a level of burden on an agency that most community non-profits can't sustain for any length of time. Without the county contract, Medi-Cal alone would not have been able to support these patients at home and they would have lost the opportunity for that -- the exercise of that choice.

Another lesson we learned is that integration of services is critical, that we have to be able to move patients across levels of care. One of the characteristics that we've seen in patients with this disease is rapid and marked changes in their acuity in very short periods of time and unless we have the flexibility to add and withdraw resources, we are not making the most efficient use of care for that patient.

We also learned that it takes a true community partnership, that referral agencies, community-based service support agencies, the county hospitals, all of these groups have their own needs, have their own systems, but in order to take care of the patient, we need to present as seamless a program as possible and that takes a major commitment on the part of every one in the organization to communicate on behalf of the patient.

In terms of policy recommendations that I hope your Commission would consider, the most important emphasizes this integrated comprehensive system of care. Right up there with that is an adequately funded system of care. If the Medi-Cal program in the State of California would reimburse care in the home on the same way that the Medicare program does, it would not be a charity care situation.

Right now the Visiting Nurse Associations are virtually the only home care agencies that will accept Medi-

Cal patients because of the very low reimbursement rate. We can't afford to do it indefinitely. Many of my sister organizations locally are cutting back on the Medi-Cal patients they can take for that reason. Without some help from the state, I see that continuing so we would request that your Commission look at the possibility of Medi-Caid reimbursement, paralleling Medicare so that more of these patients can stay home.

We thank you for your attention.

CHAIRWOMAN OSBORN: Bessie Hughes from the King/ Drew Medical Center. If you pull that close to you, I think you won't have to fight with it.

MS. HUGHES: My name is Bessie Hughes. I'm the AIDS coordinator for the EIP program, Early Intervention, state-funded program. I'm very excited about this program because this is the only one that I know of that is sitting in the inside of a hospital. I'm glad they chose our hospital because I work in southcentral Los Angeles.

My focus is on prevention and treatment. Therefore, I have five focuses to share with you today. The first one is allocate funds for the now existing alternate test sites in Los Angeles County to be turned into maybe clinics. Our clients are told by the alternate test sites, "Your test was positive. We do not treat." So I get referrals. Some never come until nine months later, until

they become ill, simple little things that could have been taken care of in a clinic setting. They do not know how to find their own private physician or hospital caregiver.

Therefore, my second concern is red tape to get our clients on some type of financial assistance. Many of our persons with AIDS go back home to Mommy after having not lived there in five to seven years. This creates a hardship on that family. Now one has returned home because they have nowhere else to go. Many of them are old and they're on fixed incomes themselves. It's not a healthy environment but Mommy is going to always take care of her child because they have nowhere else to go, no money coming in.

My third focus is home care. Provide more home care facilities in the County of Los Angeles. Yes, visiting nurse does a beautiful job, but in southcentral Los Angeles, they don't go in after 4:30 in the afternoon. It's a high risk area.

My fourth focus is more residential home care. They need places to live instead of on the street. They have one condition and now we have another one. "I have HIV and I'm homeless. Yeah, I am continuing to give my HIV to everyone else I come in contact with," and I question my clients, "Mr. and Mrs. John Doe, why do you continue to practice your high risk behavior?" "Are you kidding, Mrs. Hughes? We have to survive. I'm trying to wait until you

and Dr. Jordon find a cure, but I have no money coming in. I'm trying to wait until the dope pushers are out of the environment. You know I'm on probation and they'll take me back to prison and I don't shoot up anymore. Until the murders cease and get the gangs out of the neighborhood, until someone gives me a job, you know when they test me, they don't do the AIDS test. So I have to survive and I am very angry and what am I going to do?"

They're right -- survive; they do have to survive.

Lastly, what about the health care giver. They take care of these patients. I say to myself, "Do you make a difference?" Yes, I do. But I have to also say to myself, "Halt." Halt to me means when I'm hungry, having worked 12 hours, because I run a clinic twice a week in the afternoon from 5:00 o'clock until we finish, when I'm angry, I have to control that anger. My clients will pick it up. When I'm lonely and I have nobody to talk to except Dr. Jordan and he can't help me, he's doing the same thing and he's going to self-destruct, too, when I'm tired, he doesn't like it but I rest. I disappear on him and I take care of Bessie. So the EIP program works, but we need more of them. But we need to treat these clients. I want to thank you.

CHAIRWOMAN OSBORN: Thank you. Questions from the Commissioners? Reverend Allen.

REV. ALLEN: I'd like to ask the last witness.

CHAIRWOMAN OSBORN: Scott, you need to move in even further.

REV. ALLEN: Ask you the same question I asked Mr. Gates. Would you recommend testing due to the resources of early intervention at this point? At least testing -- saying there's early intervention in your own facility. How do you -- how do you respond to those where the resources aren't there?

MS. HUGHES: We are fortunate enough to be in a hospital setting. We test anyway without the resources and my program is also exciting because I switch them from one program to another. I switch them from the state program to the county program if they don't meet the requirements. Many are walking around and do not know they're HIV positive. I get in contact with people that donate blood that are positive and they don't know it. So I think they should be tested.

REV. ALLEN: I have no arguments with testing and I, too, want to encourage that. It's just -- my concern is we are saying test because there's something there and people that do that and find that there's nothing there, that's -- it's what we -- what we are encouraging people to access and I'm just -- I'm overwhelmed by the lack of resources across this nation and I don't know how to respond to that. I can see testing of course to know the HIV status, of course to

hopefully access change in behavior and start living a life that's constructive and so forth. That makes all the sense in the world to me.

But that's -- you know, there's a difference when you're saying get tested to know this, to start living a healthier life, but the resources aren't there to help them and assist them.

MS. HUGHES: Sir, I think you misunderstood me. I'm not saying test every one. I'm saying we have alternate test sites. The alternate test sites that now exist, they inform the client they are positive tests. Many of those clients have signs and symptoms right then and there. That's what took them in to be tested, but they have nowhere to be treated.

REV. ALLEN: Let me ask --

MR. WEINSTEIN: Can I make a comment on this? I think the issue here is everything in AIDS has come about through the empowerment of the -- of the HIV infected community and their supporters and I think that I'm certainly as alarmed as you are about the lack of resources, but the reality is, is that if people do not know the status, they're not going to advocate for their needs. And I think that as the million people in the United States who are infected, the majority of them don't know their status, begin to learn their status, we have at least the possibility of making the

example to the policy makers of what the needs are, so I think that both for saving their own lives and for making the change that's necessary, it is essential that people be tested.

REV. ALLEN: Yeah, it certainly is an aspect of the dynamic. A question I have on the alternative test sites, what type of post-test counseling is available? Is that an accessing of systems? Is that counseling solely for how to alter behavior or what is it when a person does test positive in L.A.? Are they given some resources? Is there a needs assessment perhaps available there and then moves on into those that can meet those needs or is there anyone that can answer that?

MS. HUGHES: There are test sites in L.A. that just test. You come in for a test. You're counseled. Your blood's drawn. It's sent to the lab. You return for your results. You're counseled.

I visited all of the sites and I was in West Hollywood and I was on my way out the door. The phlebotomus tech, not the nurse, said to me, "This man has a temperature of 103." I said, "So?" "He needs referral." I got on the phone. Thank you, sir, and called me on the line and asked for a physician. A physician wasn't there. And I told him, "I'll see you in the clinic tonight." It was a Tuesday. I was glad I saw that man. He was an Iranian, illegal alien,

no insurance, no nothing. He came to our clinic that night but three days later he committed suicide. He didn't know what to do. So -- but he was informed of his results but he was also having symptoms.

MS. DIAZ: I'd like to ask --

CHAIRWOMAN OSBORN: You have to use this one now.

MS. DIAZ: I'd like to ask Michael to elaborate what have been some of the obstacles in setting up residential facilities in Los Angeles and also Hospice? It seems to many of us that it's such a logical step in the extension of compassionate care and homes for terminally ill persons with AIDS and what has been some of the experience?

MR. WEINSTEIN: Well, I mean, you know, ultimately the issue is reimbursement. And currently the only reimbursement that's in place is Medi-Caid reimbursement for home hospice care, and the fact that the person is in a facility that we're paying room and board and providing psychosocial needs, et cetera, is not taken into consideration in the current structure of reimbursement.

But in order to get to the place of being reimbursed at all, we have to clear the hurdle first of all of constructing facilities for which there is no money that's available and we had to find a way of being licensed as a health care facility, of which there was no appropriate licensing, so I mean just to give you an idea, in order to

open one 25-bed facility in Los Angeles, we've had four pieces of legislation go through in Sacramento. We had to clear the way for the first time for bonds to be issued for this type of facility. And now with this bill that we put through for reimbursement, which is now dependent upon federal action, we wait still further for this to be put into place.

Because what we're trying to do is to take these programs out of the realm of grants which are always limited and always uncertain and move it into the area of entitlement because without that, -- because the entitlement system now is geared towards hospitalizing people. That is how the federal and state reimbursement system is geared towards, putting people into the hospital. There is really very little reimbursement available for anything else and even in the area of grants, like the HRSA grants, in Los Angeles County, none of that money is going into residential care. So the whole system is set up -- you know, two points -- you know, the current system -- a lot of this could be eliminated in one fell swoop if you didn't require a person with AIDS to wait 29 months to be eligible for Medicare. Okay. The average life span is significantly shorter than 29 months.

I saw a close friend of mine, Chris Brownlie, for whom the Hospice is named, go on to Medicare in the last few months of his life, and the difference was absolutely

unbelievable. I mean, it was the difference between three days on a gurney in County Hospital and going to the finest medical institute in southern California for care.

On the health access issue, one other point I want to make on what could be done federally about the issue of discrimination against persons with AIDS in insurance is that the Federal Government has authority under the ERISA program to eliminate medical underwriting for health insurance. It now prohibits it for companies with 20 employees or more. If it extended that down to any health insurance policy -- I mean, the way the system is set up now is to eliminate any risk on the part of the insurance company so, you know, and it seems in California that insurance companies are in business to collect premiums and deny claims.

Well, the Federal Government could play a significant role in that through the ERISA exemption in bringing about a change in that area as well.

CHAIRWOMAN OSBORN: Thank you. Harlon Dalton.

MR. DALTON: My question is for Pam Anderson. I unfortunately missed the first part of your talk, but I did get back in time to hear you talk about Joey and it triggered in my mind a visit yesterday, a site visit, to Dignity House, which was a wonderful experience, but one of the things that I was told there was that it made a lot of sense to separate out persons who are I.V. drug users or who might become

active I.V. drug users again from other persons in the residential care facility. My impression is that you don't do that kind of separating and you have at least some success, stories like Joey. But I wanted you to address yourself to that question of whether it would make sense to have a separate facility with different -- maybe a different philosophy and make those arrangements for people who are a high risk of relapsing or, for that matter, are active drug users.

MS. ANDERSON: Well, there has been and, you know, continues to be a precedent set for treating dually diagnosed people in the same facilities. There are a few facilities here in Los Angeles that do that, that will treat people with substance abuse problems and a psychiatric diagnosis, so that was not unusual.

It boiled down to being able to structure a program to meet the needs of the individuals that we served and we had one facility and limited funds to do it, so we took on that challenge to structure a program. I think probably idealistically, yeah, if you could have your substance abusers here and your psychiatrically diagnosed folks here and your -- all -- maybe that would work better, but as it stands now, structuring a program based specifically on this population and, you know, bringing in things like A.A., groups like that to help these people keep clean and sober,

and not all of them do, not all of them do.

CHAIRWOMAN OSBORN: I think we'll break at this point. I want to thank these witnesses and in fact the whole morning's slate of witnesses for a wonderful and informative discussion.

(Whereupon, at 12:40 p.m., the meeting recessed for lunch.)

AFTERNOON SESSION

CHAIRWOMAN OSBORN: The meeting will come to order. We will now hear from Commissioner Diane Ahrens .

MS. AHRENS: Madam Chair and Members of the Commission, your working group comprised of Larry Kessler, Charles Konigsberg, and myself, focusing on the responsibilities and role of Federal, State, and local governments in addressing the HIV infection met January 4 and 5 in St. Paul, Minnesota.

We heard from 13 individuals, all experienced people in confronting the HIV epidemic at either the local, state, or federal level of government. Five of our presenters represented national public interest groups: The National League of Cities, The National Conference of Mayors, The National Association of Counties, The Association of State Legislatures, and the Department of Health & Human Services.

The other eight presenters, chosen for their special involvement at various governmental levels, representing our ethnic and geographic diversity, participated in a "roundtable" discussion the second day with the Commission members, facilitated by Pat Franks of the Institute of Health Policy Studies of the University of California at San Francisco.

I describe this process because the interaction of

these experts provided for an open and challenging discussion as ideas emerged and could be practically examined.

My presentation will be a summary of a summary.

You have the summary report and I do not intend to read it.

What I would like to do is, drawing from that document, give you my impressions of the substance of the two-day meeting.

What we attempted to do was to highlight the various roles of government, the problems confronting all levels of government in responding to the HIV epidemic, examine what is working, what isn't working, and forge a consensus as to how we might all better respond to this epidemic. Admittedly, we do not have all the answers. Nor have we covered all the issues. But we have taken the first step in answering the question: Who is responsible for the action?

Several themes permeated our discussions.

First, the lack of clear definition of government roles has seriously hampered efforts to attack this epidemic.

A lack of definition has hampered our ability to: end discrimination, finance health care and services, recruit and train health care workers, provide housing for the sick, provide effective AIDS education and prevention programs, and provide substance abuse treatment and

prevention.

The second theme and a strong recommendation of the working group is that the Federal Government must adapt a greater leadership role in helping to delineate government responsibilities and to create effective partnerships between the various levels. We have some specific recommendations as to how this could occur, administratively at the federal level.

What we were repeatedly told was that care and services for people with HIV are too often haphazard, inconsistent, isolated, unequal, and non-integrated.

In the real estate world, there is a principle of retailing success. It is location, location, location.

In addressing the HIV epidemic, we too have a principle of success, a compelling need -- that is leadership, leadership, leadership. We were urged to insist that the President and the Congress break the silence of denial and speak out candidly about the ways to curb the spread of the virus. It is not the role of local and state governments to mobilize this nation. They do not have the tools to do that. Mobilization to meet a national crisis is, and always has been, a federal responsibility. What is called for in this national epidemic is a national mobilization. Not that the Federal Government can or should do it all. Local governments are prepared or are preparing,

state governments are and will increasingly be planning and funding for services. History demonstrates that when there has been national leadership that has called our people and institutions to action, we, as a nation, have responded.

The third theme that permeates this report is the need for partnerships -- and partnerships we have where communities are struggling to end the epidemic, assure access to treatment, protect civil rights, and assure adequate funding.

So as we on the Commission worked with the presenters at our meeting, what emerged was a recognition at all levels -- federal, state, and community -- that across this nation our response was inconsistent and uneven, that leadership from the White House and the Congress was needed to mobilize us and that partnerships at every level of government and between levels of government were required, but that the driving force for developing these partnerships should come from the Federal Government.

We heard, as we will today, about creative and often heroic efforts at every level where agencies are reaching out to serve those at risk and to mobilize local communities. Many states have developed sound responsible policies and guidelines to assist local communities. You have some of those examples in the report. What one senses from those in the trenches day in and day out is that they

see the tidal wave that is coming at them. They know they are on the beach. They desperately need our help and when they cry out, is anyone listening? Does the America that is on the dry land tending their gardens know about the tidal wave?

We heard from national public interest groups that the U. S. Conference of Mayors has described a leadership role for cities in assessing need, establishing policies for services, education, financing, anti-discrimination ordinances, and advocacy at the state and federal level for resources.

Likewise, the National Association of Counties has sent to every county a call to action describing the county -- elected official -- leadership required and a blueprint for county action to address HIV in their communities and in the workplace.

The National Governors Association has issued a Governors Policy Guide on AIDS which speaks to priorities and allocating resources for AIDS, defining the state's mission in managing AIDS, mobilizing the citizens, assigning responsibility, et cetera.

And at the federal level, much has been done as they have focused on epidemiologic studies, biomedical and clinical research, development of the HIV antibody test, development of drugs, guidelines for infection control, and protecting the blood and tissue supply and in regulating

drugs.

Much is happening all over this nation. But like an orchestra without a conductor, we are all playing our own tune, and it may be a beautiful tune. Sometimes we harmonize, sometimes we don't. Most of us want desperately to play the right notes -- complement the violins -- even begin and end together. It's pretty tough without a conductor.

