TRANSCRIPT OF PROCEEDINGS

NATIONAL COMMISSION ON

ACQUIRED IMMUNE DEFICIENCY SYNDROME

HIV DISEASE IN HISPANIC COMMUNITIES

Pages 1 thru 186

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NATIONAL COMMISSION ON AIDS

HIV DISEASE IN HISPANIC COMMUNITIES

The Park Hyatt Hotel
Terrace Room
800 North Michigan Avenue
Chicago, Illinois

Tuesday, March 12, 1991

COMMISSIONERS

Chairman June E. Osborn,

Dr. James R. Allen, M.D.

Commissioner Scott Allen

Commissioner Harlon Dalton

Commissioner Eunice Diaz

Commissioner Donald S. Goldmar

Commissioner Don C. DesJarlais

Mr. Larry Kessler

Commissioner Charles Konigsberg

Mr. Irwin Pernick

Dr. Michael Peterson, M.P.H., Ph.D.

Ms. Maureen Byrnes, Executive Director

NATIONAL COMMISSION ON AIDS

COMMISSION BUSINESS

The Park Hyatt Hotel
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Tueseday, March 12, 1991

Present

June E. Osborn, M.D., Chairman

Maureen Byrnes, Executive Director

James R. Allen, M.D.

Scott Allen, Commissioner

Harlon Dalton, Esq., Commissioner

Eunice Diaz, M.S., M.P.H., Commissioner

Donald S. Goldman, Esq., Commissioner

Don C. DesJarlais, Ph.D., Commissioner

Larry Kessler

Charles Konigsberg, M.D., M.P.H., Commissioner

Irwin Pernick, Esq.

Michael Peterson, M.P.H., Ph.D.

I N D E X

P R O C E E D I N G S

CHAIRMAN OSBORN: Good morning. I think we'll get started, even though I know that there are some other people who will be joining us -- lots of other people will be joining us. Anybody who has spent any time watching out the window understands why they're late, and I guess those of you who came from outside the window can tell us even more about it, because I guess it's quite icy, and in the sense of accidents and stuff. Thanks for the hearty few who have arrived already, we appreciate it.

I'm June Osborn. I'm chairman of the National Commission on AIDS, and I thought after some conversation with a few people last night it would be worth taking just a minute to explain to you that we are not the Presidential Commission on AIDS, because that's a common source of misunderstanding. At the risk of boring you with a little bureaucratic history, the Presidential Commission on AIDS was created by President Reagan in 1987, and in fact, done a heroic job over the course of the year in compiling a study that itemized in great deal a lot of things that needed doing to improve the national response to the pressures of epidemic of HIV and AIDS. But it was a one-year commission. It was decommissioned promptly, and in the context of that, the Congress felt

that there needed to be a more durable structure, and one in which there was considerably more independence on the part of the Commission, in order to give previews and well spoken views about what needed doing as time went on in the epidemic, conforming much more closely to the kind of commission that had been advocated by the National Academy of Sciences and Institute of Medicine in their 1986 report called Confronting AIDS.

So it was in the context that the National Commission of AIDS was created -- on AIDS was created by an Act of Congress in 1988. And it stipulated, in order to try and achieve that kind of independence, that five members would be appointed by the Senate, five by the House, and two by the President, and then three Cabinet secretaries were ex-officio non-noting members of the Commission, the Secretaries of Health and Human Services, Defense and Veterans Affairs.

Further, it was stipulated that that Commission should elect its chairman, and that is how I became chairman. And Dr. David Rogers, who can't be with us at this meeting, was elected Vice-Chairman. And we began our work after all the appointing and electing and whatever was done. We got Maureen -- persuaded Maureen Byrnes to become Executive Director of the Commission, after her distinguished career in the health issues in

the Senate as one of the chief staff people, the chief staff person in health for Senator Rieker.

We began our work in August of 1989, and the final detail that may be of some interest is that we were appointed for an initial two-year term, renewable on request of the President. We note with interest that we are written into next year's budget, which suggests that we will probably continue beyond our two years, but we are coming to an interval where we are -- we can perceive the language of the bill that created us to request a substantial report on our first two years of work. So we're in the final stages of sort of data gathering and seeking input from people around the country as we prepare to submit a substantial two-year report.

Some of you may have seen we have not felt constrained only to submit substantial two-year reports, and we have reported at intervals as we have topics that we feel require considerably more pressing discussion, and will continue to do that. So we are not just settling into a mode of only weighty documents that people have trouble reading. We will try and continue to comment as we go.

With that as introduction, I will also, as I did last night, but not everybody was here, voice our thanks for the wonderful welcome we received yesterday,

and for the participation that you all have already given us, or will in the course of our hearings. In particular, I want to thank the focus group which Eunice Diaz helped convene. This includes Dr. Aida Giachello, Dr. Raul Magana, Mr. John Zamora, Dr. Ileana Herrell, Dr. America Bracho, Dr. George Rivera, Dr. Nilsa Gutierrez, Mr. Miguel Gomez, Mr. Jessie Sanchez, and Ms. Miguelina Maldonado.

Of course, Eunice has been extremely helpful, and I wonder, Eunice, if you'd like to say a few words before we start.

MS. DIAZ: Thank you, Dr. Osborn. It is indeed a pleasure to find ourselves here this morning in Chicago. About a month ago, a number of people who Dr. Osborn just let you know about, met in this city. It was also snowing that day, and we planned the many aspects of the hearing today.

I'd like to again thank those individuals again that gave of their time, their energy, but more than that, I would like to thank the people from around the country that will not be here today that, first of all, gave input, voiced their concerns, provided recommendations -- some of that you will find in your packets and can be also gotten from the Commission staff -- of the number of people who have written the

Commission, and also continue writing, giving their suggestions and recommendations for the topics we are about to discuss today, the Impact of HIV in the Latino Community.

This is the first, and perhaps the only time, that the Commission will look at this subject in its entirety. However, we have received no less input from different people of different forms that the Commission has had about how this problem is impacting, but we really are very hopeful that today we will clearly outline some major priorities for our community, and also establish that this topic needs to be dealt with as a subject in and of itself. Although the hearing is a short one, just this morning, we hope that there will be audience participation and opportunity for you also to assist in determining what the recommendations and suggestions might come forth, not only from this Commission, but what this Commission needs to hear, in terms of being able to project this on to the people that we are responsible to, in terms of framing this problem for the country.

Again, thank you very much for your participation. We feel that this draws upon the work of many individuals and communities around the country. And again, the input is obtained from the individuals who

represent a very unified and also a very important voice in determining what is to be done for our Latinos around the United States.

COMMISSIONER OSBORN: Thank you, Eunice. I am rather spoiled, because normally in these hearings, Dr. David Rogers plays the role of the bad cop so I can sit and smile at everybody when they testify. Unfortunately, I have to be both good and bad cop today, and will, therefore, ask you to help me in that.

We have a very rich and full agenda for the morning. And the Commissioners, as you will soon discover, like to be very active with the people who talk to us, so to the extent that you can make your initial presentation even briefer than you were planning, summarize the key points that you would like us to focus on. If that can be done, then that just gives us more opportunity to interact and follow up on issues that you've raised for our attention. So I hope that will suit, and if it begins to drag a little bit, I hope you will forgive me for being a somewhat inexperienced bad cop.

With that, I think we could start with Dr. Aida Giachello. And you've already figured out that I don't speak Spanish, so I guess I'll have to ask a blanket forgiveness there. The Midwest Hispanic AIDS Coalition

in Chicago will launch our deliberation. Thanks for joining us.

I. FRAMING THE PROBLEM

AIDA GIACHELLO, Ph.D.

DR. GIACHELLO: Good morning, and it is, indeed, a great satisfaction to have the opportunity to address this very important body on issues that affect the Hispanic community, which is the problem of HIV and AIDS. I really want to commend the Commission for having the vision of conducting national hearings on Hispanics and AIDS, as well as on other ethnic groups, and for selecting Chicago, for that matter, for this particular purpose.

What I would do, briefly, is to give a brief socio-economic and demographic overview of the Latino population in this country, with some selected health status indicator and access to medical care as a way of setting the tone. I will not necessarily elaborate too much on HIV AIDS as statistic, as I was instructed, as most of you already have been saturated with so many presentations on AIDS.

With that brief remarks, let me begin with the first overhead. And originally I was going to prepare some handouts, because that overhead I usually not use, but I thought that to begin with it is extremely

important to be aware that when you are referring to the Latino population, you are actually referring to people that come from more than twenty countries. And here you see in the map the different countries from which the Latino population consist of. And obviously, Spain is not included, but it's another country from which we have a large Latino population.

According to the 1980 census, Latinos are defined as people who either consider themself Mexicans, Mexican-Americans, Puerto Ricans, Cuban, people born or descended in Central or South America or Spain. It is the first time since 1980 that the census decided to use a self-identifing file. I happened to be able to count the Latino population prior to that, or other unreliable and inconsistent ways of counting the Latino population. Also, you'll probably hear me and others using different terms to refer to Latino. Sometimes we use the term Hispanic. Actually, I usually prefer to use the term Hispanic. I also prefer the term Latino. I use it interchangeably. The term Hispanic was permanently adopted by the federal government in 1976 when they needed -- they were pressured by the Office of Budget and Management to come out with standard ways of defining the different ethnic groups, and they adopted that term.

The Latino grassroots who have resented that

term, they argue it was not -- it was a term imposed on them, so that's one of the many arguments that has been used. The Puerto Rican population are also at times called New Yorkican, because the largest population of Puerto Ricans are in New York City. And obviously, you have all the terms, Boricua, also to refer to the Latino population.

Moving on, the next slides provide information about the 1990 census, which has recently begun to release some of the data. Clearly, you see here that according to the 1990 census, there are about 22.3 million Latinos in this country, and that the percentage change was about 53% since 1980. If you recall, from 1970 to 1980 the population, the Latino population, increased about 61%. During 1980, slightly -- that changed slightly. It was reduced to 53%. And there, you compare Latino with Whites, African-Americans and Asian, you see that the Asian-Americans are the faster growing population group, and obviously, Latino is the second fastest population group. And clearly, as we're going to see in the next slide, the Latino population is duplicating every twenty to twenty-five years. Actually, 1960, we had about seven million, and now in 1990, we have 22.3 million. So clear, the population is growing very rapidly for many, many factors.

One has to do with the high birth rate. Latino population has the highest birth rate of any ethnic group in the United States. It is about twenty-three per thousand, compared for fifteen per one thousand live birth for the non-Hispanic population. And that's one of the key factor responsible for the rapid population growth. The other factor has to do with immigration. When you look at the data provided by the U.S. Immigration Office, you realize that since 1930, most of the legal person that have entered this country has been Hispanic, despite the fact that people think that we are all undocummented worker. But in reality, the immigration has been a key factor in population growth, and demographers are predicting the growth will continue, because one-third of the Latino population are below the age of fifteen, about 50% are below the age of eighteen; therefore, you're starting to see the trend of Latino becoming sexually active, forming family, and for that reason you are expecting a baby boom, or at least demographers are expecting a baby boom.

The next slide was actually estimated on by the Census Bureau last year, before the -- the previous year, before the 1990 census data was released, and they were at that time thinking the Hispanic population was going to be increased only by 39%, when in reality, as I showed

previously, it increased to 53% since 1980. So we are also assuming that the U.S. Census will fall short in predicting the percent of growth among the different groups.

Here is one of the table that illustrate how the high birth rate and fertility rate among Hispanics. And you see the Mexican cohort particularly is the one that is particularly responsible for the high birth rate.

Here, this particular table gives you the sense of -- of the growth in other states. California, Texas, New York, Florida, Illinois, New Jersey, Arizona, New Mexico and Colorado, where you have the largest Latino population, you again experience, again according to the 1990 census that has been released, a very dramatic increase when you look at the extreme right, to my right, the Latino percentage of each state. And you realize how Latino person is very clear. And therefore, we are expecting the Latino will be moving on into more political positions, will be able to impact public policy, and that will be particularly crucial because the Latino population is a young population. Most of the social policy in this country is based on a more middle aged population, not addressing the needs of the Latino in terms of us trying to get an education, trying to get training, trying to form families, housing, et cetera.

Here you see the distribution of the Latino population, again based on the 1990 census data by the different states. So with twenty-two million Latino, you realize that 37% live in California, 21% in Texas, Illinois, which ranked fifth, account for 4% of the total Latino population in this country, et cetera, et cetera.

In terms of composition, Mexican-American is the largest group within the Latino population, followed by Puerto Rican, 12%; Cuban, 5%; Central and South America, which by the way, the Central and South America cohort are the faster growing group within the Latino population, and then other Hispanic. So clearly, you realize that the Mexican-American are primarily the larger Latino population.

Trying to understand some of the migration patterns, although here this particular map doesn't really illustrate it to the best, but usually, though, the Mexican population, Mexican-American are in the southwestern state, which would cover California, Texas, Colorado, New Mexico, Arizona. They tend to have the Cuban primarily in the southeast, in the area of Florida, and you have the Puerto Ricans primarily in the northeast area.

Now this particular map tries to illustrate some of the internal migration that began in the 1970's

and have continued in the 1980's, which means that the Puerto Ricans are now concentrated only in New York City. They are moving into all the northern eastern area states, and also starting to migrate further to the south and migrating to the west. Then you have the pattern of those Latinos who live in the southwest moving further south, and those Latino in the northern central region also moving further to the south. And in the case of the Cuban, Cuban are not only concentrating in Miami, but are also starting to move to different parts of Florida, they're moving to Missouri, further to the midwest, they are also moving to Louisiana, to North and South Carolina. So right now, you find Latino in every single state and every single town in this country.

And here are just some basic selected social and economic characteristics. The first one is the median age. The Latino population is a young population. As I mentioned before, that has tremendous impact in terms of population growth. The other aspect related to the age is the fact that the Latino, in average, is about 23%, 24, the median age, compared to 33.2 for non-Hispanics. What you find is that this has also implication in terms of planning of health services.

Most of the kinds of services in the main are in the area of family planning, are in the area of

pediatric services, are in the area of OB/GYN, all those kinds of services that particularly the young adult and children will be most in need. There you also have a family size, another indicator. You clearly see how Hispanic has larger family size. Primarily the Mexican tend to have larger family size over all.

In terms of educational level, one of the key factor that has tremendous impact in the AIDS epidemic and health service in general, health status, is low level of education among Latino overall. Close to 50% of Latino with 25 years of age and over, have not completed a high school or a vocational school. And this has tremendous impact, because the kinds of program, education programs, accents in services, levels of education is key. The median income, again you find the Latino income is considerably closer, one-third lower than for the non-Hispanic population. And then the percentage of female head of household, as you see there, the Puerto Ricans appear to be worse off with the highest percentage of female head of household, and the percentage of family living below poverty level is also higher among Puerto Ricans, and Puerto Ricans who are female head of household below poverty not shown in this table is about 66%.

Now, when you look at some selected health

status indicators, you find that in general, the literature, the research literature indicate that Latino experience poor health status. Measure is many different indicators. The incidence of diabetes is three times higher, and this is particularly true among Mexican-Americans. Cancer, you have an excess incidence, particularly in cancer of the stomach, esophagus, prostate, pancreas, cervix. Hypertension is a clear problem. Tuberculosis, which is now arising as a result of AIDS. Sexually transmitted diseases, teen pregnancy, alcohol, other drugs, homicide. In this case, 2.5 times higher. AIDS we're discussing today, and poor lifestyle practices. Regarding poor lifestyle practices, measured in this case by obesity, limited physical exercise, smoking, poor nutrition, cigarettes, the data indicates the lifestyle practice of a Latino gets worse as they become assimilated and acculturated into this country. The more you live here, the longer you live here, and the more you adopt the mainstream pattern of behavior, your lifestyle gets poor. And obviously, some of the kinds of values, like jogging, are not applicable to the Latino community. If you have Latino jogging, you have a battery of people think that he stole something and that's why he's running very fast, to make sure he won't get caught.