Our roundtable identified 11 areas to be addressed. What was interesting was that only four of the 11 were clearly defined in terms of responsibility. That was where the Federal Government had stepped forth. There was mutual agreement that in these four areas, the Federal Government had assumed its proper leadership role. Those four areas were research, epidemiologic surveillance, drug and medical device regulation, and blood tissue supply.

Let me list for you the other seven: anti-discrimination and civil rights, health care financing -- public and private, health care and social service organization and delivery, recruitment, retention, and training of health care personnel, housing, prevention and education, and substance abuse prevention and treatment.

Here is when our orchestra is in disarray -- in seven of the 11 critical areas of need. Here is where we sound like we are tuning up -- all the time! Waiting for the conductor.

I am reminded of a very Minnesota experience -- not terribly analogous, but I'll share it anyway.

A few years ago we opened a very elegant concert hall in St. Paul -- the Ordway Music Theatre. In an effort to show off our newest cultural attraction to County Commissioners from around the state, we bought a block of tickets and took them to a performance of the St. Paul Chamber Orchestra. Unfortunately, no one examined the program before making the reservation. When I saw it I thought "disaster." The entire program was a performance of a "commissioned" work from one of our most avant garde composers.

I will always remember at the intermission a rural County Commissioner turning to me and saying, "Well, now they have tuned up. When does the music begin?" We could surely ask the same question. We have long been tuning up. When will the music begin?

Who is responsible for these seven areas of policy and service?

On page seven and following, we make nine specific recommendations. Two of the nine we single out for further in-depth study for this Commission. We simply did not have the time nor the expertise at our meeting to tackle the issues of health care financing, health care and social service organization and delivery, and substance abuse prevention and treatment.

We do make the following seven further recommendations: 1) Efforts at all levels of government should be guided by four policy goals: to end the HIV epidemic through prevention, education, and research; to assure access to treatment for all persons with HIV; to protect the civil rights of all citizens; and to assure adequate funding for HIV prevention, treatment, care support services, and research.

2) Federal, state, and local governments should develop comprehensive plans for implementing identified goals. (We strongly recommend that the Federal Government take the lead in developing a national HIV plan and the President should designate the Secretary of Health and Human Services as responsible for chairing a cabinet and Federal Task Force to develop this national plan. This Task Force should include each department in the Federal Government and should solicit input from state and local governments, the private sector, community-based organizations, and persons with HIV.)

The third recommendation is that immediate action is necessary at the federal level to assist states, counties, and cities that are disproportionately impacted with HIV.

The fourth recommendation is that the Americans with Disabilities Act should be passed by the U. S. House of Representatives and that state governments should supplement

in areas not covered by the AWD or other federal statutes.

The fifth recommendation is that incentives at the federal, state, and local level need to be created in order to recruit and retrain -- I'm sorry -- retain and train health service personnel.

The sixth recommendation is that federal, state, and local governments should develop housing programs that meet emergency, short, and long-term needs for people with HIV.

And the final recommendation is, again, that the federal, state, and local governments and community-based agencies need to develop more effective partnerships in HIV prevention and education.

Well, Madam Chair, it's hard to do justice to all of the information that very good people provided us during this meeting in our -- the two-day meeting in just 15 or 20 minutes.

I know that my colleagues, Larry and Charles, will want to give you their impressions.

I just close by saying that I do hope that you're going to have further opportunity to discuss this more extensively among the Commissioners and one thing I would ask is that the members of the Commission send, after you've had time to read the report, send any suggestions or recommendations you might have to me or to Maureen and we will see that

that is attached as an appendix to the report and so when we discuss it, we'll have as much input as we can. Thank you.

CHAIRWOMAN OSBORN: Well, on behalf of the rest of the Commissioners, thank you for both a very diligent piece of work and for a rather brilliant presentation of it which we very much appreciate.

I think that the -- I do want to hear from Charles and from Larry. I think to finish off Diane's last suggestion, a proposed way of proceeding would be that we set an arbitrary, say two week interval, during which Commissioners should look very intently at the document that the small working group has prepared and make any suggestions of the sort that Diane indicated and that we use -- we set a sort of an internal deadline of our own that way so that we can bring forward what are really quite central recommendations in a timely fashion and yet have full -- as a full Commission report, so if that is a generally satisfactory time frame, that's what we might want to accept.

Let me get Charles and Larry to add their comments and then I'll get done.

DR. KONISBERG: Yeah, I just wanted to make just a few comments. One of the things about my experience in public health is that I've had both state and local experience and I've been to so many federal meetings that I feel like I've been sort of an unpaid part of the federal

establishment and it gives an interesting perspective.

I think the report -- the people we had to testify tended to bring us a lot of good news in terms -- I guess what I'm saying is we had some real leaders and community organizers, elected officials and appointed officials both, who brought us some very good news about what they've been doing yet at the same time recognizing the intergovernmental problems.

One of the comments that I made was that I wasn't sure how well we had documented that there was an intergovernmental problem. I no longer worry about the lack of documentation after the discordant notes this morning. I think that's probably as graphic a documentation as could possibly be.

I think that the emphasis should be on every level of government having a comprehensive and integrated strategy, a plan, and I think that's a real important point. As a matter of fact, putting my money where my mouth is, back home in Kansas, that's exactly what we're in business about right now, including planning an evaluation is one of the things that we should be doing. That often does not go over well because of turf guarding and buck passing and it's not just elected officials. It's bureaucrats as well. I mean, it's a common problem. We didn't hear too much about that this morning.

I think what we need from the Federal Government is an overall strategy. It's not so much that each agency that has something to do with AIDS hasn't taken a strong role, but what none of us could identify is what the total Federal Government response was. And we recognize, for example, that the National AIDS Program Office played an important role in coordinating and integrating what goes on in the PHS but that doesn't touch HCFA as I understand it. And if we're going to get the health care delivery component tied in with the Public Health Service components tied in with the Justice Department in discrimination components and the list goes on and on, it's something that's got to be addressed in some fashion.

That's all I have.

CHAIRWOMAN OSBORN: Thank you. Larry, would you like to comment?

MR. KESSLER: I think Diane very eloquently captured the flavor of the hearings and the only thing I would add to that is that -- is what Charles said, and that is what we did see and hear great examples of leadership.

What was missing was the confluence of that leadership in -- and, if anything, I guess I would describe it as the glue was missing.

There was horizontal and vertical leadership occurring, but sometimes in most parts of the country, no one

to really coordinate the effort so that it didn't break down at some other intersection.

Overall, great praise, too, for the efforts of community-based groups. That I think would have changed the picture dramatically had they not been there. Unfortunately, they also were able to articulate that although their presence has continued to be needed more than ever, it is more difficult because of the sheer numbers that we're dealing with, not only in infected people but people who have been diagnosed and all the other psychosocial conditions that small community-based groups or even medium or large-sized ones aren't equipped to deal with in terms of the magnitude of this epidemic, where we are in 1990 and where we will be going down the pike.

The other thing that was striking I think was the importance of recognizing the distinctions between public health and legal issues and this in particular is the matter of drug abuse and where leadership that was present often confuse the public health concepts around drug abuse with the legal issues, and I think there, too, we need strong leadership at -- from the top, the middle, and the lower rungs of the ladder to help Americans distinguish when we cross those lines and where the epidemic of AIDS intersects with the epidemic of addiction.

That was still a problem, even among some of the

leaders that testified I think in clearly understanding where they were stuck in terms of changing behavior, getting people into treatment, finding the funds for treatment for addiction so they wouldn't have to find the funds for treating AIDS later on.

And, thirdly, I think that the national groups have clearly thought this out. The Association of County Commissioners, the U. S. Conference of Mayors, the Governors Conference people, all had position papers that are quite helpful as technical assistants' tools to local leaders, but all arriving at them independently and, again, without a sort of a national mandate or national leadership to have them all come together at some point for the most impact and the most effectiveness.

DR. ROGERS: Let me just add to what you June said. Diane, that was not only beautiful but it was absolutely poetic and we may use your notes at any time. I have read the report, Madam Chairman. It is to me an elegant report. It's thoughtful and it's -- and it's highly persuasive and I would like to just congratulate all of you who took this material that I thought was going to be very hard to put in some logical order and you've put together a very powerful, persuasive document here and I love the way you presented it and I hope that goes into the introduction of your report.

CHAIRWOMAN OSBORN: Don Goldman.

MR. GOLDMAN: Yeah, just as a matter of procedure as much as anything else, I share what -- I share what Dr. Rogers has said and I think that the working group did a marvelous job in putting together what I thought would have been an impossible task, a task that would have required a year of hearings and a year of working it out rather than the short time frame that you managed to put together what you did put together and I think that your presentation was eloquent.

I am concerned, however, about merely being able or having to give responses because many of my responses are not critiques or criticisms of the report as it stands, but rather questions that I have that I simply don't know the answer to and I'm not in a position to be able to critique or give response to. So, I mean, some of the things I have are questions that I'd like to somehow or other have some way of getting feedback from the members of the working group in response to those questions, not that I have a set point of view, that I think that something they said was right or wrong. Maybe -- there may be -- there are areas that were not covered and there are areas that I have just some questions about that I don't fully understand.

CHAIRWOMAN OSBORN: Well, I think that we have some time for that now and I'm sure that Diane and the other members of the working group would be glad to pursue that

discussion to a point of resolution or satisfaction. The reason I'm giving the short time frame is because the statement has the same kind of urgency that most everything else does in this epidemic, but I think that within that constraint, I would hope we can talk it through.

I think it would be good if there are some substantial points of -- where you have questions, to bring them forward because we have a few minutes now and at least the discussion could start and people could start thinking about your concerns, and then I would urge you and the other Commissioners to take advantage of the good nature of our working group and follow through in discussion in preparing any written comments. I mean, if a preliminary discussion would help you to make written comments that very well represented residual concerns, that would probably be the way to proceed and I think that can still be done in a timely fashion.

Do you want to bring up a couple key points now?

MR. GOLDMAN: Yeah, let me just raise -- let me just raise three questions and whether or not you choose to answer them all now at this point or whether or not you want to do so later in some other way or even call me on the phone and talk to me about it --

DR. ROGERS: Don, could you be a little closer?

MR. GOLDMAN: Sure, talk -- or talk to -- talk on

the phone about them. But the three questions that I have, first of all, what is the proper role of this Commission in the formulation of the national plan you referred to in one of your recommendations?

The second question I have is that have you determined on a philosophical basis whether or not federal funding should be dependent upon the willingness of local communities to share the burden in terms of the kinds of forced governmental allocations?

And the third question that I have is that how do we develop a national policy or even a statewide policy in light of such diverse needs and resource capabilities as for example we heard today within a relatively small geographic area and what kind of generalizations and is it fair to make the kind of generalizations that we sometimes tend to do in light of those diverse needs? It just seems to be fundamentally unfair that the kind of treatment that a person with AIDS or HIV infection gets should depend upon the geographic happenstance of what boundary within a relatively small geographic area that he or she manages to fit in. And we talk about the responsibility of counties and yet we hear some counties are apparently unwilling to even share any of the burden at all and is it really realistic to expect the Federal Government to provide funding when the local government has determined that they're not going to spend a red

cent? And those are really some of the questions that I have and maybe you want to respond. I don't know.

MS. AHRENS: Well, let me try and then I think Charlie and Larry should chime in here. On the role of the Commission in terms of this overarching task force that we're suggesting that should be set up and chaired by the Secretary of HHS, actually we really didn't discuss the role of this Commission, I'll be quite frank to say, and that is something I think this Commission might want to consider further. What we were trying to do was to get the people at the highest policy levels to deal with this issue, how this nation addresses the HIV epidemic. We were concerned less it be relegated down the line to where some fine statements might come out but they would -- they would not be able to be held accountable because the powers that be would say, "No, we can't do that."

It should be at the very highest level. And we wanted to have adequate input at that level and that's why we said that state and local governments should at least be consulted, that people with AIDS should be consulted, community groups, and so forth.

We didn't talk about ourselves and I just have to say that, so perhaps we would want to discuss that.

HON. ROWLAND: Let me tell you what I thought the Commission was supposed to be about, and this is in very

general terms. The debate in Congress has been taking place in an atmosphere of political and philosophical differences. That's all that had gone on for the period of time that we had debated it up until the President's Commission had gotten involved. There had been almost no legislation enacted to try to establish a national policy and you -- you mentioned this in your remarks, that it should be the responsibility of the Federal Government to take the leadership role in developing some kind of national policy and that was my thought about what the Commission ought to be doing, was trying to establish some national policy because we had approached this epidemic in a fragmented, disorganized, and sometimes duplicative manner and it seemed as if the epidemic was just continuing to escalate and we would -- by "we," I mean the country was doing nothing in general to try to deal with that, so it was my idea that this Commission ought to make some strategic or long-term recommendations in setting a national policy about how to deal with this or making recommendations to the Congress about how national policy ought to be developed. We've got problems with discrimination and confidentiality and testing that we still haven't dealt with. And my idea was that we needed to be discussing those types of things and making recommendations to the Congress.

The other thing was to determine what kind of

tactical problems we had that needed to be addressed immediately, and some of those have become evident during the course of the hearing. So my feeling about what the Commission ought to be doing is making recommendations about what we need to be doing immediately, addressing tactical problems, and we've already talked about a couple of those here this morning, and long range making recommendations about what our national policy ought to be. Now, that's very general but that was my idea about what the function of this Commission ought to be.

MS. AHRENS: Excuse me. Could I just respond to that for -- I think what -- maybe it was something that was unwritten that we all were assuming as we developed this recommendation, but it had to do with buying in. It had to do with if you're going to change the way you do things, that the key players have to buy into it, and that in order for them to buy into it, they need to be a part of the development. I think that maybe one reason we came to this and we really didn't sort of raise the issue of well, isn't that the job of this Commission, commissions make reports and people can say "yea" or "nay." It may not change the way people do business all that much unless they have been a part of that development and in a sense buy into it, and I don't know, Roy. Larry and Charles could comment on this. That may have been a kind of a silent undercurrent of why we came

at it this way.

MR. KESSLER: I would agree. I think what this report actually does, Congressman, is say what we found in terms of discordant notes and the buck passing and the failed expectations and so on at federal, state, county, city levels, and that -- dependent on the region of the country where it breaks down.

But in regard to Don's second two questions, I think what this really is about is about climate and atmosphere. And we've seen some of that here today, some scapegoating discrimination based on who has this disease. We've seen plans not implemented because certain risk groups were impacted. And if we're going to implement recommendations that come out of this hearing or the hearing that we had in St. Paul or future hearings, it seems real clear to me that we've got to deal with the issue of discrimination in whatever form it takes. Sometimes it's very overt and very clear and sometimes it's very subtle, but it all has the same impact and that is that programs don't get implemented. They don't get -- they're not part of a plan. They don't get funded. And so often when you get down to the nitty gritty, it's because people -- the first people in town who have gotten AIDS are gay or they're I.V. drug users or whatever, and that seems to cut across some of the planning issues, and instead of responding to gay people with AIDS, we need to

respond to Americans with AIDS. Instead of treating I.V. drug users as criminals, we need to, you know, react to them and respond to them as people with a disease that now have a second disease, and we haven't done much around the first one and now we're failing to respond to the second one.

But, again, somehow capsulating the issue of leadership in terms of response that's fair and equitable and consistent across the country at every level seems to be what we need to do so that there aren't these pockets of the country where you have plans that are touted to the world and other parts of the country where you have no plan that's an absolute disgrace or totally inadequate to meet the needs of the people who live in that region.

CHAIRWOMAN OSBORN: Harlon Dalton.

MR. DALTON: Larry, it's hard to understand how anybody at this table would disagree with that, but I would respectfully don't feel that that quite responds to Congressman's Rowland's observations and let me just try to build on that.

I think it's a good report by the way, and I sort of read through it and tried listening to Diane at the same time and then looked back through it, and the only recommendation that I really have trouble, at least at the first reading with, was this particular number two that calls for task force chaired by the Secretary of HHS and bringing in

local governments and private agencies as well to develop a comprehensive HIV plan addressing prevention, education, treatment, care support services, research, and funding.

That's one of the reasons I thought this Commission was set up to do was to create -- to recommend that we create this Federal Government Task Force to do these things but in effect renders what we do irrelevant. So particularly that's where the Congressman was coming from.

Moreover, when I read this, I thought, "My God, this will take at least five years." I mean, I hope we come in in two years with a report that does, but I can't imagine the first step you're talking about with as full as their plates are being able to pull this off in a time frame that anybody would be happy, so I think that's -- that's at least where I'm coming from. I don't know that anybody else is. And I don't know what that has to do with being against discrimination.