Selective health status indicators of Puerto Ricans. Now, the data, and again, I've been involved in many research myself comparing Puerto Ricans and Mexicans. And the data indicated Puerto Ricans have the worst health status. The profile of a Latino health status is similar to the African-American profile. If you look at data, for example, high numbers of restricted data due to illness within the year, Puerto Ricans happen to have the highest number among all the ethnic group, including black and white. They have the highest number of symptoms of illness reported within the year, they have high numbers of acute and chronic condition. They have high incidence of infant mortality, high incidence of teen pregnancy, high incidence of low birth weight, high relative risk rate of AIDS cases, high rate of alcohol and other drugs. So Latino, over all, clearly find that the incidence of the poor health status is worse among the Puerto Rican population. That is clearly due to the poverty issue.

I think there was another chart that I was going to try to explain some of the -- I think maybe it was this one.

CHAIRMAN OSBORN: Dr. Giachello, if you can --

DR. GIACHELLO: Sure.

CHAIRMAN OSBORN: -- kind of summarize some of

these so that we get a chance to proceed --

DR. GIACHELLO: Okay.

CHAIRMAN OSBORN: -- because this is giving us a very helpful overview, but I want to make sure we have time to get into the --

DR. GIACHELLO: I appreciate that. And obviously, one of my frustration in trying to prepare for this presentation was the fact that in ten minutes it was very, very limited time --

CHAIRMAN OSBORN: We've given you a very hard task, and we appreciate it.

DR. GIACHELLO: -- in which to provide a profile.

But anyway, highlighting the recent situation clearly, you will find there is a series of factor related to poverty that is accountable for the high incidence of the poor health status of this population.

Now, this chart, the one prior to that, clearly indicate, and I could just say that in my own words, the Latino community, when you look at access measures, the data done at the national level or the local level, clearly indicate that they are less likely to have a regular source of care, or a family doctor or a clinic to relate to. Whenever they report a family doctor or a clinic, it tends to be a public health care facility.

This is varied by Mexican and Puerto Rican. Mexican use the public health care facility. Puerto Ricans tend to use the private physician, and I'm going to explain that in a second.

The other indicator of access is whether or not they have health insurance coverage. The data clearly indicate that Mexican-American, in particularly, are less likely to be covered by any kind of health insurance plan. Those are related to a source of employment. They tend to occupy low status occupation that doesn't provide that kind of benefit.

Puerto Ricans, the difference there, they tend to be more covered by Medicaid and Medicare, because we said already that 43% of Puerto Ricans are female head of household. Therefore, they are eligible to Medicaid and Medicare program. So you see tremendous amounts of differences there. Other indicate or access has to do with inconveniences in accessing the system. Some of those inconveniences are lack of bilingual, bicultural staff, lack of sensitivity among health care provider, and I'm talking as fast as a Puerto Rican to be able to say more. The fact that physically the clinics and centers are now accessible to that population. You also find that whenever they access the system, they have to wait longer, a month be able to get an appointment. In

Cook County Hospital they were saying to took between six and nine months to get an appointment to go to Cook County Clinic. That is the pattern very clearly here in the City of Chicago.

Once you get to the clinic, to the health care facility, you have to wait long hours, because sometimes you don't have the bilingual staff to talk particularly to those who don't speak English, they have to wait longer. And I could go on elaborating the many kinds of access issue, but the data on health services utilization clearly tell us that Puerto Ricans or Cubans, for that matter, are higher user of the medical care system. Mexican use the services the least.

Now, one of the many question as a researcher now, is we don't know whether that discrepancy is due to the fact that Puerto Ricans have Medicaid or Medicare coverage, and for that matter they have access into the system. The Mexican-American do not have coverage, and therefore, they do not access the medical care system. That could be one possible explanation.

The other explanation could be the Puerto Rican has the worst health status. So if you are sicker you tend to use the medical health care system the most. So those are some of the questions we are trying to research in literature.

Now, obviously, I still have transparencies that has to do with the AIDS epidemic. But briefly, instead of going into detail, because time is almost up, what I basically wanted to share with you, and as we all know, 60% of all cases of AIDS are happening among Hispanic. We know that women are affected, all the cases among women represent 20%, we know that among children it represents about 26% of all the cases, pediatric cases. We know the IV drug use is a heavy predictable factor clearly manifested in AIDS cases among Hispanics, and also, this is true among different region, like New York City, Puerto Rico, et cetera.

And one of the key conclusions to see for thought is that when you look at AIDS, you really cannot analyze this problem in a vacuum. It is related to sexism, it's related to racism, it's related to poverty, it's related to classism. It's extremely important that you, as I have already been able to document, hopefully, Latino is not only been affected by AIDS, it's been affected by every single other health problem, including tuberculosis and many others that the chart provided. You have to realize that in our community, AIDS is really one of the many problems that is affecting us, that AIDS is really making an impact that is tremendous. And that when you deal with AIDS, you really have to deal with the

entire family, because it's the entire system. And when you see the second decade of the epidemic and look at the patterns and the trends of HIV, clearly you see that it is affecting the Latino as a unity community, it's affecting women, it's affecting children, clearly we have to deal with Latino in terms of AIDS differently than the way you deal with other groups.

Now, obviously, it's not all Latinos that are affected. Only certain segment of Latino population who are affected the most. Latinos who live in barrios, in segregated area, Latinos who are in extreme poverty, Latino who somehow don't have options who are part of the underclass, as many sociology are calling lately. Latino who somehow, and even when you look at women, you realize that those who have less level of knowledge and education, those who are already in oppressed situation, Latino who lack empowerment in terms of having control over their lives, we really need to focus and frame the problem by understanding that it's only certain segment of total population, Latino population who is affected the most.

And I guess with those comments, I will conclude. Thank you.

CHAIRMAN OSBORN: Thank you so much. And in particular, I want to thank you for trying to squeeze so

much into such a short time. We always feel unfair when we ask people to do that, and you did it wonderfully.

We're going to take advantage of -- I hope you will have a chance to -- do we have any questions? I think because of the schedule we may proceed and perhaps defer questions at the moment.

We're going to now have a panel of discussions on the matter of prevention. Ileana Harrell will be making the initial presentation, and then she will facilitate discussions by Hortensia Amaro. America Bracho and Adolfo Mata. And if they could all come to the table and --

II. PREVENTION

ILEANA HERRELL, Ph.D.

MS. HERRELL: If I could have the panel join me.

Buenos Dias. It is indeed a privilege for us to be here this morning testifying before this Commission, and I would like to proceed by first introducing the panel.

I am Ileana Herrell. To my immediate right is Dr. Hortensia Amaro, and to her right Dr. America Bracho, and to her right Mr. Aldolfa Mata.

What we will try to do this morning, in the short period of time that we have been allocated, is to

do the impossible, and that is to address the issue of prevention in the Hispanic community. I say it is impossible, because we are talking about a community that, all thoughts to the contrary, is not homogeneous, but rather heterogeneous, is not monolithic, but rather consists of multiple groups that really are not subgroups, but identifiable groups in and of themselves. And therefore, it's almost an impossible task to do, but something that we welcome, because we are concerned about the needs, about the legends, and about the stereotypes which Hispanics are usually portrayed. And hopefully after our meeting this morning, you will go away not only being culturally sensitive, a term that is not a classic, but rather more culturally competent.

What we will be doing is I will be presenting a short issues paper, and then the other panelists will be reacting to the issues that will be raised during my presentation, and with Aldolfa Mata specifically highlighting programs that are targeted toward Hispanic communities across the country, with the exclusion, of course, of Puerto Rico, because as I'm sure that you've learned, the characteristics of the Puerto Rican population in the island are much different than the characteristics of Hispanics in the U.S. mainland and its other territories.