Diane, I do understand when you say that people really need to buy into this ideas before they implement them, but I don't know that it means they have to generate the ideas.

MS. AHRENS: Could I just say something else about this? In a sense, we need to challenge the nation. I keep going back to what June says about driving for a consensus as to how this nation needs to deal with this issue. That

doesn't mean that we ourselves draw up an administrative plan as to how you do it. And I think herein lies the difference in what we're saying here.

I'm not sure that we want to get into that kind of, "Well, your department -- you should be doing this and your department -- you should be doing that." I mean, I'm not sure that's our job and I think that's what we were trying to get at. To say to the Federal Government, "You've got to have an overarching plan and you have got to identify what needs to be done by various agencies in the Federal Government to get on with this issue," at the same time we thought that they might learn something about this issue and about how local governments are equipped or not equipped to deal with it.

CHAIRWOMAN OSBORN: Dave?

DR. ROGERS: Yeah, I'm going to build on what Harlon had to say and on what Roy had to say because I think that's the one recommendation that needs a little work. I'm completely reassured by what you say, but when I first read that it did sound as though we were trying to again pass the buck and I think that was Congressman Rowland's concern and Harlon's. Clearly, that's not your intent. You're saying the details should be worked out by those who have to implement them, but it seems to me your ringing message at the start is a critically important part of that and if that

one could be perhaps rephrased in the way where it's absolutely clear that you mean what you just said rather than the Commission backs away from that responsibility.

DR. KONISBERG: Let me see if I can kind of pick up on this a little bit because I really think this is one of the very most important points.

DR. ROGERS: Can you get a little closer?

DR. KONISBERG: Yeah, I'm sorry. I really think this is an extremely important point of the work that we did for those two days and the work that's gone on since. I think that what we're saying -- I think we can do more than just say to the Federal Government, "You've got to have an overall plan." I think when the total Commission report is done, this Commission's report, we're going to be getting more guidance than that. There's going to be, if you go back to number one, broad policy goals, I've got a real suspicion we're going to be enumerating what we think those are.

But I don't think that we have any business really trying to then write the whole plan or assume a leadership role that in fact the working arm of the government should do.

I'm not sure I'm entirely clear on where the discomforture is in this, but I think maybe that ought to clarify --

DR. ROGERS: Well, I think it was simply -- simply

that I think a number of us felt that isn't our responsibility, but the way you've explained it, I'm perfectly comfortable. I just think it needs a little reworking in terms of how it's phrased.

DR. KONISBERG: I think if we rephrased that to indicate that the Commission is taking a little bit more proactive stance than that than it implies, but it's just absolutely critical that we have a broad national policy. I mean, there's a lot of unknowns. I have no idea with this disease how we expect to get a uniform level of responsiveness in service throughout the nation. We don't do it with anything else that I'm aware of.

But I have about come to the conclusion, after being involved at the local level with the AIDS Service Project, that this disease could lead the way to improvements in the entire health care system and we shouldn't be constrained, "Well, we didn't do it with something else."

But it's a monumental task. I don't know how it gets done but it certainly starts with knowing basically where you want to go.

CHAIRWOMAN OSBORN: Well, let me -- oh, excuse me. I want to suggest that we do most of our commenting now interactively later 'cause I want Scott to have time, but let me just take a couple more.

DR. DESJARLAIS: Okay. I would like to make one

strong comment with respect to what I see the role of this Commission. I think if the Federal Government had been able to put together an overall national plan, this Commission never would have been created.

CHAIRWOMAN OSBORN: Exactly.

DR. DESJARLAIS: The fact that the Commission had to be created because of the philosophical and political differences within the Federal Government means that we really have to take a leadership role in developing some sort of national plan, including guidelines for funding responsibilities and that we can't turn that back to the administration or to Congress or some mixture of the two, that really that's one of the major reasons this Commission exists and we need to do the best job possible fulfilling that responsibility.

HON. ROWLAND: That's just about what I wanted to say. We've got to be relatively specific in recommendations that we make. We can't make general recommendations, in my opinion. We've got to be -- we've got to really give some rather specific guidance about what needs to be done. That's --

CHAIRWOMAN OSBORN: Well, I am grateful to Don Goldman for posing three very good and useful questions to get this much discussion started because I think that will initiate an interactive process that other Commissioners can

follow along on, but I would like to maintain that roughly two -- let's say absolutely two-week interval as kind of a deadline for those things so that our other busy selves don't take over and we forget because I think this is an important report and it sounds to me as if the sense of what you're talking about is something that people can find a wording to agree on. The concerns I think are quite clear, too, and we'll make sure that the language doesn't mislead people further.

Let me take the prerogative of asking Scott to give some update about the other working group and I have one comment I want to make as an update, too.

REV. ALLEN: Okay. Just real quickly, our working group on the social and human issues have decided to meet in Boston to deal with the issues focused around testing and early intervention. The meeting is open to the public and to all the Commissioners who wish to attend.

DR. ROGERS: Talk right into your mike.

REV. ALLEN: Okay. February 15th, which is a Thursday, and Friday, February 16th, we are going to be meeting in Boston. The first day will be testimony centered around the testing and early intervention issues, and the second day will be a roundtable discussion.

The issues that we will be looking at will be testing as a component of early intervention, discriminatory

practices and policies based on testing, public health practices related to testing, and psychological issues for testing. We are working rather closely with Charles and the public health arena and to coordinate that effort.

And just for your own information, the Commissioners on the working group are Harlon Dalton, Eunice Diaz, Don Goldman, and Larry Kessler.

CHAIRWOMAN OSBORN: Thank you. So that will be an ongoing and intensive activity. In early discussions with the Commission, I had indicated or we had agreed that I would try and maintain a very active interface with the Institute of Medicine and the various studies and programs that they have going relating to HIV and AIDS. I have been doing that and there's a good deal of intense discussion going on. I have not bothered you with much about it because, contrary to popular press opinion, there are no breakthroughs to be reported.

But, on the other hand, there have been some very substantive and forthcoming discussions and my own sense is that a lot of the very important -- all of the very important players are represented at the table in these discussions and that as long as -- we had an operational sense that as long as that was true, given that we do not focus expertise, particularly in the biomedical side of things, that that would be a source of reassurance to the Commission. So my

report is basically that there's a good deal of intense discussion going on on the biomedical side and some progress but none of it of such excitement that we don't have to do our work.

There was this week, for instance, a roundtable update on where AIDS vaccine issues stand, and it was uniformly agreed that the pieces of progress recently reported do indeed represent pieces of progress but not of the sort that will shorten our task any, and of course none of them as they stand now have much to say about the problem we have in our lap for years to come regardless. So, without going into further detail about that, I wanted to let you know that there is a lot of activity going on and that I'm quite happy about the way this is all working out in terms of maintaining an awareness. They have been very forthcoming in trying to make sure the Commission was represented at all of these events and, thus far, I've been able to do it.

We're now coming up on the time when we want to go back to welcome another group of witnesses to tell us some more about the circumstances in southern California. In this instance, substance abuse and AIDS issues.

Could I ask the people who are going to speak to us to come to the table. I hope we have enough chairs. And introduce yourselves as you speak and as you probably have gathered from our problems, there are only a couple of those

-- the bigger microphones are the ones you'll want to talk into and they don't work real well unless you move right into them.

We are -- I will apologize to you as I did this morning, because of the tight time schedule, we're using a nice low tech kitchen timer that gives a gentle beep when your time is roughly up and I don't particularly like to use the gavel, so if you could listen for that and try and condense your comments, what that buys for us is the opportunity to talk with you and get -- and respond to questions that you've brought to our minds. So as brief and succinct as your initial statements are, that will give us more chance for interaction.

Thank you very much for coming. I guess we start with Dr. Irma Strantz from the Drug Abuse Program Office.

DR. STRANTZ: This mike?

CHAIRWOMAN OSBORN: And close up to it. They don't --

DR. STRANTZ: Dr. Osborn and esteemed members of the National AIDS Commission, I am grateful for this opportunity to provide you with an overview of the AIDS problem in the County from the perspective of its relationship to drug abuse. My title is County Drug Program Administrator and I'm responsible for administering the program of drug abuse services to all of the residents of Los Angeles County which,

as you've heard, is a population of about 8.4 million.

About 95 percent of our program is provided through community-based contracts, 65 in all. Our total budget this year is $44.2 million. We receive about $32 million of federal, state, and county funds.

At any one time, this month we have about 5500 people in publicly-subsidized drug treatment programs. Many use more than one illicit drug, depending upon choice or availability, but the profile of those in treatment that's typically a primary problem of cocaine, 38 percent, heroin, 34 percent, PCP, eight percent, marijuana, eight percent, and amphetamines, four percent. Only one out of five are referred by the criminal justice system. Sixty-five percent of them are 18 to 24 -- 34 years of age with ten percent younger than 18 years.

In December, 1989, there were over 1800 people waiting to enter residential or outpatient programs, including methadone, in the County. Among the young people and the adults waiting for treatment are crack users, needle-sharing intravenous drug users at risk for AIDS, drug-abusing pregnant women, and women with toddler children, homelessly mentally ill drug abusers, and youth who have dropped out of school or who are involved in drug abuse and delinquent activities.

In October 31st, 1989, of the 8,256 diagnosed cases

of AIDS, about 12 percent had I.V. drug use as a risk factor. That's close to a thousand people. Hispanics and blacks particularly are over-represented in the IVDU risk group. In December, the number of new AIDS cases, in December, 1987, was -- pardon me -- where intravenous drug use was the sole risk factor was about 5.8 per month. As of December, '88, the rate of increase in this group was 8.7 per month, a 50 percent increase.

We have done various surveys, both of zero prevalence and knowledge attitudes and behaviors among our clients in treatment, we're now starting one for those who are not in treatment, but with regard to the in-treatment group, we've found that 74 percent of I.V. drug users report always or sometimes sharing needles. In terms of risk reduction behavioral change in the past two years, we have found a change and that the use of bleach or alcohol has increased 13 fold. But, nevertheless, two thirds of those who share needles report never using bleach or alcohol.

With regard to treatment, my office has been aggressively pursuing every avenue for program expansion, including response to federal or state announcements of funding through RFPs or RFAs. Our waiting list reduction grant proposal to the Federal Government totaled almost 7.2 million, constrained in size only by the fact that agencies were reluctant to search for new treatment sites, hire new

staff when funding was clearly limited to one year only.

We have received the first wave of funding through that application. The next wave is to be received sometime in February. My time's up. Okay.

In terms of Outreach Workers, you're going to hear a lot about it. One little comment I would like to make. We find that in terms of drug users in treatment, there is a high prevalence of communicable diseases, such as sexually-transmitted diseases -- syphilis, gonorrhea, and tuberculosis, and drug users find it very difficult to go to public clinics and -- public health clinics to receive treatment for this, and we would hope to be able to implement with funding, federal funding, CDC funding, or whatever more programs where services are provided on site to drug users in treatment, both methadone and residential.

We would also like to have more intervention services on site because we believe that in this County, I.V. drug users are not being given full access to or taking full advantage of intervention programs and prevention drugs, such as AZT. Thank you.

CHAIRWOMAN OSBORN: Thank you very much. We'll now hear from Connie Norman.

MR. NORMAN: Hi. It's freezing over here. I thank the members of the Commission for allowing me to speak today. I'm particularly proud to be on the substance abuse and AIDS

panel as you saw in my bio. I have some past history of substance abuse and I have a sensitivity to that community and it will help shape today some of the areas of my concern that I want to speak with you with.

While I'm sensitive to the needs of the I.V. drug user population, I think here in Los Angeles -- I know it's everywhere -- but I know here in Los Angeles I'm afraid that we're ignoring how big the problem of crack cocaine is and how large crack cocaine and the areas of sexuality associated with that are going to change the face of AIDS.

I'm afraid that we're blind to it and all levels of our society are being affected and impacted by it. I refer to Mary Barry. We cannot turn our blind face to this problem. It's not just the I.V. drug users. When this virus hit the gay white male community, there was a heroic effort to respond. That response impacted our community. You couldn't go in a bar without finding a condom. And it changed our behavior. We cared enough about each other to be our brother's keeper. And if not for our own life, if somehow we couldn't rise up out of our own internal homophobia, we were at least able to protect the lives of our sexual partner and feel good about that.

Today, in the substantial portion of the crack cocaine using population, there is no one doing that job. No one is helping them to care about each other and they're not

caring enough to care about the people there.

There are women in the skid row areas of Los Angeles today who prostitute for nothing more than crack cocaine. We even have a colloquialism to describe them -- strawberries. Nobody's reaching out to these women. Nobody cares about these women. They're homeless. They're hopeless. All they have is crack cocaine to help them forget about their plight. They're also forgetting about AIDS. Nobody's got to remind them about AIDS.

Outreach to this group of substance abusers has been minimal and piecemeal and fragmented. County workers who are trained and should be doing the job of AIDS prevention have been saddled by the bureaucratic red tape of this Board of Supervisors and local county government and all the high level who insist that passing out condoms is against the best interests of their various constituents. They keep politicizing the message. It's not a political message. It's a real simple message. If you do this, you'll get AIDS. If you do that, you'll get AIDS and you'll die. We've got to start caring enough to get past the politicization of the AIDS prevention message. It's not a political message. It's a real simple human issues message and we've got to start telling people the message.

The CBOs in our communities, not just L. A. but all the various communities, they're tapped, folks. They're at

the end of their community funding level. Our community can't fund it anymore. They're tapped. We need help. We need funding help. There's funds out there. We're mismanaging and misappropriating funds all over this country for AIDS. There is no leadership. There is no cohesiveness. And it's a simple message. I don't understand why we can't get a simple message out to the American public. If we'd address transmission groups instead of risk groups, this whole little box that we're put in of making sure that every human being on the face of the planet is at risk with this disease, there's no such thing as risk groups. There's one risk group -- the human race. And we're not addressing it.

While our local government officials have taken a tact that is in direct opposition to all sound medical advice, to the recommendations of the Commission previous to you, and to this Commission, they're ignoring the advice. Health and Human Services, who are supposed to be a leader, they're being ignored. Who do these people answer to?

In I.V. drug using, we know our record's murderous. We saw what happened in New York City. We have the experience of what happened with AIDS in New York and our local government again chooses to ignore all that advice.

While volunteer outreach workers have gone into the streets and passed out bleach and condoms, no funding has been coming from this county for that. We have to do it on

volunteer dollars with volunteer people who well intentioned just are not prepared to change behavior. They can give the message. They can't change the behavior. They don't have any Shep Shawnee models in the crack cocaine using drug population like we do. We had Shep Shawnee. It saved lives. I know it did.

We've got to begin seeing lives as valuable, all lives, whether it's an I.V. drug user or a crack cocaine user. These are all lives and we're just ignoring them.

Distribution of bleach, condoms, sterile needles, safer sex information that is culturally sensitive, sexually positive, and information that addresses transmission routes as opposed to risk groups are all powerful weapons in the war on AIDS. They're weapons we're not being allowed to use.

Members of the Commission, thanks for listening. Your response will be eagerly awaited in our city as it's going to be awaited in every city in this country. But, please, make your response be in the form of action. We don't need any more Commissions, any more task forces, any more councils, any more red tape. We need some action. We need some leadership. We need people at high levels of government to stop talking about rationing health care and start talking about caring. We need to care. What's wrong with us as Americans that we only care about some of us? That's not how we started as a nation and if we don't start

caring, it's how we're going to end as a nation. I'm afraid. I fear for what's going to happen if we don't start treating people as valuable. They're the best resource we have and I say the environmentalists and all of us should hook up together and realize that we're trashing not just our trees but our people and people are resources.

I'm an ex I.V. drug user. Twenty years ago I lived on Skid Row. I was hopeless. Somebody took the time under a democratic administration to put me in treatment because I asked for it, to get me back into school, and to point me on a direction in life. I now am a co-owner of a $200,000 a year business and I give to this community constantly and consistently and right now today on Skid Row there's somebody like that. If we let them go through getting off drugs, which is hard to do and the most empowering thing in your life to have gone through that and won, if we let them go through that and be devastated by having AIDS, we're over as a nation. We're over as a people. We've got to care. Thank you.

CHAIRWOMAN OSBORN: Thank you very much for setting a very important tone for our thinking. We appreciate it very much.

MR. NORMAN: My pleasure.

CHAIRWOMAN OSBORN: I think next Henry Alonzo from El Centro Human Services Corporation.

MR. ALONZO: Yes. First of all, thank you for allowing me this time here. My name is Henry Alonzo. I am a Street Outreach worker, targeting intravenous drug users not in treatment in the northeast and east Los Angeles area.

I am part of a five-member group that calls itself the L. A. County Coalition of AIDS Outreach Workers. This group is currently developing a Los Angeles model for reaching IVDUs not in treatment. Although bleach and condoms have proven to be effective tools for this population, we are not allowed to utilize these options.

Los Angeles County, as you've heard, is unique, eight million people spread across 4,000 square miles. Nearly one third of these residents are Latinos. I would like to say that Latinos are especially young population with an average age of 23.7 years compared to the median age of the United States population of 30.4 years.

I wish to address in particular the Latino intravenous drug user in the Los Angeles area. Los Angeles accounts for more than half of California's Latino AIDS populations. Latinos in the Los Angeles County represent 18 percent of the total AIDS cases. In comparison, only six percent of AIDS cases among Latinos are linked strictly to I.V. drug use and another seven percent are cases transmitted through homosexual and bisexual contacts among males who are also I.V. drug users.

County-wide, it is estimated there are 125,000 intravenous drug users. The median age is 35. Latinos represent 67 percent of intravenous drug admissions in the Los Angeles County. Of those entering treatment programs in the County, five percent have been found to be infected with the HIV virus. This represents 6,250 individuals provided that the infection rate of those not in treatment is no higher. My personal observation is that these numbers are much greater in the Los Angeles area than most believe.

What I would like to tell you is that many IVDUs are very scared, very aware of AIDS, and wish to avoid it.

Next, I can only speak to you from my experiences and share with you what we are observing and being told by the IVDU population. Observations, more homeless IVDUs, including couples with children, more IVDUs who are HIV positive not in treatment. The IVDU population received -- appears to be getting younger, more chronically mentally ill with multiple diagnosis, more IVDUs in available treatment slots, more IVDUs on general relief, more undocumented substance abusers, more drug-related violence in the communities. The Latino community is finding it hard to accept condoms into their behavior patterns. We also see more community-based organizations networking closer together in relation to IVDUs. We also do see there are very few, if not at all any treatment or case management programs directed

to the intravenous drug user.

What are we hearing from the I.V. drug user on the street? More requests for drug treatment, not wanting to wait 20 weeks for government-subsidized residential and methadone programs. We're hearing more concerns, requests, and questions regarding condoms, bleach, HIV testing, and free needle exchange programs. We hear that IVDUs are afraid to carry bleach bottles, fearing repercussions from law enforcement. We hear that large shooting galleries are less frequent, rather smaller clusters (two, three, and four) are more frequent and more mobile. We also hear the use of beepers by heroin dealers, more speedballing. Cocaine mixed with heroin has become popular among I.V. users. Female addicts hustling for their drug in between general relief, female addicts preferring oral sex which is easier and faster for more customers. We hear incidences of male prostitution among immigrant day workers. More undocumented intravenous cocaine users. We also hear a more positive response from -- for the outreach worker out there to get the AIDS message into the community. We also hear of more needle-using behaviors; that is to say, inclusive and exclusive of substances. Referring to tattoos, ear piercing, and for medicinal injections among the Latino community.

Therefore, the need for culturally, linguistically, sensitive case management and AIDS prevention services

designed to meet the needs of the substance abuse person within the Latino community are urgently needed.

I've made other recommendations and I've had to cut out a whole lot, but I would like to say lastly, a community program that we networked with yesterday went out -- one individual went out and got 100 signatures, and it says, "As an I.V. drug user, I believe that passing out bleach is an important factor in stopping the spread of the HIV virus among intravenous drug users" and I have a hundred names here and this was one day by one outreach worker.

Thank you.

CHAIRWOMAN OSBORN: Thank you very much. Next, William Edelman from Orange County Drug Abuse Services.

MR. EDELMAN: Thank you. I'm not going to bore you with reading my prepared comments. I'd just rather talk to you straight from my heart and tell you what we've been able to do in Orange County. I have to tell you that it's a little bit different than Los Angeles in a lot of ways, but I also have a lot of feelings for my colleagues in Los Angeles that have to deal with the problems that they've outlined so far.

We've been lucky. We've had a very cooperative effort with the public health section of the -- of our health care agency. I've had immense cooperation in doing testing and doing outreach work. We've developed an outreach program

and we feel we've begun to reach all of the I.V. drug abusers that are known to us. The staff are given a great deal of freedom to do as they see, and to engage people in any way that they can to involve them and to bring them into treatment.

We've seen the treatment programs grow and grow and grow, but one of the problems that we do have, which is true for this whole, entire state is inadequate funding for treatment. We're not adequately prepared to deal with the number of people who need treatment. I've spoken with people in Washington who indicate that treatment is a bottomless pit. It's a waste of time. It's a waste of the taxpayers' dollars. I don't know what they read. I don't know who they talk to. I don't know the research that they reviewed.

As a past member of the National Council on Drug Abuse, I reviewed thousands and thousands of proposals and results of those research projects, and everything that I reviewed and everything that I've spent time in my 23 years devoted to this field of drug abuse has indicated that treatment works and we need to be proud of that. We need to be involved in trying to get more and more people into treatment. And that saying that they're losers, it's just a pleasure to be on this -- to sit here with you, to sit next to you, and to hear you talk and in your remarks, and we need more people to speak out.

We've created a stigma in our society that if you're a drug abuser, well, you're a user. Well, if you're a drug abuser, then you're a crook, then you're a thief. We've created an environment in which hate and violence is part of drug addiction and that hate and violence prevents us from doing a lot of things that we should be doing.

Recently, the State of California has proposed a budget. The Governor of this State has proposed to eliminate heroin detoxification as a Medi-Cal benefit. Do you know what that means? That means that poor people cannot enter into detoxification without stealing to pay some private vendor for detoxification services.

The results of that are going to be devastating to us. The result of that can possibly jeopardize the federal grant that California is receiving currently and its grant and its additional funds that we're intending to receive. We need your help. We need you to educate those who are in public office to realize that we cannot -- we can ill afford to cut off those avenues to people who need to hear from us, who need to learn about, you know, prevention techniques, who need to hear that treatment works, who need to see their fellow colleagues, their friends, to bring their wives and their husbands into treatment, not to cut it off.

We've had a lot of successes in Orange County and I will tell you that it's been 11 years that I've worked

there. Even though it's considered a relatively conservative place, I've not had to be tortured with having to burn pamphlets or do other things like that. And some of my colleagues have tried desperately to get the word out and had difficulty with it. I've had the cooperation, as I indicated to you before, from everybody and I'm very appreciative of that. Thank you very much.

CHAIRWOMAN OSBORN: Thank you very much. Dr. Xylina Bean from the King/Drew Medical Center.

DR. BEAN: First, I want to thank the National Commission on AIDS for allowing me to present today. I am not an expert on AIDS and, therefore, I will not reiterate all of the statistics that you've already heard and hopefully have gotten an impression of how bleak the picture is, especially in the minority community, regarding AIDS.

Since I'm not an expert on AIDS, I assume that you asked me to speak because of my expertise in working with substance abusing women and children.

You've already heard testimony -- Irma, have you talked yet? Thank you -- from Irma -- from Dr. Strantz who's already told you I'm sure a great deal about this problem and so, therefore, I decided rather than reiterating what she could do better in terms of talking about the County as a whole, I decided to talk specifically about how that translates then into one institution in this community and that's

into the area in which I work.

King/Drew Medical Center is in southcentral Los Angeles, a predominantly minority community, black and Hispanic, and the Martin Luther King Hospital and the Drew University of Health and Science are the primary providers of health care for this area and I saw on your agenda that you are planning on spending some time with us.

The largest number of drug-exposed infants in Los Angeles are born at Martin Luther King Hospital. The number of infants has risen from 28 infants in 1981 to over 500 infants in 1989 that were identified.

Before I came down today, I reviewed some of our most recent statistics. Though the last two years that we have been keeping extensive data on all of our NICU admissions, 19 percent of all admissions to our neo-natal intensive care unit had positive toxicologies for drugs and that would only include those who actually had a positive toxicology and not those who had a positive history.

The neo-natal intensive care unit would be the area in which the babies are the sickest and those are primarily premature infants. Of our total premature population, around 25 to 30 percent of them are born to drug-exposed mothers.

In our Level 3 nursery, which -- Level 2 nursery which is the intermediate nursery, 47 percent of all admissions are for the diagnosis of infants of drug-abusing mother

as the only diagnosis and we currently are admitting between 30 and 50 infants per month who have positive toxicologies for illegal drugs.

In 1981 to '85, the primary drug abuse was PCP and now crack cocaine accounts for over 80 percent of all of our related admissions.

Nationwide, as you probably heard, parent at risk accounts for about 80 percent of all pediatric AIDS cases. In the parent of this category, about 75 percent of the mothers are either I.V. drug abusers or are sexual partners of I.V. drug abusers. The number of pediatric AIDS in Los Angeles, as I'm sure Dr. Church has already told you, is relatively small to that which is nationally.

Of the cases that we have diagnosed in our institution over the last three years, only 25 percent of those cases were born to mothers who were I.V. drug abusers. One case was a mother who was Haitian and the other cases about 60 percent were born to mothers who were cocaine abusers and who denied a history of I.V. drug abuse.

Female drug abusers, as you know, are at high risk for AIDS given their lifestyle and especially cocaine abusers since the major mechanism that they use for paying for drugs has to do with sexual activity. And when you are trying to get a fix, you don't spend a great deal of time talking to your partner about using condoms and safe sex.

The other thing, of course, is the natural history of cocaine abusers, that it takes about -- before crack cocaine, it took about three years to progress to I.V. use of cocaine. It's slow -- the process has slowed somewhat because you have a very similar high with smoking it or using crack cocaine as you do with I.V. but you still see the same progression and we're beginning to see that progression in Los Angeles and we're about five to six years into a crack cocaine epidemic. That was to be expected.

Did Dr. Church go over the results of the anonymous core blood screening that they just completed in the State of California?

CHAIRWOMAN OSBORN: I don't think so.

DR. BEAN: In the State of California, as in other states, they have just completed an anonymous core blood screening and they did 135,000 infants in the last -- over a three-month period of time. Did he review that already?

CHAIRWOMAN OSBORN: We did hear the single -- the brief summary of it, yes.

DR. BEAN: Okay. Of that statewide HIV prevalence rate, 7.4 per 10,000, or one in 1,344 new mothers, was HIV positive. However, if you look specifically at black women, there was one in 275 for black women. This is 12 times the amount that was seen in white women. If you look at the rates for Hispanic women, the rate for Hispanic women was one

in 1,377, which was twice the rate that you see in white women.

In Los Angeles as a whole, the rate was one in 1,043 births because of course we have a high percentage of both black and Hispanic patients which makes our rate higher. The nationwide as you know blacks and Hispanics make a disproportionate amount of the population of pediatric AIDS.

So, in conclusion, AIDS in the context of minority communities are already devastated by the impact of a number of already pre-existing major health and social problems. It's awful -- it's difficult to understand for those of you who are not part of the community. In communities which have to live with the reality of infant mortality rates that are two to three times that of the majority population where black males have less chance of living to age 55 than men in Bangladesh and where drugs are destroying whole communities and totally dominating the economic, legal, and social service systems, it is difficult to convince people of the importance of wearing a condom. AIDS becomes just another problem that one has to deal with.

A drug-abusing woman who has only one commodity to barter and exchange for drugs cannot be expected to bargain for supply over safe sex.

Recommendations. More resources need to be put into minority communities, not just to study the problems and

count the number of black and brown dead and dying victims, but to provide medical treatment and social support for the victims and their families.

I would consider it unethical to attempt to conduct research in a community such as ours without linking it to the provision of services.

AIDS education for minority communities need to be culturally appropriate and linked to the existing community resources. The realities of AIDS in minority communities at the battle of AIDS will not be won without addressing the problems associated with drug abuse.

Provision of both the technical resources and financial resources to develop AIDS treatment and research centers in minority communities. Given the already pre-existing limited resources, most minority institutions do not have the technical resources to compete with large university centers for most AIDS funding.

And specifically for children, more focus needs to be put on developing the medical and social service resources to keep minority children in their homes and communities either with their parents or extended families. Some of these children, however, will have to go to foster care and we need to develop better trained and more foster parents to meet these children's needs.

And, finally, as we develop new drugs and research

on AIDS, more attention needs to be directed to the needs of treatment for children and at this point most children, treatment for children seems to be almost an afterthought when you look at AIDS treatment.

Thank you.

CHAIRWOMAN OSBORN: Thank you very much, Dr. Bean. Danny Jenkins from the Tarzana Treatment Center.

MR. JENKINS: Thank you. I appreciate this opportunity to testify and I'm honored to testify with this particular panel.

My name is Danny Jenkins. I'm the HIV Project Director at Tarzana Treatment Center, a county-funded drug treatment program, detox, residential, and outpatient. I won't go -- I'm also a recovering drug addict and alcoholic and I won't go into the details of our facility except to mention that we serve drug addicts county-wide, although we're nestled in the valley section of Los Angeles.

We serve I.V. drug users, other substance abusers, such as crack addicts, pillheads, alcoholics, homeless people in treatment diagnose, meaning addiction, HIV, and/or mental illness, AIDS for expectant mothers. Many of our clients, approximately ten percent at any given time are HIV positive, as are many of our staff.

I need to mention because I feel that it's important that only 40 percent of those HIV positive addicts are

IV drug users. I feel like we do a disservice to people as far as education is concerned when we classify I.V. drug use as the substance abuse problem which has been highlighted by this panel.

The progression of HIV disease of course among IVDUs and other substance abusers is deceptively slow, perhaps manifesting a different but parallel pattern to that on the East Coast.

The response from every level, political, resource, and service provision, appears to underestimate the potential threat to many populations -- racial minorities, women and children, and drug-dependent populations.

In L.A., we need of course to emphasize primary and secondary prevention among I.V. -- among drug addicts in general.

Locally, direction is needed -- this is probably the most important thing I have to say -- locally, direction is needed to help reverse an attitude reflecting a sense of hopelessness, surrender, and avoidance in reaching addicts. That this population is difficult to reach is justification for increased focus, innovative research, and aggressive intervention.

Our experience demonstrates that this population, though under-served and disenfranchised, can be effectively reached with prevention strategies, counseling, case

management/guidance.

Problem areas include the narrow definition of I.V. drug user as a risk population when in fact the predominant risk factor among addicts continues to be sexual transmission, especially among crack addicts and cocaine users to obtain drugs or in the use of -- in unsafe sex practices after the use of the drug.

The pristine denial among local communities and of course some political bodies that have been mentioned this morning that drug use and abuse continues, fosters a dangerous atmosphere of complacency, one which the human immunodeficiency virus thrives on.

Recommendations would include primary and secondary prevention, treatment, and service, the inclusion of all addictive behaviors -- IVDU, IDU, meaning injected drug use, including intramuscular and skin popping injections, and all chemical dependency, including alcoholism; cross-training to HIV service providers at every level, including governmental entities and resource providers on addictive substances and addictive behaviors; the aggressive consideration of the spectrum of addictive persons in educational, primary, and secondary prevention and treatment modalities; and of course the involvement of recovering persons at resource, planning, and implementation level of all such programs.

We need to try every strategy possible. I used to

have a very -- I used to have a very opinionated feeling about the "Just Say No" campaign, but in fact just say no has to be part of our message as well. However, we need to try every possible prevention strategy, including condom and bleach distribution and we need to look into -- into distributing clean needles as well. I appreciate this opportunity. Thank you.

CHAIRWOMAN OSBORN: Thank you very much. The panel is joined by Dexter who has some additional comments.

MR. SHAW: Good afternoon. My name is Dexter Shaw. I'm affiliated with Minority AIDS Project. When I was first asked to speak before you, I was reluctant to do so because of the stigma attached to the subject of AIDS. However, I came to the conclusion that maybe, just maybe, something that I said here today might be beneficial in saving someone's life, so here I sit.

The subjects I have chosen to address are AIDS education, health care, social services, and agencies like Minority AIDS Project. All these subjects I feel in turn deal with the drug user.

AIDS education is a priority. Conventional methods, those being the uses of television, radios, and publications are good at reaching the general public, yet they fail to reach the homeless and indigent populations who are without such things as television and radio. It is hard

to get electricity into a cardboard box. Seeing that conventional methods do not work at this level, we must begin a strong and vigorous campaign to educate these people now using agencies such as Minority AIDS Project to perform one-on-one contact to public agencies such as Department of Public and Social Services, Social Security, et cetera, should provide pamphlets and be trained, you know, to handle incoming questions from people with AIDS or the general public.