One of the most urgent tasks confronting public health officials today is the prevention of HIV infection and AIDS. Public health professionals distinguish between mass and high risk strategies. Most strategies are aimed at whole populations. High risk strategies are targeted to specific groups known to be especially vulnerable to a health problem.

Increasingly, funds for research and program development are aimed at high risk groups, such as injecting drug users, women and men engaging in high risk sexual behaviors, et cetera. Approaches to HIV infection risk reduction have been primarily information, the provision of facts about HIV infection and AIDS to a target population. And education, which are programs intended to help people make better use of information, to make better decisions, and to be more assertive in resisting peer pressure.

Such approaches, in contrast to those focusing primarily on information, typically involve active participation of target audience, such as discussions or role playing, rather than the passive receipt of facts. Intervention programs involve the provision of help to people during critical periods of their lives. It may take the form of professional treatment, peer counseling, special discussion groups or empowerment programs.

Persons in the health professions may be more familiar with the traditional public health model of primary, secondary and tertiary prevention. Kaplan, in 1964, defined prevention as "comprising reduction in the incidence of a problem," which would be primary prevention within a population, in the duration of a problem within an affected individual, which would be secondary, and in the impairment resulting from a problem, which would be tertiary.

In 1991, the second decade of the epidemic, we still have not effectively addressed these program components in working with Hispanic population groups. The HIV epidemic is not a monolithic event of caring in the same way and at the same rate in all populations. It has been called a collection of epidemics with different modes of transmission and rates of spreads in different segments of society within this country.

The reality among Hispanics is that we are infected with HIV faster, converting to AIDS faster, and dying faster. Our reality of life still remains an unsolved puzzle to many in public health. All the surveillance and epidemiologic investigations provide data on the extent and magnitude of the problem. There is a great deal of concern among Hispanic population groups that the data that is being collected is not being

used for the best purposes.

This data must be used for program planning activities, it must be used for program implementation, and it must be used for the evaluation of the effectiveness of these programs as they relate to the Hispanic community. We know where the problem is. The question is what are we going to do about it?

In this presentation, I will highlight and describe some pressing issues and concerns among Hispanics related to our experience in the prevention of HIV transmission. Examples will be used to illustrate the various Latino experiences, because we are not a monolithic group in which a Cuban is not a Mexican-American, is not a Puerto Rican, is not a Nicaraguan, because our heritage is varied, and because we still have, in spite of our differences, that binding tie which is language, and that other very, very strong tie, which is culture.

When we talk about ethnicity among Hispanic groups, we are not talking about the biological factors related to ethnicity. We self-identify. We choose to acknowledge ourselves as Hispanic groups. This choice is not based on race or on skin color, and our community varies in hues from white to coffee to dark, but we all have one thing in common. That is our shared common

heritage. We are Hispanics.

The socio-cultural issues, which are pressing upon Hispanics in these communities, are the issues of acculturation and assimilation. People will adopt and will become adept at working in both environments, both the Anglo environment and the Hispanic environment. And then, there are those that choose to assimilate, to try to become part of the mainstream of the American dream. And many of those have left our communities. So there is a possibility of choices.

In addition to that, we have a wide variety of issues as they relate to language. Yes, there is something called standard Spanish, but no, the dialectical differences are also an important part of Spanish, and standard Spanish will not address those dialectical differences.

I would like to bring to your attention, in talking about public information campaigns, some literature that came across my desk from a concerned individual that mailed something to me to review. And I immediately knew that although the Spanish had been standardized as much as possible, it was totally unacceptable to a Puerto Rican community. And there were at least fifteen uses of terms that were ambiguous enough that would have either meant something different to a

Puerto Rican or would have been found offensive by a Puerto Rican. An example of this is the issue of "jeringa". Jeringa is injecting equipment.

Well, in Puerto Rico, a jeringa is a bother. What it really means is don't bother me. Tell your children "noma jeringas", don't bother me, stay away. And so anyone reading that document well versed enough in dialectical differences would have found that statement incomprehensible.

Another example is body fluids. When you translate that into Spanish, ladies and gentlemen, body fluids is a spirit that emanates from your body. "Fluidos", okay? It's something more associated with spiritual aspects of life than it is with the real situation that we're trying to address.

Individuals may be bilingual, and they may be bicultural, but there is always that subtle interpretation in meaning that makes language significant to an individual's way of life and state of life. Not to belabor the point, but to share with you some additional differences in concepts, specifically between the Anglo population groups and the Hispanic population groups, when we talk about "educeacion", about education, and Dr. Lawrence Sly has done extensive work in this area, the effective meaning of language. What comes to mind

immediately to most mainstream individuals is a title, a university title, the number of years of education an individual has had. You will be surprised to hear that to Hispanics, titles are the last thing on an individual's mind when they talk about that individual, that individual is well educated. What we mean is that individual is caring, that individual is responsible, that individual is well-mannered, that individual knows how to behave in the best and in the worst of circumstances. So you see that there is some cognitive differences, as well as effective differences in the use of language.

Other important concepts that no Hispanic presentation can go without include the concept of "dignidad", dignity. The dignity of the woman who may be poor, but still maintains that sense of self-respect and self-worth that maybe society doesn't give her. The sense of "respeto" or respect. We respect our elders. We respect authority figures. We respect individuals, and our whole life is permeated with respect. Trust is another one, and it translates into "confianza". When we trust, we give of ourselves, and therefore, we are open to new learning experiences. That's a way in which we learn. You may use the best methodology, the best educational materials, and if respect and dignity and

trust are lacking, it will not be a learning experience for the individual.

Very quickly, and some of the panel will address these other issues, we're talking also about altruism. The willingness, the self-sacrifice of the Hispanic individual, particularly the woman to clothe and feed everybody else in her household, and only then think of herself as an individual who needs to taken care of. It's making sure that her children are properly fed, properly clothed, that your family has whatever it needs. And the concept of family, again, is an extended family concept. It's not the traditional nuclear family. As well as reciprocity and cooperation. You're good to me, I will owe you a favor, and I will go through life waiting for the day in which I can repay that favor. And cooperation, we learn best in small group settings as cooperating individuals. That's one of our learning styles.

Our belief system is also very different. Our system of attitudes and values is also very different. For example, when we try to change attitudes, we have to take into account, those of us in the behavioral sciences, that there is some personality characteristics, such as, for example, the loss of self control. We tend to be more externally controlled than internally. That's

why you hear sayings, such as "Hey bandido, no hay remedio". I mean, you know, that's life, it was bound to happen. It will happen. Destiny has determined that's the way life will go. And these are important concepts, because prevention programs need to take into account these individual characteristics if they're going to be effective.

Existing social norms, family values and peer pressures are key determinants of the initiation or modification of behaviors. From the point of view of official health agencies, education is the major approach available to prevent initiation of risky behaviors. Specific clinical services, such as provision of condoms are also important in modifying existing behaviors. That's why attitudes and belief systems are so important in our attempts to change behavior. And if we don't know what those attitudes and belief systems are, we may be changing the wrong behaviors.

Education can be addressed at several levels, societal, group and individual. In the United States, substantial efforts have been direct to educating the public. Unfortunately, however, Latinos remain largely uninformed. Public information and education efforts have been targeted to the mainstream population groups. As a result, Hispanics have had to assume the

responsibility for providing programs and services with shrinking, and at times, nonexistent outside support. Education programs directed toward Hispanics have to culturally competent, not just culturally sensitive.

What do I mean by culturally competent? For example, in using methodology, we need to be aware that interventions to change behavior and educational activities are much more effective when they take place in the individual's home, because again, the Hispanic is not an individual entity. It's primarily a family type of entity, where the family is of great importance to that individual.

We also need to look at interactive educational approaches where there is an exchange with the teacher. We also need to look to small group interactions, and also to teaching by examples. The transmission of factual knowledge is important, but it is not as effective if it is not accompanied by the opportunity for individuals to ask questions or to set examples and then ask the teacher or the educator to react to those examples that have been presented.