Programs such as those to exchange intravenous drug users' needles are innovative, yet they will barely touch the subject. Stop and think for a moment. What drug user's going to take the time to exchange a soiled syringe if they need or want the drugs right then?

What needs to be done here is that such items as syringes should be made available for sale without a prescription or, as you said, exchange.

In regards to health care, our nation's hospitals are understaffed, overworked, crowded, and because of it, inept at providing services. In this area I think what must be done is monies must be provided now so that health care can -- health care services can be expanded and made accessible to all. Preventive health care now will avoid cost overruns down the line, fewer AIDS patients will have had to be placed in the hospital, medicines must be made

available to those who are willing to test them at first opportunities instead of the red tape that goes along with the new drugs that come out.

Agencies, such as Minority AIDS Project, must be given the funding that is so desperately needed to reach people, maintain services, and meet the ever-increasing need of both PWAs, HIV positive, and the general public.

We have the opportunity to save lives. If, as we say, we are indeed humans and humane, then let's waste no more time in doing so. Thank you.

CHAIRWOMAN OSBORN: Despite the press of the clock, I want to take a few minutes for questions because your testimony collectively and individually has been very powerful this afternoon. Are there questions from the panel? Congressman Rowland?

HON. ROWLAND: Yeah, I just want to make a comment. I was listening to Connie Norman describe the female drug abuser here in Los Angeles and you also describing the female drug abuser in the district that I represent in Georgia which is very rural. It could have been a woman in the southern part of the district in Okefenokee Swamp and the dairy country and the upper part of the district, mostly black, who felt hopeless, who had gotten hooked on cocaine, who was really not concerned about AIDS or syphilis or gonorrhea, concerned about her next fix, and she got her next fix by

selling herself to get the money to do it.

So it seemed that it's the same kind of situation --

MR. NORMAN: Sure.

HON. ROWLAND: -- over and over and over and it's really a severe problem, just as you have described here in the urban area and the rural area also.

Let me ask a question about methamphetamine, ice, which seems to be coming into this country. This question is directed to anybody on the panel. As I understand it, that is coming more and more to be the central nervous system stimulant rather than cocaine, although cocaine is still prevalent at this particular time. What -- I believe four percent was a figure that was given for amphetamines by Dr. Strantz there, but could you all make the comment about that because as I understand it, heroin, central nervous system depressant, cocaine or amphetamine are being used together now and is getting increasingly prevalent. Is that --

MR. ALLEN: Just going back to my own experience with drugs, I shot speed. That was my drug of choice. There's never been a smokable form of speed, so not having to get a needle, which is what ice is, not having to get a needle, not having to deal with that whole thing, and being able to buy the drug and smoke it instantly in small pieces like crack cocaine, it's very dangerous, very insidious.

HON. ROWLAND: Now, methamphetamine is available in that form now.

MR. ALLEN: That's right -- yes. That's what I'm saying. It is a new form of the drug. There's always been a portion of the drug-using population that were speed freaks. They like that speed. I was one of them. And -- so, yeah, that's a real problem. It's going to be a growing problem for us. And as dealers learn to combine these drugs so that you have essentially -- speed is not physically addictive; it's psychologically addictive. But when they start combining them with heroin and putting it in crack and ice, you've got an addictive substance there. It's not only psychologically addictive; it's physically addictive. We've got to be aware of it.

DR. STRANTZ: In terms of California and law enforcement attempting to or finding -- looking for ice because they've certainly -- we've all received so much material from Hawaii, apparently there was a seizure in Sacramento last week. Now, there have been rumors in the Long Beach area, particularly in one of our pre-natal care clinics serving drug-abusing women, that ice has been seen, but we have not been able to corroborate that as yet.

MR. ALONZO: If I may interject, representing east L. A., we already are hearing incidences of houses selling ice in that community.

MR. NORMAN: And you're right about Long Beach. That's just where it is. I've had people tell me so.

CHAIRWOMAN OSBORN: Dr. Rogers.

DR. ROGERS: Dr. Strantz, first let me echo June's comment, very impressive testimony. Thank you all. If I heard you correctly, you said you have 5500 people in drug treatment. I think this morning we heard there was an estimate that 112,000 drug users in your area. Is that about the right proportions? You've got 5,000 under treatment and you've got 112,000 drug users?

DR. STRANTZ: The 112,000 to 120,000 is the estimate for the number of intravenous drug users. If we add crack smokers, PCP users, amphetamine abusers, then the number is I'm sure 400,000, 450,000, whatever. We have not been able --

DR. ROGERS: And you have 5,000 slots?

DR. STRANTZ: Yes, publicly-funded. Now, I'm only talking about treatment capacity for those who cannot afford to pay or can only pay a little bit. The private sector, the chemical dependency recovery hospitals, et cetera, there are quite a few of those in the county and there's no waiting list to get into those.

CHAIRWOMAN OSBORN: Dr. DesJarlais?

DR. DESJARLAIS: There were several comments about some of the difficulties in getting drug users to be con-

cerned about health, but if I'm accurate with reflecting what you're saying, there are more difficulties getting certain public officials to be concerned about health.

Sexually transmitted disease rates have been pretty good markers for sexual transmission of HIV and I was wondering if any of you have any information about sexually transmitted disease rates in this area and hospital linkages to drug use?

DR. BEAN: At least among women, one of the -- in Los Angeles County, we have one -- we are one of the areas of the country which now has an epidemic of congenital syphilis. Congenital syphilis, as you know, is syphilis in babies. Using that as a marker, sexually transmitted diseases, at least among women, is one of the major risk factors associated with cocaine abuse, but then sexually transmitted diseases are increased in that population as a whole.

The estimates are anyplace between 18 to 20 percent of the cocaine -- I shouldn't say cocaine -- of the drug of the perinatal -- the identified drug-abusing women are -- come into delivery or into pre-natal care with a sexually transmitted disease. The most common one is syphilis, followed by Chylamidia and G.C. is actually third down the line, interestingly enough, of sexually transmitted diseases that these women come into, and it's already well documented in New York City as well -- there have been a couple of CDC

mortality and morbidity weekly reports specifically documenting the association between syphilis and cocaine usage and it's also been documented that syphilis specifically appears to be a risk factor in transmission of AIDS. There's -- nobody knows exactly the association except that if you've got syphilis, then the incidence -- you appear to be more susceptible to getting AIDS or at least there's a very strong connection. Of course, if you have AIDS, syphilis is a major complication associated with AIDS and once you have AIDS and you get syphilis, the syphilis is extremely difficult to treat as well.

And we do recommend testing for anybody -- we're doing routine -- offering routine testing in the STD clinics and we do recommend to clients who come in with a sexually transmitted disease that they get screened for HIV as well.

CHAIRWOMAN OSBORN: I hate to slow us down here because this is such an important topic. I think I'll take one very quick other question. Diane, did you have --

MS. AHRENS: No, I had a question of something that I just don't understand, is what the high level of -- with the high level of drug use and drug use in this area, why is there so little AIDS infection in this population? At least the figures that came at us this morning would indicate that there was not and I don't understand that.

DR. STRANTZ: Well, Los Angeles County is huge.

And you have communities of drug users, just as you have communities like Hollywood and Long Beach and Santa Monica and Pasadena and whatever. Because of the social networks or communities or drug users, we feel that we've got some extra time because there hasn't been too much cross-over from one network to another. When we -- we see the highest rates among I.V. drug users. They're among those who are gay bisexual, but the number of heterosexuals that they share needles with increase the risk in that community and then, you know, we have a galloping epidemic, but that's what we feel is going on in this community.

MR. SHAW: A lot of the drug users remain untested until their illness comes upon them. Then they go and get tested. That's why figures are so low. A lot of people are still running around, unaware that they are HIV positive or infected with the AIDS virus.

DR. BEAN: If you look at the sero-positivity rate that I gave you for California, we should be identifying something in the range of ten times the number of clients that we're identifying, but we don't have the resources at this point to put into identification and, frankly, I -- even though I think it's extremely important that we identify the resources that are available in most minority communities, including ours, extremely limited and identification of sero-positive HIV clients is not at this particular point a

priority.

MR. EDELMAN: I'd like to make one comment about drug treatment in terms of what the state budget for the State of California has been like in the past six years. We have not gotten one nickel, not one nickel, not one percent, not any increase in that state budget in six years. You say, "How could that be?" Every politician talks about drug abuse. But it goes back to the thing that I spoke about earlier. We want to blame people. We want to say that they're bad. We want to forget about them. We want to push them off into a corner. We want to label them a certain way and we don't want to deal with them. The only way we really want to deal with them if we take a look at the budget for building new prisons, then you see that increasing. If you look at probation and parole budgets, they're increasing. I'm not saying that they should and I'm not making a political statement about it, but you need to understand that the system that we operate in and work in has been kind of kept down and it's kind of collapsed. There is some new money coming in, new federal funds, but that still remains to be seen what really will happen.

CHAIRWOMAN OSBORN: Let me thank all of you again on behalf of the Commission for your very important testimony.

We are running behind for a very good reason but,

nevertheless, behind. So let me suggest a ten-minute break and then we'll come back.

(A brief recess was held.)

CHAIRWOMAN OSBORN: I think I will start while people are reconvening because we want very much to be able both to hear from additional important witnesses and I will repeat my usual refrain, in case you haven't heard it, that we would like very much for you to summarize, to the extent possible, your prepared remarks so that we have a chance to interact. If you did hear some of the earlier discussions, the Commissioners are very eager to interact with the people we hear from and it's very helpful to us. To that end, we have our kitchen timer here which periodically will go off and that will be a suggestion that you finish up quite quickly.

The next group of people talking with us will be talking about street youth, prostitution, and homelessness, and I guess Gabe Kruks from the Gay and Lesbian Community Service Center will be our first discussion.

MR. KRUKS: Well, I would like to thank the Commission for the opportunity to be here, as is everybody else, and I also want to just commend the level of dialogue that I heard today. It's really quite encouraging for me.

I'm going to talk mostly about street youth, but also try and tackle the bigger issue of youth and HIV

prevention in general.

Before I get into what I want to say, I just want to add something actually from the IVDU panel, the substance abuse panel. I work with street youth in Hollywood and I've got to tell you, we see a lot of ice now. We've been seeing it for about six months. It's there. It's not something that -- I would guess ten, 15 percent of the kids we work with have reported using ice as well as crack and crystal methamphetamine, so I just wanted to add that before I got lost.

Los Angeles has a particularly large problem with homeless youth and I make a distinction between runaway youth and homeless youth. Homeless youth are the youth that are really on the streets integrated into that subculture. The low estimate is about 10,000 county-wide, high estimate 20 to 25,000. They come from all over the country. About a third of them are self-identified as being lesbian and gay, and that's a big factor in a lot of these kids leaving home and that they may be running from homophobia, directly kicked out of their home, or running indirectly from what they perceive going on in their home environments. So sexual orientation is a big issue and it's important that that does not get lost.

The clearly are a population that is at great risk for HIV. Majority, 70 percent, of these kids are involved in

survival sex of one form or another. Thirty-five percent of them IVDU. And about 90 percent of them with other non-intravenous substance abuse problems.

Major history of physical abuse, sexual abuse, suicide attempt, it's a very chronic, multi-problem population. That's the bad news.

The good news is that for once, Los Angeles has something to offer the rest of the nation. We don't really call it the Los Angeles model, but maybe we should. In the last four years, we have built a coordinated system of care that works with homeless youth, that encompasses over 20 community-based agencies, which includes Department of Children's Services, the local police force, juvenile probation, and we really have built this as a coordinated system. We share funding. We coordinate services. And avoid the sort of struggles and turf wars and funding battles that we see happening in other cities where there's population, that we see in the larger HIV service community.

Because this is a population that has a great potential for coming into contact with HIV, we have built a very large HIV prevention, treatment, and early intervention piece into this system.

Now, while we don't have any empirical data as to what the overall sero-prevalence rate with street youth is, there's one study out of New York done by Covenant House

that's not a very good study. What I can tell you anecdotally is that in my own shelter, at any given time about 25 percent of the kids in the shelter are reporting a seropositive status and it may be higher than that but it's at least 25 percent. That's high.

The issues around treatment with these populations are very critical. The reality is that street kids, even if we set up the clinics and the kind of health care is available to them, they're not going to access it. They're not going to schlep down to 5B21 at the County and sit there for four hours and wait for their AZT and get their blood work. It just is not a reality for these kids.

What we have done and what we need to do and what we want to encourage other areas to do is that you have to build coordinated systems that really work with this specific population. They're a subculture. Case management is the glue that holds it together. Independent living programs, stabilization programs, counseling, addiction recovery counseling, mental health services, if the whole thing doesn't sort of plug together, it falls apart.

Most of these youth will find whatever crack there is in the system and they'll head right for it. Now, as I said, this is -- the good news is that I think we've really developed a model in Los Angeles that is really beginning to address this. Unfortunately, it's a model that's still too

small to reach current need.

You know, in any given night, we probably turn away more kids than we provide services to.

The most gratifying thing, however, and this is really something again that we're seeing in the last couple of years, I don't have strong empirical data right now -- if you came and asked me in about six months' time, I probably would have some stronger data -- is that HIV prevention seems to be beginning to work for a lot of these kids. We're starting to see some behavioral change.

I heard the buzzer and I'll try and wrap it up in one minute. The market that we're using for that is the incidence of gonorrhea. Four years ago, about 20, 25 percent of the kids that came into our program had a case of gonorrhea at intake. Today, that's about three or four percent. Something's working. That doesn't mean that we by any means have done everything that we need to do. There's a lot more to do but we've made some steps. What I just want to tie that to is that if we have the moral courage as a nation to raise the subject and to raise the level of the debate around youth prevention, and I'm now talking about mainstream youth and youth in schools and youth everywhere, what I have to say is that if we can start to get street kids to change some of their behaviors, we can do that with any population, and so the argument that says, you know, "Gee, if we talk about sex

and if we give them condoms, it's just going to encourage" is plainly not true and it's been demonstrated with -- in our programs and with our work with street youth. Thank you.

CHAIRWOMAN OSBORN: Thank you very much. Ruth Slaughter from Project Warn.

MS. SLAUGHTER: I would like to thank the National Commission on AIDS for having me here and to be an advocate for women. My name is Ruth Slaughter. I'm with the National Women and AIDS Risk Network. We're a national project funded by NIDA and we're in Boston, Phoenix, and Los Angeles.

Warn was one of the first nationwide programs providing AIDS education information to women and we will be ending here in Los Angeles as of March, 1990, so I want to share with you a program that is working or research is showing that women are changing behavior and some of the ways that we have helped them to change behavior.

But like many federal programs that work, now that it's working, it's going to end. And it doesn't look like we will be getting any state or county funds because there are -- or they claim no resources for the Warn project to continue.

In Los Angeles County, we have very few programs working with women. We have three or four and they're very small. Some of the staffs are part time. And so to lose another program when we are seeing so many women at such high

risk, it's really very, very critical for this -- for this county as well as Boston and Phoenix.

Our major population that we are working with are African-American women in southcentral Los Angeles and Latino women in east Los Angeles. We are working in the Headstart programs. We're working in churches. We're going to the WICK programs and we are reaching out to the women. But I want to share with you some of our street outreach because I think that's the area that I think that we're being very effective.

We are one of the few programs in Los Angeles County that can hand out condoms and bleach and that's a first step of raising the consciousness but it's only the first step. And we have found that just by passing out bleach and condoms does not change behavior with our population, that we need to be there for a year or two years. And one of the areas that we're working in southcentral, we have been there for the last -- for a year. We're working out of a church. We're working with women who are primarily using crack, who are sex workers, women in the community that no one in the community cares about. They are called strawberries. They are called a number of names, but we see them as women and we see them as mothers, as sisters, and daughters. They have young children. They are trading sex for food, for clothing, for a way to survive.

Our outreach workers walk along the street in the morning, pass out condoms and bleach. Then the women come back to this church site and we have found that you don't deal with AIDS in a vacuum, that if a woman is hungry, if a woman needs housing, if her children need clothing, that many times you have to deal with those things first and then you deal with AIDS.

By being there consistently, the women now are volunteering and are helping each other. They bring women to the Warn site. They are telling women to come to the Warn site, pick up condoms, pick up bleach. "If you want a referral, you can get it there."

It's so important for programs for women to be sensitive to women, developed by women, and women from the community, women who care about the community. And our research has shown that over a period of time, the women do change behavior, even some of the highest risk women. We have very little resources for drug treatment programs. But because we know people in the drug treatment programs, we have been able to get them in or put them in at the top of the list, as well as our staff will take them to N.A. meetings. They'll take them to A.A. meetings.