We also need to use the existing formal and informal networks. For example, an informal network would consist of the "compadres" approach. Have any of you heard that term before? The "compadres" approach is

children are baptized when they're infants, and there is a relationship that is as strong as a blood relationship between the Godparents of that child and the family members. And the whole concept of compadres is one of substitute parents. And one of the difficulties in our communities has resulted because mobility has been that because families use to live in local neighborhoods where people use to know one another. The "compadres", the "comadres", the Godfather and the Godmother, served a function of also making sure that that child was growing up, quote "right," because they also serve the parental functions when the parents were not around. So the mother and father knew what that child was up to, even before the child knew that somebody had seen him or her. So that family function has now been diluted somewhat, but "compadrazco" are still a very, very strong influence in the behaviors of the parents that they are related to.

We also have to use existent systems of operation, such as community leaders, and we need to begin to view the Hispanic woman as a primary care agent of change. And training women to understand that AIDS is an issue could be an important first step in working with these communities. We also need to use a more personalized approach. We need to become invested as persons. And, a situation that is often seen in

management, where the Hispanic employee will come and attend a meeting with a supervisor. And the supervisor, there is a tendency immediately to go to the grain, to go the matter, and we intend to feel very uncomfortable because it's a great show of disrespect. It means that you still have not addressed the welfare or the health of the family members, you haven't had the opportunity to inquire how is your family, and that is a show of disrespect if you don't do that.

Also, you need to inquire about the individual, how that person is feeling on that day. And after you've taken care of observing "niceties," you can proceed to talk business and become involved in a situation. And that is critical when people go to our public health clinics, or to any service provider. It is unfortunate to see young physicians, nurses and other public health workers address individuals they have just met by their first name. It is perceived as a sign of disrespect. And that already sets a negative setting for the interactions that are to follow that client and that service provider.

In addition to that, we also need to use formal as well as non-formal educational approaches, and I hope that Dr. Bracho will address some of the specific techniques that we are using in working with Hispanic

women. School-based educational programs are another societal approach to primary prevention. For Hispanic children, however, family involvement is critical. The child is not an island unto itself. The child is part of a family unit, and that child can be used, also, to educate the family, but at the same time, the family needs to sanction educational activities that child is involved in, because again, there has to be a sense of ownership.

I will make a little aside here, because one of the disturbing situations that I have seen across the country has been the use of children as interpreters for their parents, whether it's in school or whether it's in a clinic setting. In a clinic setting, it violates the issues of confidentiality. There are some things that are private and that no child should be aware of, unless the parent so desires. And by using children as interpreters, we are violating that principal.

Secondly, we are subverting the parental authority when we use a child as an interpreter or as a translator, because the parent becomes the child to whom things have to be explained and have to be told. And what we're doing, we're corroding, contributing to the corrosion of the Hispanic family structure.

Perceived social norms within the Latino

community are also important determinants of behavior. It is critical to work with a variety of groups whose members may be at increased risk of transmission. There have been initial results of the California study with heterosexual partners that indicate that the information that is obtained when individuals are interviewed separately is much more different from the information that is obtained when the individuals -- the heterosexuals partners are interviewed jointly. There has been a higher percentage of men engaging in sex with men who have indicated that they have engaged in this behavior when interviewed independently. And yet the myth still persists that heterosexual couples are, indeed, heterosexual. So we need to begin to make sure that women, in particular, understand that their behaviors that may not be -- that they may not be aware of behaviors within that family unit or that partnership.

Special issues that merit attention, and I will do them in bullet form and have the panelists elaborate, the Latino family. We need to understand, for example, that when one single individual is affected with HIV or AIDS in that family, whole family is affected. It's not just that individual. That we need to use existing community networks, we have to train people that there are special women's issues, such as, for example, the

intended effects of prevention strategies on our women. There has been an increase in the number of physically and verbally abused women who have been abused as a result of our effective prevention strategies. We have told them they should only engage in safe sex, and what we're finding is that when they try to do that, when they try to follow the public health line, the men are responding by verbally and physically abusing them. We are doing these women a disservice by not training them and giving them the skills they will need to safely negotiate their own behaviors.

We also need to begin to look at integration of services, follow up, and sexuality. I am often times, and I shouldn't be surprised by now, but many of you have heard the statement Hispanics don't like to talk about sex. That is a myth. It is a myth. We know when to talk about sex. We know when to discuss about sexual behaviors. We do it when we feel comfortable with the people we're discussing it. We do it when we understand what the issues are, and when we choose what the approaches are that are going to be used in engaging in a discussion of this nature.

We also need to begin to conduct research as it relates to bisexuality in Hispanic communities, and also begin to work against the myth that great injustice has

been done to our men by using the concept of "macho" as negative concept. It's been Anglicized. One looks at the term macho and what it means in the Hispanic community. It means a caring man who takes care of the needs of his family. It's been the media that has distorted the use of the concept of macho with all of its negative attributes. And we need to examine that.

In closing --

CHAIRMAN OSBORN: We need to hear from the others, and we want to have a chance, too, please.

DR. HERRELL: Right. I'm a step ahead. In sum, I would like to close by saying that some of the issues that will be discussed here this morning in this panel will be public health services as related to men, the disfranchised members of our own ethnic group, the neglect of male issues, the need to identify and use community rein forces and motivators for behavior change. Making sure that we conduct follow up activities and provide sustained support in order to sustain behavior change.

We need to look at outward strategies for the workplace, churches, service providers and indigenous community activities. And consequently, in order to have significant impact on the HIV epidemic, we must employ the full range of culturally competent and effective

approaches while looking for other tools.

And with this I close and want to thank the Commission, and would very much like to indicate our willingness to have a, perhaps, three-day seminar in the future in which we can really role our sleeves up and begin to discuss what Hispanics are all about. We would like to open the floor now for questions.

CHAIRMAN OSBORN: Thank you. Let me interrupt you just a -- I'm going to ask you to facilitate the discussion as planned, but I'm afraid we need to try and aim for ten o'clock, which will still be behind the schedule that we had arranged.

DR. HERRELL: Well, we have fifteen minutes.

CHAIRMAN OSBORN: We do need to be -- well, I do want the Commissioners to interact, as well. If you can be succinct and give us an opportunity, we are very happy to have all of your --

DR. HERRELL: In that case, to establish the rules for the panel, I think it is important that we not only hear the comments, but also that Adolfo Mata be given to opportunity to highlight the activities. So why don't we begin with some comments from Hortensia, and move to America.

HORTENSIO AMARO, Ph.D.

DR. AMARO: The point of discussion that I wanted to bring up today are really two, and you have some information that's been passed out, so I'm not going to go through the numbers.

One is the study that was conducted by the Northeast Hispanic AIDS Consortium, and I believe you've all received copies of that now. I'm not going to go through the numbers, but I really encourage you to read it, because what that study points out is the continued astounding lack of knowledge and high levels of misinformation about HIV infection among Latinos in the Northeast and Puerto Rico that have severe and critical implications for how we do our prevention work and the areas that need to be emphasized. I think it also is witness to the failure of current efforts in our community, the fact that they haven't reached our community, the fact that such a large number of people in our communities think that there is a cure for AIDS, think that you can tell who's infected by looking at them, and they have misconceptions and lack of knowledge about modes of transmission and have very serious implications for prevention and work that we need to do. And some of the other panelists will talk a little bit about models for prevention that we think are effective

and that seem to be showing some effectiveness in our community.

The second issue that I wanted to bring up, and I'll be brief because you've also received an article that I wrote on considerations for prevention among Hispanic women, is the role of women in our community, especially mothers as AIDS educators and prevention specialists. It's a resource that we have that's really untapped and we really, I believe, need to focus on women -- on developing models of women and mothers as family educators.

Now, our study on the Northeast Hispanic AIDS project also show that men in our communities are even less informed than women about HIV, and I think we need to think seriously about how we're going to get men informed and develop models that appeal to men, and that men will respond to, because we can't leave men out of the picture. But women, as family members, may be, since they are the traditional health educators, may be the good approach to that, and I'll close by just telling you, just relating to you, a very personal story in my own family.

It's two years ago today that my brother, Armando died. And I never know when it's going to get to me. And what I want to emphasize about my own experience

in my family, is that before myself, as a public health researcher, talked to my brother about taking care of himself, before my older brother who's a physician talked to him about talking care of his health, it was my mother who would cut out newspaper clippings and send them to San Francisco to him and talk to him, you know, in her own indirect and shy way, because she was not used to talking about these things in such a direct way with her son. But it was my mother who really pushed him to try to look at this.

And, of course, it was late by then, but even when he got ill, she went on to work with a group of mothers of AIDS patients, and I think you probably all know that group and the wonderful work that they do. She now visits Hispanic families in the hospitals and other mothers, fathers, sons, daughters who are infected, and helps to provide some support.

Well, I think there is a potential, incredible potential for mothers, to also be involved before infection occurs, and we really need to start looking and spend some time thinking of what are the models for them.

CHAIRMAN OSBORN: Thank you very much, Dr. Amaro.

AMERICA BRACHO, M.D., M.P.H.

DR. BRACHO: Thanks a lot for this opportunity. Can you hear there? Can you hear?

CHAIRMAN OSBORN: Yes.

DR. BRACHO: I want to share several things, also. I work in Detroit, Michigan with the -- in southwest Detroit with all the community, but in particular with Latinos. And what we are seeing around the nation is a lot of Latinos affected. But this is the virus, the HIV, is true that can affect everybody, but AIDS is not an equal opportunity disease, and is not an equal opportunity disease even among Latinos.

We are seeing that these numbers are increasing more in those so-called pockets of misery. And this is not by chance, because Aida Giachello was very explicit in saying what are the conditions of living in those pockets. What we are seeing, and this really is frustrating when you work in low income communities, is all this rhetoric and all this analysis about the socioeconomic determinants in this epidemic, and the solution is always "wear a condom".

And I think there is a huge discrepancy between the analysis and the solutions that are being proposed. I think that when we talk if we are going to spend time in the analysis, we should at least take that into

consideration for the intervention.

One of the issues that Ileana talk when she says the interventions are being short, the interventions are not being efficient, and then she introduced the concept of competence. The concept of competence has to do with the ability of the worker that understand and is able to handle a culture in a group, to make that group solve a human problem. And this is not happening. Even if you have a brochure that talks the right language with the right dialect, is that intervention going to change? Is that intervention going to solve the problem in that particular community? No. Well, it is not a competent intervention. It might be -- it might be appropriate from a language point of view, but it is not competent.

The concept of competence has to do with being comprehensive. And in this type of community, this so-called pocket, we need more than ever to be comprehensive in our intervention. The education is not getting to our community, is not getting there. We are being infected faster, we are progressing to AIDS faster, we are dying faster. And I read some articles that I forgot to bring about some areas in New York where Latino women are living forty-five days after diagnosis. I'm very glad that white, gay males in San Francisco are living longer, and I'm very sorry with that situation. They can live

five or more years after their diagnosis, but I'm not happy at all about the fact that Latino women are living forty-five days after diagnosis, because in the moment that they discover they have AIDS, is already extremely late.

We have to, then, redefine the education, we have to do it. When we talk about prevention, we are not talking about dreams. Prevention is action. And unless we see action, we are not actually doing prevention. And then when we define education, we have to make it simple, direct, competent, and sensitive, appropriate and personal. And when we talk about cultural values, and we talk about respect, we are not talking about being respectful to June Osborn or to Eunice Diaz, we are talking about a respect that can make you forget your rights.

If I am being disrespected in this hospital, I'm not using that hospital anymore, period. And we have to do interventions in which we have to go to the hospital and make a problem right there so the clients can continue using that. It they feel disrespected, they won't use the services.

Language is a key component of compliance, and we know that from the literature. And sometimes you think -- we think that people that come to this country

should speak English, talk English. What happened is the Mexican-Americans were here before you and I. And the first language of Mexican-Americans is the Spanish. And they were here with native Americans. Puerto Ricans are here because some people are there. So Puerto Ricans first language also is Spanish. And I think we need to recognize there is a community there to whom the first language is Spanish, and we need to be very sensitive and appropriate in this regard.

We need to measure the intervention, know what behavioral objectives. Oh, yes, you know about AIDS, because you were able to describe in a very warm manner that AIDS is Acquired Immune Deficiency Syndrome. No, we have to stop, and it's true, we have to measure the behavioral objective, but we need to follow up in our intervention. We have to be able to allocate money in some strategy that can let me continue working with this family. Not only the money toward the change, but to assist with the behavior modification, and to assist with that sustained modification in behavior. And this is true by developing a strategy and story telling.

When we go to the families, we then define the families through the bilingual programs in the neighborhood. With those lists, we made appointments with them, we went there, and remember, we don't speak

Spanish, we talk culture. I know what culture mean, I walk culture. I drink coffee with this culture. And I -- with the coffee, of course, with this type of strategy of drinking coffee, and the Institute of Social Research asked us what is the strategy, and we said just knock at the door and say hello. If the people know you, they will let you in. That's the whole chart of the strategy.

We go there and we tell this story. And people will repeat the story again. People will try to solve the problem of the story. This is much known in the strategy. Ten minutes after finishing the story, people will be relating to you personal things and will be telling you about this son that is masturbating too much and may be doing crack. And at that moment, that person will say I cannot deal with this. My husband is in alcohol. He is not supporting me. What can we do? And we can plan with house 2143 what is strategy that it will be different from 2150. And we have to individualize the strategy or we don't talk anymore about personalism. If personalism is important, it's important to do it, and it's important to have money. We got cut, the budget for that program. We had to lay off our family worker.

The other thing that we seek in a desperate way is to define the cofactors. The cofactors that are always factors that can make a person progress from HIV

to AIDS. Then they talk about the stress and nutrition and the trauma and injuries, et cetera, et cetera. And all those cofactors are present in our community. Early intervention is nothing but a dream in our community. So we really think that we should research and address the issue of progression of infection faster and progression faster.

We also develop activities in the women population, in the female population. And I had a group of women discussing about condom use. And one woman told me that she had a friend that used condoms, and the condom got stuck in her vagina. And then a second time he got it stuck in her vagina. So she was afraid about condoms, because of many condoms get stuck in one's vagina, we have to go for surgery. And I had to take a deep breath and explain this woman that she has to start using her fingers and putting her fingers into her vagina, to actually get to know their body. But that situation told me we have to go a lot before. I mean, we have to move back to basic principles of anatomy, self-esteem, family power, participation, support and follow up before even dreaming of condom use.

MR. MATA: What an act to follow. I should just sit here and take the applause since the lady did such a wonderful job.

We are pressed for time, and I do want you to hear about some of the successful strategies and approaches that are being conducted in the Latino community throughout this country. It's interesting to know that I talked to several different programs throughout the country and there is no one program that is doing the same thing. Everyone is doing a different approach to serve the needs of their community. And I think what clearly came out of this was programs need to be developed at the community level with people from that community, with people that know that community, people that know the characteristics of the community.

I think we clearly know that what has worked in the Anglo and non-Latino community does not necessarily work in the Latino community. I think we know -- last night we were talking about the issues of hotlines or "linear calientes", and what -- very impersonal. I mean, I think calientes approach needs to be a tailored, personal approach with a lot of contact, a lot of one-to-one where you get to know the individual, where you get to know who the person is, who the family is, where

do you come from. It's very labor intensive.

Furthermore, it cannot be done piecemeal. It needs to be a comprehensive approach. And I think we've learned with that in STD's. I think right now in this country there's a terrible problem with syphilis, gonorrhea, however, for all this time STD has been dealt with in a vacuum. But the problem has not gone away. I think even now we have outreach workers out on the streets who are doing HIV education and prevention, but they're not even talking about syphilis, gonorrhea, herpes. All those things are not being mentioned. Why? Well, you know, there's only so much an individual can do.

If an organization is not provided with the funding to be able to hire the individuals, to train the individuals about STD's, to be able to go out into the community and make referrals to STD clinics, it cannot be dealt on a piecemeal approach. It has to be a comprehensive approach.