We have also been talking to the women about being tested and I know many programs are saying, "Let's not have the women tested," but we feel that we give as much

information about testing as possible. The women now, 80 percent of the women now, are getting tested and a high percent, very high percent, about 85 percent, are coming back for test results. So with trust and believing in the women, change can happen.

My concern is that we know that there needs to be more resources for women, but we don't want to take it away from men. We want to make sure that more resources come into this county so women can be helped, so children can be helped, so teens can be helped. We also would like for -- as we're organizing in our community that we can move on to another community that the women are helping themselves, so we're trying to build a volunteer base where the women are helping each other.

Thank you.

CHAIRWOMAN OSBORN: Thank you. Michael Cousineau from Los Angeles Homeless Health Care Project.

DR. COUSINEAU: Thank you very much and again as everybody has said here, thank you very much for inviting me here to speak to you. It strikes me that as we talk about different groups who have been the population that live in Los Angeles, many of the people who are at risk for HIV infection are in fact maybe the same people.

You know, you don't have to go very far out of the -- from the Hollywood Roosevelt Hotel to encounter a homeless

person and he or she will be probably a street person that you will see pushing a cart or maybe chronically mentally ill, but what you won't see perhaps and it is obvious to you is a young woman with her child pushing a cart to the grocery store with a bag of diapers and some food. You might not think she is homeless, but in fact one of the biggest and the growing problems in Los Angeles is homeless families. In fact, I was quite shocked to hear even recently that while we've been talking about maybe 30 to 50,000 people homeless in Los Angeles County, data from the Department of Social Services in the state showed that there were 15,000 families that applied for and obtained special homeless assistance under the AFDC Homeless Assistance Programs. And if you assume that, you know, each family has two or three kids, that's 45,000 homeless families at any one time in Los Angeles County alone. That's just families.

We really have a very severe problem of homelessness in this County and it is related to a tremendous problem of lack of access to affordable housing, a breakdown in the delivery system for health services and mental health services, and the tremendous lack of access to substance abuse treatment, particularly detox.

There also has been an increased awareness among people who work in shelters for the homeless of people who have HIV infection and who are homeless. We've done some

studies of the shelters and all have reported an increase in the number of people who have come into the shelters who have -- who they know have AIDS because the person has reported it or for some other reason, but in many cases those shelters are -- do not have the resources to respond adequately to deal with the case management issues, the treatment issues that are required. Many of the shelters in Los Angeles -- all of them, in fact, are not licensed. There are no licensing requirements. They're very seldom inspected by the Health Department. And the shelter workers are often unaware that the conditions in the shelters put the people who have HIV infection at the greatest risk and so we try to emphasize ways to prevent the transmission of communicable diseases.

We're also concerned about the aspect of drug treatment. We have a small program from the drug program office for doing outpatient directory to refer homeless drug users and we are required to see only I.V. drug users or their sexual partners who are drug users unless they're alcohol users, and those kinds of regulations oftentimes prohibit us from the kinds of flexibility, using flexible approaches and alternative approaches that we need to deal with homeless people.

When they come into our program, the thing that we need to deal with first is to get them off the street and into some sort of housing. Stabilize their lives. They're

not going to get to first base unless we can try to deal with just their basic life skills and maybe things that Ruth was talking about before. And to have to fit this kind of a program into models that have been used in the more stably housed population is not as useful as trying to use those resources to apply more flexible alternative approaches for dealing with substance-abusing homeless people.

Finally, let me just also say that what's needed in Los Angeles, as in other cities, are more alternatives for specialized housing for people with AIDS. Many people are coming out of the County hospitals finding that their apartments are closed up, their roommates have left, and they have no place to go, and we need not -- I hesitate to say we need more shelters for the homeless, but we certainly need more programs that provide transitional housing, service-enriched permanent housing for the homeless who have HIV infection, and we also need new programs that address the emergency and immediate needs of the people who are homeless and have AIDS.

Thank you very much.

CHAIRWOMAN OSBORN: Thank you. Jackie Goldberg.

MS. GOLDBERG: Good afternoon. My name is Jackie Goldberg and I'm president of the Board of Education for the City of Los Angeles. We have about 650,000 daytime students and another probably 150 or 200,000 in the evening.

I don't want to repeat everything that's been said. I just want to say ditto by the other panel members, and then add a couple of things just in terms of youth in general.

The biggest problem that we face in educating youth about HIV infection is is that they believe they'll live forever, that they're immortal, that their youth means that nothing can harm them and touch them. And since the onset of any serious repercussions from their behavior is so delayed in this particular disease, it's a really momentous task.

We believe in Los Angeles Unified that we've done a tremendously wonderful job in getting people to understand how you get it and how you don't get it and what's dangerous and what's not dangerous and I think we've done a wretched job in getting anybody to change their behavior at all.

Now, we believe that so dramatically that we have recently, by directive of the Board of Education, begun to empanel a blue ribbon panel and given them the charge to advise the District on any steps that they think we should take to make it possible to encourage young people to not see themselves as quite so immortal so that they might change their behavior.

We think there are some things that we have begun to learn already, but we don't have any scientific facts to back it up. I'm just going to share to you anecdotal information.

One is we think that PWA educators are essential. They are thus far the only part of our program that seems to make it real. This person really has AIDS. You really can get it. You can really talk to this person. You can really find out what it means to this person's life and their family. You can find -- and frequently they look just like you do, except a little older and it makes it real, so we think that there's going to be a necessity to find some ways to make it much more possible to get PWA educators, and I say that not just PWAs but PWA health educators, people who we do some training with in conjunction with the Red Cross so that they have -- they know a lot about the personal end of it. We want to make sure that they know how to relate to youngsters and how they can be most effective.

Another thing that we know absolutely is is that we have to address the need of young people to socialize. There is increasingly nothing for teenagers to do. There are no teen posts as there were 25 years ago to speak of. There are very few teen dances and clubs and places to go that aren't alcohol-serving or at least if they aren't alcohol-serving, they're so expensive as to exclude everyone. We need to get back to being able to organize free dances and social activities in abundance on the weekends in particular and recreational activities and arts and crafts activities. We have got to become a nation again that provides something

wholesome and enriching for children and youth to do or they'll do whatever they're going to do in the back seat of a car and it isn't going to help their health and it isn't going to make them safe, and if we don't, we have a generation teenagers raising themselves. And I'm not talking about the homeless. I'm talking about people with parents. But their parents are so involved in making a living today at the high pace that we live in and this cuts across income lines, folks -- we're not talking about only poverty here. We have a generation of teenagers raising themselves and if we don't change that condition, all of the education in the world is probably not going to change their behavior. We've got to have more youth activities free and low cost available in every neighborhood everywhere that kids can participate in.

Finally, I believe -- no, not finally, almost finally, next to finally -- next to finally -- thirdly. Thirdly, I think we have to have a social marketing strategy to make condom use socially acceptable. It is not good enough to just make them available. We have to have marketing research. People who know how to sell ideas. We have a lot of them in this country. We need to employ them to come up with a marketing strategy which says that it is socially acceptable to use a condom and, in fact, it may be socially unacceptable not to if you're going to engage in sexual

activity.

Now, finally, we need to have factual nonjudgmental age-appropriate information and discussion about AIDS, sexuality, and sexual behavior, and it's got to begin in the elementary schools. I think that's all I have to say. Thank you.

CHAIRWOMAN OSBORN: Thank you all for a most impressive testimony. I'd like to see if the Commissioners have some questions. Congressman Rowland.

HON. ROWLAND: Listening to you talk about kids, I guess you're talking about kids from middle-class families. No, you're not talking about kids from middle-class families?

MS. GOLDBERG: All kinds of families and including kids on the street. There's just -- they don't have anything to do. Is that part of it, you mean?

HON. ROWLAND: That's my question.

MS. GOLDBERG: Yeah. I'm talking about -- in terms of not having anything to do, it is increasingly a problem at all income levels, low income, medium, and upper.

HON. ROWLAND: Okay, not just the groups of people we've been focusing on here today then, but it --

MS. GOLDBERG: It is a problem at least -- unless other cities are doing better than Los Angeles, which I'm not really familiar with, it may be nationwide, but it is certainly true in Los Angeles. There is very little to do.

HON. ROWLAND: I'll ask you the question that was asked me a little bit ago by someone here. What about the incidents of AIDS? We've been talking about blacks and Hispanics and people from lower socioeconomic levels. What about the middle-class people? What about the incidents of HIV in middle-class people, so called white Anglo-Saxon Protestant?

MS. GOLDBERG: Right.

HON. ROWLAND: Is that --

MS. GOLDBERG: I remember them.

HON. ROWLAND: Okay. Well, tell me what about that?

MS. GOLDBERG: We have increasing evidence -- we have increasing evidence that while there is a larger propensity in lower income groups, it is definitely not restricted there, and it goes back to my first statement. If you believe you're immortal, you might try intravenous drugs once. That may be all it takes. You might engage in risky sexual behavior once. That may be all it takes. The fact of the matter is is that the biggest problem we have with young people is convincing them it could happen to them. I believe truly that if they believe that, most of them, a very high percentage of them, will make some pretty good choices but, boy, that's not a -- that's a big if, that's a very tough thing to do because at 13 to 17 or 18, you think you're going

to live forever.

MR. KRUKS: If I can add something to that, I mean, just -- it's real simple. A million teenage pregnancies a year in the United States, two and a half million teenagers getting an STD each year in the United States. Our youth are having a lot of sex, whether we like it or not. They always have. They're having more, not less through the AIDS epidemic. "Just Say No" is a jinglistic slogan, clearly hasn't worked.

And when you raise the issue of, you know, well, what about, you know, white middle-class kids, they're having sex, too.

MS. GOLDBERG: Oh, yes.

MR. KRUKS: And we have to think about the dynamics of the sexual networks, and I use the term "sexual networks" and that term has been used here before. Schools represent sexual networks. Within schools, you have groups of kids who are having a lot of sex with each other. The network's fine in terms of HIV until you get HIV in it. Once you get HIV in it, it will spread rapidly.

MS. GOLDBERG: Yeah.

MR. KRUKS: And the situation in this nation where we don't want to act until we have the problem upon is is ridiculous because this is everybody's kids.

MS. GOLDBERG: Well, and we know in Los Angeles

County we have the problem on us because one in five of the AIDS cases, not just sero-positive, but AIDS cases in L. A. County are in young people 19 to 29 and you know what that means when they got it. So we know that it's almost 20 percent right now today. So it's there.

CHAIRWOMAN OSBORN: Don.

DR. DESJARLAIS: Okay, a question for Ms. Slaughter. You mentioned that you are starting to see behavior change --

MS. SLAUGHTER: Yes.

DR. DESJARLAIS: -- among the women you're working with and the examples you gave were people going into treatment, including A.A. and N.A.

MS. SLAUGHTER: Yes.

DR. DESJARLAIS: Are you having much luck at getting women using crack and their partners to practice safe sex?

MS. SLAUGHTER: That's been the most difficult thing. We really talk to the women about violence, if there's any violence in their lives because it's very difficult for a woman to ask her partner to use a condom if he is violent, so we have groups on violence and then many times we will make referrals to women to battered women's shelters. We talk about sexuality. We have groups on sexuality and self-esteem. So if the woman wants to come off

drugs, then she's really interested in changing behavior. If she's not going to come off drugs, she is using condoms with her johns and sometimes not all the time with her partners.

DR. DESJARLAIS: Even the women exchanging sex for crack are starting to use --

MS. SLAUGHTER: Yes.

DR. DESJARLAIS: -- condoms with their johns?

MS. SLAUGHTER: Yes, uh-huh, but that's only when we've had interventions with them for a period of time.

CHAIRWOMAN OSBORN: Scott Allen?

REV. ALLEN: I have a question for Jackie. Is Los Angeles -- is the school district in Los Angeles implementing any of what you say you need, the education at an early age and so forth?

MS. GOLDBERG: We're -- we have a program that is in the seventh grade and in the tenth grade that's required. We have about 40 schools now in elementary school with a third and fifth grade program that's being tried that involves a tremendous amount of parent involvement. We are seeing this as a part not of just HIV/AIDS education but also sex and family life education. But -- but the part that seems to be the most successful in terms of evaluations by teachers about what they see happening in their classes has thus far been PW educators, PWA educators.

REV. ALLEN: What kind of response have you

received from parents?

MS. GOLDBERG: Parents have been just fabulous. In fact, the elementary program was started by parents and at the insistence of parents because the District -- I don't know -- maybe just hadn't quite had the nerve to do it yet because we did junior high and senior high and we were fairly early on in doing it. But we're not getting yet to the point -- we're doing the factual non-judgmental age appropriate education. I don't think we're -- about AIDS and HIV itself but I don't think we're quite there at all on factual non-judgmental age appropriate discussion of sexuality and sexual behavior. We have some advantages. We have a counseling program called Project 10 which particularly targets gay and lesbian youth, but that's not everywhere in the district yet and it's -- but it's better than before we had that although it's been under attack since the day it began.

REV. ALLEN: Is this education incorporated in the curriculum or is it special?

MS. GOLDBERG: No, it's incorporated into the health education curriculum and we do twice yearly seminars with the health educators. We are fortunate. Many districts have somebody who is a converted something else teacher teaching health. Most of our teachers are actually health educators, trained to be health educators. That's also helpful. Not all of them. But again, as I said, we don't

feel comfortable that we're making a dent in actually changing behavior. Our kids are very well informed, but I don't -- they think it's another interesting topic, if you know what I mean, doesn't affect me. And that's why we've gone to this blue ribbon panel to say, you know, "Help. We don't really know," and I'm candidly sitting here telling you we don't really know how to get teenagers to take this seriously enough to actually do something different. And we hope that we will get some advice.

MR. COUSINEAU: Dr. Osborn, if I could just make a really brief comment related to that, as some of the members of the Commission may know that there is debate in the state legislature now about funding of the family planning clinics that provide access to family planning services and prevention of sexually transmitted diseases. Many of those are accessible, the only ones accessible to teenagers, and right now with the Governor's proposal, most of those programs would be eliminated and we're just hoping that the legislature will reinstate those -- that funding and the Governor will not veto that legislation.

CHAIRWOMAN OSBORN: Irwin Pernick?

MR. PERNICK: Mr. Cousineau, I was struck by the lack of licensing requirements for homeless shelters that you mentioned. Do you think it would really be better to impose licensing requirements and so make the shelters more at least

hospitable and perhaps more attractive to people on the outside or would it actually impose more barriers to the -- to increasing the number of shelters around the community?

MR. COUSINEAU: It would be -- it would increase barriers because there -- if there would be increased licensing requirements, there would be no new funding to help shelters come up with -- come up to any kind of standard. Most of the funding available for shelters are for building, bricks and mortars, and there are very few funds available for services within the shelter system and that's because of the federal and state regulations, so I mean I mention it only because it's a particular problem for people who go into those shelters and may be exposed to infectious agents. On the other hand, we realize that if we impose something like they've done in New York, for example, it would be -- we'd have to shut down most, if not all, the shelters in Los Angeles.

CHAIRWOMAN OSBORN: There's a lot of Commissioner interest and I'm going to ask that the questions be -- or comments be brief but nevertheless Don DesJarlais, Jim Mason, and then Dave Rogers and then we'll have to go on.

DR. DESJARLAIS: Just for Ms. Goldberg with regard to the school programs. A number of European countries have approximately comparable levels of sexual activity among their teenagers and dramatically lower rates of teenage

pregnancy and sexually transmitted diseases.

MS. GOLDBERG: Yes.

DR. DESJARLAIS: Presumably, the immortality factor is not just here in Los Angeles and the United States. Are you trying to develop models after the European type programs?

MS. GOLDBERG: The European type programs exist in European type societies and -- well, I know that sounds illogical, but it's true. And in those societies, you are not considered a harlot as a teacher or a slut if you discuss sex with your children. In fact, it is expected of you. In this society, it is a dangerous practice. Without parent permission, without signing away your life and blood and so forth and so on. Nonetheless, one of the things -- one of the terrible, wonderful consequences of a terrible epidemic is that more and more parents are saying to outside organizations, "We want you to talk turkey with the kids because their lives are at stake," and so schools are taking greater chances than we've ever taken before but it's a very mixed message.

On the one hand, we're supposed to only tell them -- there are state laws that require us to tell them to say no. We know that's an unsuccessful strategy.

DR. DESJARLAIS: It sounds like the major problem then is not in the attitudes of the adolescents but in the

attitudes of the adults.

MS. GOLDBERG: I couldn't agree with you more but, unfortunately, they have a tremendous negative effect on the attitudes of adolescents.

CHAIRWOMAN OSBORN: Dr. Mason?