It also needs to be a core group approach. We need to work with people who are HIV positive, we need to be able to work with their families, we need to work with their partners, we need to make it a community affair. We need to work with people who are HIV positive not only for their own protection in terms of reinfection, but

also in terms of transmitting the virus, and then at the same time, to use them as peer educators, as individuals in our community.

I think a lot of times we in the Latino community have not grasped strongly to the issue of HIV because we have not seen people with AIDS. So people say, you know, I can tell what somebody with HIV looks like. It's not true. But I want to move on and give you the report on the programs. The only other two things that I wanted to mention was the surveillance, and the importance of surveillance and epidemiology to help us focus and develop prevention programs and activities directed to a specific group.

Let me give you an outline here of what I was very impressed with what was happening throughout the country, in terms of our response to the epidemic, and this I will try to make it as short as possible. And I'll try to speak as fast as a Puerto Rican can.

The Hispanic/Latino Community's Response to the Challenge of the HIV/AIDS Epidemic in Their Backyards. "No mueras por ignoracia!" (Do not die because of ignorance), "La Familia Hispana Contra el SIDA" (the Hispanic Family Against AIDS), "Informe SIDA", (AIDS Bulletin), HACER (The Hispanic AIDS Committee for Education and Resources). By the way, HACER means to do.

Proyecto "Vecino a Vecino" (Neighbor to Neighbor Project), "Ilumintate. Como vas a menejar? Vivo o Muerto" (Know yourself, how will you manage" Dead or Alive?), Las Almas de Dios (the Souls of God), "Noche de Ronda" (Night of Sernades), La Clinica Esperanza (the Clinic of Hope), CURAS (Communidad Unida en Respuesta al SIDA) (Community United in Response to AIDS/SIDA). What do all these phrases have in common?

They and many more are the collective response of the Latino/Hispanic commounity's fight against AIDS in this country. From Miami to New York City and north, from Cleveland, Ohio to Salt Lake City, Utah and south to Texas and on to California dn Washington State, the Latino/Hispanic communities of this country have responded to the challenge of the HIV/AIDS epidemic in their backyards.

Hispanics, young, old, hetersexual, homosexual, bisexual, not necessarily self-identified, by the way, these are just terms, sex industry workers, injection drug users, migrant farmworkers "campesinos", recent immigrants, monolingual spanish speakers, mothers, fathers, sons and daughters are being reached in the streets, by television and radio, at fiestas, in their homes, in Latino gay bars, straight bars, in jails and in churches with HIV/AIDS prevention messages. Messages

that have taken their language and cultural values into consideration.

Messages that have been approved by their communities. You see, many Hispanic individuals have questions about AIDS and a deep sincere desire for factual answers. We all have heard that Hispanics/Latinos do not talk about sex, drugs and sexuality. Let me tell you. They do. When their values, beliefs and trust are respected. The secret is in knowing the community and targeting your messages and strategies appropriately.

And I'm going to just briefly give you some programs throughout the country.

CHAIRMAN OSBORN: Let me see if you can be brief, because we will be happy to read that kind of a detail.

MR. MATA: Okay.

CHAIRMAN OSBORN: And we are already now past ten, and have not had a chance quite yet. So I really want to the Commissioners to have a chance to respond to some of your -- all of your interesting input.

MR. MATA: Okay. ALLGO in Austin, Texas. Neighborhood Walks, walking throughout the neighborhood home to home talking to individuals in their home. The Hispanic Committee for Education in San Antonio, Texas.

Going from door-to-door talking to couples in their homes to be able to talk about HIV prevention. And I think what you'll see here is creating the environment where the individuals want to go in their homes.

Liga Contra Sida in Miami has done a lot of recognized of messages, radio, TV, very important for the Hispanic/Hatian community.

Programa De Educacion Sobre El SIDA/AIDS in Santa Barbara, California. Working with compesinos, actually going out to the farms, and it's taking away from the workers schedule, but during their lunch time holding sessions so compesinos can learn about HIV and AIDS and have questions answered. The Dallas Health Department working the prostitutes in topless bars and what they call modeling studios, empowering women with information about HIV.

The National Latino Gay and Lesbian Organization involved in California in creating a campaign specifically to address Latino gay men and HIV testing and early intervention services. Utah, the La Familia Contra el SIDA. Colorado AIDS Training Network is a very interesting collaboration between the Church, the gay and lesbian organization, and also their own support group for people with AIDS, Las Almas de Dios.

And again, throughout the country, these are

strategies that have been created to meet the needs of that community at that -- taking their needs into consideration, and not taking a national approach to HIV prevention because obviously, that does not work. It needs to be tailored to each individual community.

Thank you.

CHARIMAN OSBORN: Thank you very much for trying to help us with our schedule problem. I apologize for pressing you so.

I think we have -- we want to take a couple of minutes. We're very late, but I want to make sure the Commissioners have a chance to follow up on some of the important points you've made. And so let me take a few questions before we break.

COMMISSIONER ALLEN: Dr. Herrell, I had a question about when you were talking about what would be offensive to someone. You mentioned some that were inappropriate that did not communicate well. What would -- would you describe one that would be a offensive to an individual out of that example?

You said there were 15 cases where it was not communicated. I wasn't sure what would be offensive. And that's something that I struggle with is how do we define defensive for a community and not offensive? And who decides that?

And so I'm just curious on your perception of an example of that.

DR. HERRELL: In -- in terms of an interaction between two individuals, let's say that of a service provider --

COMMISSIONER ALLEN: Well, I'm thinking specifically of the literature you -- you spoke --

DR. HERRELL: Oh, the pamphlet?

COMMISSIONER ALLEN: Yeah. You spoke of.

DR. HERRELL: For example, taking the approach that some terms are acceptable when they are in -- for example, the verb coher -- to take. To coher, you never use that word in South America because it means that what you're doing is you're grabbing a sexual organ.

So you use the word tomad, which is another way of saying the same thing.

Another term which may not be so much offensive as misleading would be, for example, use of the word -- I'm trying to think of what the appropriate word -- well, another example would be jeringa. One understands when one uses the concept of jeringa that you're talking about a syringe. Right?

But unless you say needle, the individual would be confused in its thinking and will think that the danger is only posed when you use a syringe, but you can

share your needle.

COMMISSIONER ALLEN: Okay. Yeah. That's --

DR. HERRELL: Okay.

COMMISSIONER ALLEN: That's more miscommunication. The first example, the follow up question to that is would that verb be appropriate in another --

DR. HERRELL: Yes. It would. For example, it is acceptable among Puerto Ricans.

COMMISSIONER ALLEN: Okay. Another question -- just one more quick question to you, as well. You mentioned that the data is not being used appropriately?

DR. HERRELL: Right.

COMMISSIONER ALLEN: Could you describe how the data is being used now? You did describe how it should be used.

DR. HERRELL: It's mainly to report cases. What I hear our community people saying is we know we have a problem, we know where the problem is. Why isn't that information being used for program planning purposes, for example?

COMMISSIONER ALLEN: So you're saying that it is not?

DR. HERRELL: Right. Why isn't that information being used for funding purposes? Why do we

still persist in funding some activities when we know, for example, that the progression of the disease now is even within Hispanics -- among some of the Hispanic sub-groups?

There is also a concern that the information may be misused. It may be misused to categorize individuals. That we tend to use ethnicity without including social economic status when we talk about diseasing people. And that it serves to stigmatize broad ethnic and racial groups.

COMMISSIONER ALLEN: If anybody else wants to comment.

DR. BRACHO: Yeah. I would like to comment.

COMMISSIONER ALLEN: I had a feeling you would.

DR. BRACHO: Because let me give you a very short example. When we say Latino women are being very affected in this epidemic because they use drugs or they are partners of drug users in the majority. You understand what you are saying and I understand.

But my community think that they are not at risk unless they use drugs. Or that this particular group of women does not deserve compassion because we are just providing numbers. As if numbers don't have any type of meaning. And numbers have repercussions.