DR. MASON: Coming back to the recommendation with regard to wholesome activities for youth rather than the back seat or the upstairs bedroom, have you had any success in implementing those kind of activities and why do you think if these were more prevalent 20 years ago, what has been the cause of their demise? Has it been the single parent family, the working parents, and the inability to put these things together, carry them out, provide transportation? What's happened and are you having any success in reinstituting that?

MS. GOLDBERG: We've had minor successes. We have gotten in-school scouting started which is a new concept because we couldn't find any scout leaders. I mean, there just aren't any scout leaders in the whole vast neighborhoods, not just low income ones. So we do it in the school and we try to carry it over onto the weekends. We have about 300 of our 435 elementary campuses and about half of our junior high campuses with an after-school program that goes till 6:00 p.m., but it's not a very rich program. It's really just supervised free play. That's in conjunction with

the city with us together, each of us paying for two hours of the supervision.

We used to get federal funding for teen posts. That's why I picked them in particular. We used to have a lot of teen posts in the 60's in this city. I used to work with kids in Compton area in one of them. And they were open Friday night, Saturday night, and Sunday afternoons. And they were wonderful and we had a lot of kids who would hang out there and sometimes we didn't have anything in particular going on but the funding for them came under the federal War on Poverty legislation. They're all gone today.

We used to have a larger number of church agencies that ran social activities for kids than do today. I don't know why they aren't. I do think that some of it is more parents working, more adults working. They're just not around as much themselves to volunteer to do some of these things. But it's a terribly serious problem.

CHAIRWOMAN OSBORN: Dr. Rogers, the last quick question and then -- or comment.

DR. ROGERS: Well, just a comment. Thank you very much at the end of kind of a long day. Though, Mrs. Goldberg, you say you're not getting anywhere and you find four of you that have some programs that actually seem to work has made me feel somewhat better about today and I think Los Angeles is very fortunate to have all four of you steaming

ahead on your programs.

CHAIRWOMAN OSBORN: I join in Dr. Rogers' thanks and on behalf of the Commission. I think we have to move on and turn to the final panel of the afternoon, if I could ask them to come to the table.

While they're getting a chance to be seated, when we get done with this panel, I'd like to ask Dr. DesJarlais to give us a brief -- the Commission a brief comment and those of you who are interested about the -- what I guess is called the Bush-Bennett II plan or -- the structure of which was outlined in the last 24 hours and which has been a source of continuing concern for us, so we'll do that and then that will be the end of our formal business, but let's turn our attention now to this panel to talk about issues affecting gay and bisexual people of color.

Juan Ledesma, AIDS Project Los Angeles.

MR. LEDESMA: Good afternoon. I'm not going to reiterate everything that's on my written testimony nor am I going to try to repeat all of the issues that I know you have all heard all day. But before I really begin the bulk of the testimony, I'd really like to commend the Commission on taking the initial step of addressing issues affecting gay and bisexual men of color separately.

Very often, what happens to gay and bisexual men of color is that we're either seen -- either -- people assume

that we're either taken care of within minority issues or within gay issues and that's not always the case, so I think it's a very -- the Commission is taking a very important first step in just addressing this issue as the individual issue that it is.

As I mention in my testimony, I think the two biggest issues that we still contend with as a gay people of color community are both homophobia and racism. Homophobia to the extent that it is permeated in many of the minority organizations that are working with AIDS or they are trying to initiate work in AIDS, but very often don't have the sensitivity or the understanding of the culture that is a gay Latino identity.

Racism, to the extent that many of the larger organizations, including one that I work for, very often don't have the sensitivity of the culture and the heritage that we bring with us.

So to that extent, what ends up happening very often, and I've seen this many times now in the case load that I manage, clients -- people are being diagnosed. They have one bad experience. I cited a case in the testimony of a client who was in the emergency room at the County Hospital and was greeted by the doctor asking him if he was a fag. That one experience damaged him so badly that he was actually afraid of seeking further treatment at the outpatient clinic

and, consequently, I had him in my office with herpes lesions covering his face and he was barely able to walk, barely able to talk. He was in there for food. And at that point, the resources that I had and the ability that I had to help him as a service provider was very limited.

Another case that I cited in my testimony dealt with more the issue of homophobia and this was concerning a client that was seeking services from a service provider and was actually asked by a case worker why he couldn't get a job. This was a monolingual undocumented Latino who was gay, self-identified gay, and he was asked, "Well, why can't you find a job? I see people on the corner selling oranges. Why can't you do it if they can?" And it was more of a question of his masculinity and his ability to provide for himself which is, after all, what a good Latino man should be doing; right? And these are some of the issues that we have to keep dealing with as a community.

In Los Angeles, I think really gay Latinos as a whole are becoming to forage and unite. And become more vocal about some of the travesties that we've had to deal with. It's embarrassing and it's a pity that nine years into the AIDS epidemic we still have to contend with racism, we still have to contend with homophobia.

Again, I'm not going to repeat all the many issues that affect us -- lack of access to quality health care,

availability of services. I just want the Commission basically to keep -- when they focus on these issues again, to have the added insight that for someone who is monolingual, who is self-identified as a gay Latino, the issue is not only the lack of access to health care but the fact that they're not going to be understood. Consequently, these people are going for fear of not being understood, for the shame that comes with the diagnosis, with their sexuality very often for them, they're going without treatment. They're going without seeking care. Thank you.

CHAIRWOMAN OSBORN: Next Raul Magana from Orange County Health Care Agency.

MR. MAGANA: Thank you, Commissioner Osborn. Like Juan, I will just be really brief on some recommendations that we made and at the end we concentrate just on the last part of our testimony as related to identify and education.

So our testimony here will consist of recommendations to the Commission based on our ethnographic research findings and our experiences providing health education to the Latino population in Orange County.

We recommend that the development of educational intervention strategies for minority populations in the United States take into account the following:

When talking about the risk of HIV transmission, one should refer to specific high risk sexual behaviors and

not to sexual identities like "gay," "homosexual," or "bisexual." This is particularly important when formulating educational intervention strategies for ethnic minorities.

Cross-cultural differences in male homosexual behaviors within minority target populations; i.e., between immigrant Mexican laborers and acculturated Mexican-American college students, make it necessary to develop different intervention strategies for different segments of the population.

Levels of education and reading comprehension must be assessed before developing educational materials for different segments of minority target populations.

Health education campaigns directed at any particular ethnic group should take into consideration the level of education and reading comprehension of that group. We often hear the issues are being culturally sensitive and educationally sensitive, and it's amazing if you really observe the issues that exist in the schools, reading comprehension levels in the materials. It has been shown by Cole and Scribner that subjects with little formal schooling lack syllogistic reasoning. This is not a -- it's just a tactical, cognitive process that is not -- this means that any educational materials that is to be presented to individuals with little formal schooling should be simple and put into a context which the students can identify as their

own. The same argument has been made by Freire and used successfully in his literacy campaigns in Africa and Latin America. Our study has found that AIDS education materials are usually at a level of reading difficulty which is beyond the ability level of the target population the materials are intended for. I thank you.

CHAIRWOMAN OSBORN: Thank you very much. Gil Gerald from Minority AIDS Project.

MR. GERALD: Good afternoon and I'd like to thank you for the opportunity to present testimony this afternoon.

High risk sexual behavior -- I'm just going to highlight a few of the points in my written statement. High risk sexual behavior between males in racial and ethnic communities is one of the two leading ways in which AIDS is transmitted -- HIV virus is transmitted in those communities. This is a -- there's a wall of denial around this issue and it's a wall of denial that has existed over the last nine years, that one of those two main means of transmission of HIV virus is sexual -- high risk sexual behavior between men in our communities, black and Latino communities and Asian -- minority communities.

I'd like to bring you -- point out some statistics that exist in terms of looking at, you know, our client load at the Minority AIDS Project and also point you to the statistics in the County of Los Angeles.

Fifty-seven percent of our clients are African-Americans. Thirty-one percent are Latinos. And eight percent are whites, with the remaining four percent representing Asians or individuals whose ethnicity we did not record.

Ninety-one percent of our clients are males and 80 percent of the clients report that they were at risk because of high risk homosexual behavior. Another four percent of our clients report that they were at risk because of homosexual -- both homosexual high risk behavior and intravenous drug use.

Similarly, county statistics show that 68 percent of adult African-American males and 74 percent of adult Latino AIDS cases are in the homosexual/bisexual exposure category, with another 11 percent of African-Americans cases and another seven percent of Latino cases falling in the homosexual and IVDU exposure categories. So we're talking about 80 percent, 79 or 81 percent of the cases in the black and Latino community, adult cases, are cases that are attributed to individuals who were at risk because of high risk homosexual or bisexual behavior.

I have a few recommendations I'd like to make and highlight. Any interim or final recommendation of this body should explore and express in strong terms the need to increase and target resources to provide prevention and direct services designed for homosexual/bisexual men in

racial and ethnic communities, including those men who are also I.V. drug users. It's not a matter of taking resources from other -- other communities or -- it's a matter of increasing the resources and prevention. We have a real concern that you are -- you may be tempted to take money out of the money that's needed for -- take money out of the money that's needed for prevention and put that into care. We need money for care but we also need increased resources for prevention.

With regards to primary prevention, the work in racial and ethnic communities here in Los Angeles targeted to homosexual/bisexual men has hardly risen above the level of awareness and information campaigns. This work is lagging behind and there hasn't really been any resources or far too few resources have come to this community to deal with that issue.

A primary and crucial concern of those community-based organizations who are capable of providing educational programs for this target population is the lack of financial and human resources to continue programs in the consistent and comprehensive manner necessary to effectively reach out to gay and bisexual men from racial and ethnic communities.

My experience since coming to Los Angeles is that we basically end up bargaining for the leftover dollars or for the rollover dollars, you know, at the end of a funding

cycle for this community, yet this represents the largest sector of the community affected by HIV.

Some of these organizations in Los Angeles that could use support represent organizations that have access to these communities, organizations like Gay and Lesbian Latinos Unidos, Asian-Pacific Lesbian and Gays, Black and White Men Together, and Minority AIDS Project.

The volunteer-driven model, the model that has served well in communities like San Francisco and different communities, has a more limited application in racial and ethnic communities. We have volunteers. However, we need relatively more resources to pay stipends to defray some of the expenses volunteers incur. For example, expenses such as transportation become disincentives for volunteerism in a community that is relatively more depressed economically.

There are a number of service-provided base -- providers based in racial and ethnic communities that lack experience in training and working with issues of AIDS and homosexuality and bisexuality, as Juan has stated. For these providers, there is a need for training and sensitization on these issues on an ongoing basis.

In terms of providing services, our experience shows that we're dealing with an ever-increasing case management problem due to the multiple stressors evidenced in our clients. HIV is but one of the myriad of issues. Did I

hear -- okay.

I just want to basically say that we really need -- it's a more labor-intensive in our community. We need more human resources to deal with the issues. We need one on one interventions on the street and last but not least I'd like to talk about the fact and mention that when you're dealing -- you need research that is based in our community that includes this target community. If the -- if the policies and the findings are going to be valid for this community, then this community has hardly even been represented in the studies, in most of the studies that are being conducted or that have been done.

Thank you.

CHAIRWOMAN OSBORN: Thanks very much. Dean Goishi from the Asian/Pacific Lesbians and Gays.

MR. GOISHI: Konichiwa, Neohashanika (phonetic), Way (phonetic), Aloha. Good afternoon. I would like to thank the Committee or the Commission for this opportunity to appear before you and speak about the Asian/Pacific Island community and HIV.

As I addressed you in four different Asian/Pacific languages and why I picked those four was only because that's all I can speak, we have over 20 identified Asian/Pacific communities here in southern California. We speak different languages. We come from very different cultures, ethnic

backgrounds. Language is a barrier for us, not just English.

By the end of 1990, it is estimated that there will be over 1.5 million Asian/Pacific Islanders in Los Angeles County. Over 60 percent of this population will be immigrant population, monolingual or very limited English-speaking.

So along with language, we have cultural barriers as outlined in my written testimony. I won't go into them. But just to mention the concept of gan-bare, the barrier of denial, bringing shame to the family. Homophobia and/or homo-ignorance. These are all issues and barriers that exist within our community.

My testimony this afternoon, both verbal and written, is just not with the Asian/Pacific Island gay community. It is combined with the Asian/Pacific community in general because I feel that you cannot separate the gays from the non-gays in our community. We live in our communities and, therefore, we cannot be separated from our families and communities.

We look around this room and we look at the list of individuals that have testified before this Commission and we find where HIV is within the Asian-Pacific community. We don't see very many Asian-Pacifics in this line of work. The denial factor of that HIV can affect Asian/Pacifics is extreme.

I believe this Commission can assist our

communities by recommending funding that addresses education and prevention programs that are culturally, linguistically, and lifestyle-sensitive for Asian/Pacific communities. Funding for bilingual service and caregiver programs with existing agencies or Asian/Pacific focused agencies is much needed.

It's just not a matter of not forgetting the Asian/Pacific community. We need to make an opportunity for Asian/Pacifics to be nationally identified with HIV. They must become visible. There must be faces of Asian/Pacific Island ethnic communities on a national basis; otherwise, our communities will not or will continue to deny that HIV is a matter that will affect the Asian/Pacific communities.

We need to hire Asian/Pacifics on national commissions so that there are people involved at the national levels.

We must do all we can to make HIV a common subject amongst our Asian/Pacific families and communities. They must be able to talk about it. Otherwise, they will continue to deny that HIV is a concern. We have to take away the excuse that denial -- take away the excuse of denial by providing national Asian/Pacific Island statistics by ethnic communities. It's extremely important in that we be able to provide our -- each separate community with their own statistics; otherwise, they will not believe that it is a

concern. They will continue to be that it's a concern for the white, the black, the browns, the Japanese, Chinese, but never their own community.

Some of the good things that are developing here in Los Angeles is that we have tried to form and work through coalitions amongst our various ethnic communities. The Asian/Pacific AIDS Project is one where we have seven Asian/Pacific ethnic communities involved in HIV prevention and education programs as well as including the gay community.

We are trying to sensitive our Asian/Pacific health workers with homosexual sensitivity workshops because we feel that it is extremely important that they become sensitive. Otherwise, they will not be able to help our Asian brothers who are HIV infected.

We are trying our best to work through gay and non-gay issues. Unfortunately, we only have part time health educators. We do not have enough funding to provide one hundred percent full time health educators in AIDS. They are involved with other health issues in their various agencies.

With that, Arigato, Com Sa Mi Da (phonetic), She She (phonetic), and Mahalo.

CHAIRWOMAN OSBORN: Thank you. Lydia Otero from the --

MS. OTERO: Okay. Thank you. Good afternoon. I'd

like to begin by thanking Eunice Diaz for doing some behind-the-scenes maneuvering to get our organization represented here. I'm the president of Gay and Lesbian Latinos Unidos and we're a membership organization that's been around for ten years in Los Angeles.

We have a Board of Directors and it's elected by its members and we've been a very active organization, like I said. But as of November 21st, we got our first public funding and the project we started is called Gay Latino AIDS Project, Gay and Lesbian Latinos Unidos. It's the only openly gay Latino AIDS project in California. It's only the second in the nation. And if we look at statistics, and unlike the East Coast, the majority of AIDS cases in Latino community are still gay and bisexual Latinos and if the money was distributed according to this, we would be -- I would be sitting here before you representing the largest Latino AIDS agency in the city, in this county, and unfortunately it's just the opposite.

We began recently. We were not a service organization who switched to AIDS because the dollars were in AIDS. We are starting with very limited resources. We are starting from scratch to do this kind of work. We've been doing it for a number of years without funding and the financial resources are very hard to get for us. Like I said before, we're the only 501Z3 organization incorporated in the

State of California with the name Gay and Lesbian Latino in it.

And this is where we would ask the Commission to help us. And if there's something we -- and this is the main thing we would want to get across as an organization of Gay and Lesbian Latinos Unidos to the Commission, that sometimes as Latinos in general and straight Latinos, we get lost in the translation and AIDS education is getting lost in the translation to Latino gay and bisexual males.

When we look at it in the other hand, we -- when straight Latino agencies put out that information, sometimes that information gets censored in the homophobia and I think you've heard this message probably many times before today. I wasn't here all day, but homophobia is killing us and we need this to stop and to be successful, it needs to stop to be successful to get this information across and it should come from an organization. It should come from an agency. As Ruth Slaughter was talking about, Warn, when you serve women, it should come from an agency or organization that serves gay Latinos. It should come from an organization indigenous to that community.

Our time is too limited. We spent too much time trying to sensitize too many different organizations to do work we should be doing. I can't give you statistics as to how successful our program or our agency will be. As I said,

we just got funded November 21st of 1989 but I believe that our program is the first step in L. A. County to do the work the way it should be done.

CHAIRWOMAN OSBORN: Thank you very much and thanks to all the panel for giving us very succinct presentations so that we do have some time for questions. Diane Ahrens.

MS. AHRENS: I have a question. I think I should direct it to Dr. Magana and Mr. Gerald and that is how -- how could this Commission be helpful in challenging the leaders of the Hispanic, the Afro-American communities in this nation to deal with this issue?

MR. GERALD: I would kind of underscore what I think Lydia was alluding to or says categorically, is that I think that when you -- you really have to empower the people who are affected. The people who are affected by this crisis have to be empowered and what they're saying is that they're not getting a response from the government. We have the ability to do prevention in our community, to provide resources, and that we can hold our own communities accountable but we need some federal dollars.

I think that it's crazy to think that we don't have the -- we don't have the same capacity and talent that exists in the white gay community to run organizations with the kind of support that can be made available from our Federal Government, so what I'm saying is that -- I don't know if I'm

answering your question, but I think -- I really do think that where we have seen organizations develop in our community, like in Los Angeles, we have been able to build bridges but build those bridges from the position of strength you can't have people speaking for us. We have got to be able to speak for ourselves.

And we exist in the community as -- we are amongst those leaders and I think that clearly the work is not going to get done unless the resources go to those organizations that can do it.

Sensitizing -- we put a lot of value into, you know, the minister in a community, in the black community for example. The leadership of the minister. I think in many ways that is a little overblown. I think that the reality is that there's a certain power there but we're talking about getting to the community that understands the networks, understands where gay and bisexual men of color are. They need to get the message and there are people who put themselves in the front line who have the means to do it, who are organized and our local institutions, our local public institutions, public funding institutions, have not given them the kind of resources that are needed.

I think that we have the capacity to speak to our own leaders in our own community, but we can't do that on part time. We can't do that on volunteer basis. I think we

can challenge our own leaders. We can't do it on a volunteer basis.

DR. MAGANA: I might not be able to answer your question in telling you how to do it, but I think I can provide some input as to how definitely not to do it, and that would be by making a strong recommendation that we scrutinize the educational materials that we're putting out with tons and tons of those materials that range all the way from one page leaflets to book manuscripts. Very few organizations are paying close attention to the readability analysis as well as the content analysis of those materials. Readability analysis is a very straightforward and simple and easy task to do, yet hardly anybody does it. We need to pay close attention and begin to conduct more informative evaluation on those programs that are Latino and black and ethnic-based which a community having a great success in Latino communities. Oftentimes, those CBOs, those community-based organizations, have all the intention to want to conduct evaluations so that we can prove that those tax-payers' monies are being well spent. Unfortunately, we lack the technical infrastructure. We need to make strong recommendations that support be given into serious evaluation of all of the efforts that we're doing and also detection in the areas in which the gray might meet, and we're not doing that.

CHAIRWOMAN OSBORN: Tom Desjarlais and then Scott Allen.

DR. DESJARLAIS: One of the difficulties I've noticed in trying to even think about the question of male to male sexual activity among people of color is the lack of good words, that if you want to address a man of color who has sexual activity with other men, what words do you use to address him that gets his attention so that he feels it's relevant to him and conveys a sense of dignity and respect, and so this is sort of open to the entire panel and six or seven different languages, but I think it would help us if we knew just sort of what the best or better words were for addressing the issue.

MR. GERALD: Well, I'll simply say that I've worked in a number of pieces that we've developed in the community and it's a local issue. I think that it's something that has to be developed on the community-based level. I know for example in Washington, D. C., there was some literature that was developed in which we talked about going both ways, which did not mention the word "faggot," "gay," or whatever it is, but it's true that there are colloquial terms that don't apply across the board. There couldn't -- I couldn't give this Commission a word that would be valid in every community. What I'm saying is that the local organizations can develop the language and they have developed the language

where the resources are there, have the language in fact -- not developed it -- have the language but need the resources to get that -- to get out there in the community and communicate that.

MR. LEDESMA: I'd just like to add that speaking -- someone who speaks Spanish, you'll never be able to find one word that means a specific thing in Spanish. I think the point, though, is that we need to start being specific and stop beating around the bush. What I see is a lot of AIDS education material that just talks about couple sex or -- and when you're having sex with your couple instead of when you're having sex with your male lover, this is what you do.

MR. GOISHI: As far as the Asian/Pacific communities are concerned, it depends on where they are as far as homosexuality is concerned. In very conservative Asian/Pacific backgrounds, you cannot use homosexuality because they don't exist. You have to use different terminologies, different phrases. Those that are more sensitive to homosexuality, then you have to be careful of how are they using it because most of the homosexuality terms are very negative in the Asian/Pacific languages. In Chinese, when we were approving the initial translated materials, the character for homosexuality is a man and a man side by side or a woman and woman side by side with a very negative connotation of very promiscuous, loose, et cetera. There are characters that can

be devised that -- I'm sorry -- the man and man, woman and woman, was the after in the fact that they were more positive in the sense of man and man, woman and woman. The terminologies and the characters that were being used were very negative and they are very, very derogatory as far as our lifestyle was concerned and that exists in almost every Asian/Pacific language, so it really depends -- there is no answer for you as far as I can tell and it depends on for the local -- local ethnic community that's translating.

DR. MAGANA: To your point, I think that the range of sexual behaviors and the complexity of sexual behaviors, at least as it relates to the Latino males, is as complex as Latino culture can be and I think what's very, very important here is that we maintain a clear distinction between sexual identity; i.e., self-identified gay men, homosexual, bisexual, heterosexual, from sexual behavior and that if we're speaking about sexual behaviors, we'll concentrate in anorectal intercourse as a dangerous practice to have with an infected person independently of the identity and that if we're going to be developing programs that are based on fostering sexual identity, that we then pay close attention to the local cultures and we identify the proper linguistic terms that are used to address those issues. But research is needed at that level to base --

CHAIRWOMAN OSBORN: Scott?

REV. ALLEN: I have a question concerning the native American population in the State of California and beyond. I know of several tribes. I don't know what the response is in Los Angeles. What type of interaction do your organizations have? I know some very specific but with the populations such as the native American.

MR. GERALD: I would say that our interaction is actually on a national level and not a local level. There is an organization which I'm a member of, the National Minority AIDS Council, and we have members of the native American community and a lot of the activity in California, the development in California I know is centered around San Francisco, around there. There's a little more development there with respect to this particular community.

REV. ALLEN: There's one more question is that you mentioned about federal response. What is your opinion of the local response and the county response and what type of interaction do you have with the Board of Supervisors?

MR. GERALD: Well, our agency basically was the -- entered into a suit with the County of Los Angeles several years ago because we felt that the County was not providing enough resources for racial and ethnic communities, period, much less, you know, the homosexual/bisexual community.

I think that our county dollars have been extremely restricted, as you've heard before, in terms of what you can

and cannot do with them. In fact, except for the HRSA dollars that we get through the county to provide services, we don't have any education dollars that come through the county. Our dollars that we have for the homosexual/bisexual community come from the Office of Minority Health. It's a small grant of $150,000 over three years, $50,000 each year, and we have some state dollars, you know, about $100,000. This is not enough, not nearly enough to do the work that we do. As I stated before, we find that a lot of these things may be based on a formulation of having a heavy volunteer corps. Well, as I said, in our community, that is more limited. We do need to hire community outreach workers and $50,000 a year does not give you the kind of resources you need to provide the one-on-one intervention, to move individuals over time through -- through a series of -- you know, that -- of interventions that would lead to behavior change. You can't just provide information and education. You've got to move them through those different stages.

MR. GOISHI: Our dollars that come from the County that are specific for the Asian/Pacific gay community is very limited in the sense that we have -- we get leftover money, nothing from the initial start, and all of our programs are so short. I mean, the present one we have is five months to formulate an education program and in our case we have to divide that amongst six languages. It's very difficult to do

and it's only $20,000.

Amongst the -- my project, which is also county funded, which is approximately $144,000, that's CDC funding. It's very limited when you divide that amongst seven ethnic communities to do translations, speakers, et cetera. I'm not sure exactly what percentage that is as far as a total budget here in Los Angeles, but I would suspect that it's not even close to one percent, so our funding is very, very limited and the measurements that I believe the County or the governmental structure uses is based on western measurements and many of our programs may not be appropriate under western concepts and we're right now investigating non-traditional types of education methods because we're dealing with an Asian population that is monolingual and we have a hard time trying to justify our projects because we can't come up with a defined measurement program.

MS. OTERO: I'd like to add to that question one last thing. We were awarded a county grant for $30,000 in July and we started actively doing our work. We hired somebody. We got an office. And we found out that through a miscommunication, we weren't going to get the money until the Board of Supervisors signed the contract. The contract was signed in November. In that time, we're like $10,000 in debt. We had to let go of the person we hired. We tried to keep the office and the contract was signed November 21st,

like I said, but we have still not gotten a drop of money.

MR. GERALD: Red tape.

CHAIRWOMAN OSBORN: Dr. Mason?

DR. MASON: I think my question has partially been answered. I was going to just ask for my own information whether a variety of grants from the Public Health Service, through HRSA, through the Office of Minority Health, through CDC for community-based organizations, for minority organizations, whether any of these had been available to you and, Gil, you mentioned you had received some money but it wasn't adequate for what you wanted to do. Any of the rest of you, have you had even opportunities to apply for any of those?

MR. LEDESMA: Just sort of to wear a double hat, in speaking as also a G.L.L.U. member, the -- part of the problem that I think Gil alluded to the lack of human resources, the lack of grantsmanship, if you will, and consequently, you know, G.L.L.U. ended up getting this small county grant. Subsequently, we got a small grant from the United States Conference of Mayors. But we really haven't had a united community that is able to really seek that kind of public money.

CHAIRWOMAN OSBORN: Harlon Dalton?

MR. DALTON: My question is for Lydia Otero. You ended up your testimony by speaking of the need to deal with the problem of homophobia and I -- my question really is

what do you imagine this Commission can do in order to help this nation be less fearful or ignorant about -- and angry toward gay people?

MS. OTERO: Mr. Dalton, I have a problem with my own family, with my own mother, so I don't know how to solve that issue with the entire County -- I mean, country. We could start with Bush, I guess. You have his ear and I think this homophobia really is killing people and I know that you've had Act Up L. A. I think earlier this morning and I think that's one avenue. I think there's different avenues. Through our organization, we try and promote ourselves as gay and lesbians in the Latino community, make them see us. Even though they don't want to see us, they have to acknowledge we're there. They -- even if we have to put ourselves right -- this is what a lesbian looks like, this is what a gay man looks like -- we have to continually do it. It's a battle and we do it here on a smaller level.

In Los Angeles, it's just a city and as I said we're a small organization financially but we have a big, big membership and following and I think that's what's going to inspire us to be successful. I don't think the funding's going to do it because, as I said, having gay and lesbians in your name when you apply for funding is going to be very difficult for us to get that so we have to count on ourselves because I don't think -- when he comes to town, have him talk

to me.

CHAIRWOMAN OSBORN: Dr. Konisberg.

DR. KONISBERG: Yeah. I'd like to pick up on a point that I think I heard a little bit earlier, and that's the difficulty that very often smaller community-based organizations have with I guess you'd say the traditional grantsmanship. I know that some efforts at least within my own experience have been made to try to in effect incorporate training and grantsmanship and I want to emphasize that that's one thing that's got to be looked at I think a little bit more and also the red tape and bureaucracy. Now, I can -- as an official bureaucrat could probably argue this either way and we could have a discussion about accountability, but the fact is that -- we had a recent incident in the state where I'm a state health official where community-based -- well, a service organization lost a staff member partially due to I think the difficulty with them understanding our bureaucracy which is difficult enough for us to understand. When you compound that, you've got a problem. And I'm not sure that state and local government maybe really understands the kind of shoestring that many of you operate on and your difficulties and then you may not understand what we have to put up with either that may be beyond our control. I don't know how we cut through that, but there may be some sort of a statement that this Commission could make that would try to

ease that 'cause you must be dealing with a huge bureaucracy with the County of Los Angeles and the City of Los Angeles. Bigger than our state in Kansas.

MR. KESSLER: Charles, I think one of the things that could be done is short of declaring an emergency, is to put all AIDS contracts on a fast track. We've done that in Massachusetts and ASOs and CBOs get paid within six weeks whereas the rest of the agencies, et cetera, sometimes take up to three or four months, but we've -- because AIDS is a priority and the agencies are so short in terms of cash, the Governor authorized fast track for payment and it worked.

DR. KONISBERG: Yeah, I think that makes some sense and one of the other difficulties that we encountered were some changes in priorities from the CEC recently, which I won't go into it, but that caused some confusion as well, so I think the whole issue like that really needs to be looked into.

CHAIRWOMAN OSBORN: Well, -- yes?

MR. GOISHI: May I make one statement? I'd like to repeat something that I said earlier on how you folks can help us, both gay as well as Asian/Pacifics, is to, if at all possible, to recommend to national -- not national organization but the Federal Government on AIDS issues to appoint Asian/Pacifics so that they are visible to our communities and that probably goes for all of our ethnic

communities, and if they're gay, that's even better yet because that also legitimizes who we are and that we are in this fight against HIV.

MR. GERALD: One just statement that I think really addresses the issue that was just raised, and that is that there's a natural life cycle. There's a natural progression in an organizational development and organizations that are responding to HIV in the community and that you cannot apply the same standards across the board. I think that when you look at how -- where organizations are, we're now multi-million dollar organizations in 1989, where they were eight years ago, and if you apply those standards to organizations that need to be supported, if you apply those standards today, and that's what's really happening -- we are all being treated as equals. It really hampers the ability of these organizations to move forward so that we really need to look at issues of technical assistance and really look at issues of not holding us to the same level of red tape perhaps. I think we should cut out the red tape. Period. The red tape would go with the county. But the red tape with the State of California is horrendous. It really is horrendous, the amount of time that we spend doing paperwork just for the dollars we get.

CHAIRWOMAN OSBORN: On behalf of the Commission, let me thank you all for your important and helpful testimony

and in fact I'm going to choose this as a good time to thank all of the witnesses, most of whom have left, to thank Eunice one more time for the very special effort that she put into helping us have such a rich day of testimony, and then I think also on behalf of the rest of the Commission, we want to thank Maureen Burns and the AIDS Commission staff. You've probably been aware of people moving around the edges, but I want to just take a moment to publicly thank them for an extraordinary job of organizing a very effective and informative meeting.

We do I think have a little more leeway than the Commissioners probably think because we're probably going to leave for our next thing a bit later, so don't get tense when I invite Don DesJarlais. Thank you very much for joining us.

Don, why don't I give you the floor for just a minute here.

DR. DESJARLAIS: Okay, fine. We've heard today about some of the issues relating drug use to AIDS even in Los Angeles, a city with relatively low sero-prevalence among its drug users. Last September, the Office of -- National Office of Drug Abuse Control issued a report. We at the Commission were somewhat disappointed in that report in that AIDS issues were not prominent to say the least. The previous recommendations of the Watkins Commission for immediate access to treatment were not repeated or endorsed

in that first report.

The second report that the Office of National Drug Abuse Control policy is now coming out in the press. All of the early indications indicate that we will be at least equally disappointed in the second report compared to the first. Clearly, we need to have copies of the full official report before we can have an official reaction. However, it will be a long time between the issuing of that report and our next meeting, so I would like to suggest that we somehow form a subcommittee to read the report, draft a response. We clearly have enough precedents about previous Commissions' and this Commission's requirements for integrating AIDS into a national drug policy so that we're not working in a vacuum, but we will miss an important opportunity if we don't respond until we have our next formal meeting.

CHAIRWOMAN OSBORN: I think that's an excellent suggestion and I will just take the prerogative of asking you to chair such a group and ask the other Commissioners who would like to participate to let Don know that so that we can have a timely response. I see Harlon for one and David and Larry, so I think that would be excellent and we do want to maintain a presence in that dialogue. It's far too important an issue to let go.

I think at this stage I turn the gavel over to Maureen Burns who has the official role of adjourning us when

she gets to that.

MS. BURNS: I just wanted to indicate to the Commissioners that if you could join the staff and meet us in the lobby at 6:15, we'll go from the hotel to our evening activities at that time, and as the officially-designated federal employee, I'd like to adjourn this meeting of the National Commission on AIDS. Thank you all very, very much.

(Whereupon, at 5:15, the meeting was adjourned.)