And what is happening is that we are not

eliciting compassion and solidarity and why can we not elicit this? If we are not making them actually prevent. Instead, you could do this. You can say there are a lot of women affected in this epidemic. You provide the real number instead of saying this 16%. They may not understand a statistic either.

And -- and instead of doing that, you provide a number and you say there are a lot that are being infected for this and this and this reason. And here we are, the ones that are not infected ready to help them and prevent AIDS in this community.

And you give a non-deficit approach to that message. You use the numbers in a way so that you stereotype and you elicit that solidarity and compassion.

CHAIRMAN OSBORN: In the short time that we have, I'm going to have to sort of cut things off. But, Don Goldman and then I'd like Eunice to make a comment.

COMMISSIONER GOLDMAN: Thank you. When I went to college, I was struck by the numerous different names that were given to sexual organs and sexual activities within the United States. But, yet it really didn't cause a whole lot of communication problems.

I mean, when somebody said something, I said, oh, you must be from the south. Or, oh, you must be from the midwest. And at least there was some understanding

as to I'm from the northeast, so that's where things are -- that's where -- from my perspective, that's our -- we use the right words, of course, and vice versa.

Isn't that same understanding and sensitivity existent within the Hispanic community? And I'm wondering whether or not the problems in terms of language that you're referring to are, in fact -- are, in fact, the problems that you say they are or whether or not that understanding doesn't exist.

That the understanding -- that Puerto Ricans don't understand that Mexicans use different language; is that -- is that true or what? I'm just --

DR. BRACHO: It does, but it can bother to read a word that you consider not appropriate. There is a problem. I reacte. The reason I don't use bad words in English is because it doesn't mean anything for me. Listen to me in Spanish and it will mean something for you.

I mean, it doesn't anything. But there are words that reactivate me a lot. And then I don't use those words. Let me use an example that is not even considered a bad word. Casual sex -- casual sex or casual relations. If you say you don't get AIDS by casual contact, but don't engage in casual sex; what is that?

I mean, either it's casual or it's not casual. It's very complicated. And remember that you are talking in -- into this pocket. The level of education is very low. And you have to be as simple as possible. Make it simple.

DR. HERRELL: And also, there are numerous nuances in language. For example, positivity. To be positive is a good thing in Spanish. And when people have a TB -- tuberculin skin test and you say, oh, gee, you were positive. They say, wonderful! I don't have anything to worry about. I'm positive.

And as much as you try to explain that there are differences to some of these individuals, it never truly registers. So we have that problem also with sero positive. It's a good thing. It's something you should have.

MR. MATA: That clear -- you know, states the point of generic programs. You cannot take a generic program and make it applicable to the Latino community across the country.

The American response to AIDS campaign, which is a very generic type of program and you expected it to work in Puerto Rico, in Texas, in New York City and -- it doesn't work. What works is community -- at the community level, people that know the nuances of that

community, indigenous workers.

DR. AMARO: I think that the problem that comes up is related to the demographic characteristics of the populations that we're talking about. And Dr. Giachello talked about lower -- the low levels of education.

So you're dealing with that kind of base to start with. You're dealing with very low levels of knowledge about reproduction, anatomy and so forth. And so you are already barraging the person with all types of information. And then when you use on top of that language that is unfamiliar to them, you're then asking them to make another -- you know, to cross another bridge, to extend that gap themselves.

When what we should be doing is trying to limit any barriers and make it as familiar as possible so that then they can really understand and digest and begin to accept the information. That's very difficult to understand -- you know, as it is. So we don't want to be providing information that asks people to extend themselves further and -- you know, close gaps between them and a piece of paper.

And that's what these differences in language do sometimes.

COMMISSIONER GOLDMAN: So then what you're saying is the -- that the differences in language are

perhaps more -- more understandable and it is less critical the higher the educational status of the individual.

DR. AMARO: Well, also, intervention is personal --

DR. BRACHO: Like you were saying that you are from the northeast. If you are there, and you say -- and you use a word that is not appropriate and people react to you and say, what is that? Okay. And then you say, well, what do you understand for that? I don't mean this.

And that's why to be there is more important than that pamphlet because actually you can help people understand. So we will understand, but we have to talk about what we are --

DR. AMARO: The point also is that -- I mean, there's no need for us to put ourselves in a situation where we're using educational materials that are not targeted to the audience that we're serving because we can -- those materials can be adapted.

So I don't see it really as an issue that -- you know, it presents such barriers that we have to think through whether these materials are acceptable or not. They are not the best materials. They have to be adapted locally.

And, I mean, we're already dealing with information that's very difficult. Why make it more difficult for people?

CHAIRMAN OSBORN: Eunice has kindly yielded me her time because we really do have to move on. Let me express the gratitude of the Commission for your very important input.

And we are going to take about a 20 minute break and then we will be -- 15 minute break, I guess we'd better do. And then we will be back.

(Recess.)

CHAIRMAN OSBORN: The next segment of time over to Dr. Nilsa Gutierrez from the New York AIDS Institute. And I'll let you sort of introduce people, as well as proceed in the manner that you've discussed with our staff.

Thank you so much for taking the time to be with us.

DR. NILSA GUTIERREZ, DR. EMILIO CARRILLO

MANUEL FIMBRE and PAULA AMARO

DR. GUTIERREZ: Sure. Why don't we start with Emilio Carrillo. We will introduce ourselves, what we have done in terms of AIDS work and where we are now.

DR. CARRILLO: My name is Emilio Carrillo. I am originally Cuban, brought up and raised in New York City. Physician and public health -- epidemiologist and MPA's, trained at Harvard where I worked for many years in the faculties of the two schools.

Am engaged in community based prevention, research in the fields of prenatal care, low birth weight and smoking prevention. And have been an activist in the community in the area of AIDS for many years.

Currently, for the past year, I've been the President of the New York City Health and Hospitals Corporation and am very pleased to be here with you today.

MR. FIMBRE: My name is Manuel Fimbre. I am on the faculty of the School of Social Work at San Jose State University. I've been a social worker for about 25 years. I'm a native of Arizona. I now reside in the bay area -- San Francisco Bay area.

And have been quite involved in the field of social work trying -- especially within the National

Association of Social Workers, trying to get them to respond to the whole threat of AIDS.

MS. AMARO: My name is Paula Amaro. I'm an AIDS patient and I've been half my life here in Chicago.

CHAIRMAN OSBORN: Where was the other half? Before that, where did you live?

MS. AMARO: Miami.

CHAIRMAN OSBORN: In Miami.

DR. GUTIERREZ: Okay. I have been the Associate Medical Director of the AIDS Institute for the past -- almost one year. Prior to that, I spent ten years in the Harlem community as a primary care internist in a community based clinic -- a primary clinic care setting.

We'd like to start with a formal statement of protest with regard to time. I spent a moment with -- with June, who expressed her own concerns about how we are all pressed for time, but we do need to say that four hours is an extremely short period of time when we're talking about an issue as complex and as socially stigmatizing as HIV AIDS.

And especially when we put that into the context of such an economically, culturally and ideologically diverse group of people. But we should, at this point, move on. That just needed to be said.

The framework of the discussion for this morning will be first establishing that our -- that we embrace the approach of the continuum of care model. That we as health care providers, and certainly within the health care system as -- as planners and as providers, we know that it is that kind of model that really embraces all of our service needs from beginning to end.

And by that, I mean we start with education and prevention work. We then move on to early identification, early intervention, periodic monitoring, medical monitoring, prophylaxis and treatment, integration into clinic trials, psycho/social support and then all of the other supportive services that come after and in between someone is hospitalized.

So that is to say that what we will do now is to kind of format the questions into three areas. One that is directly related to health care service needs, and in particular, access issues. The second area is income maintenance issues and the third is supportive services.

That's our format.

I think it's important to say first of all that in the last couple of months, all of us have been reading in public health journals new information regarding

access to care issues. If we've been reading this literature for the past 25 years, we all know that the information is not new. That essentially it is saying the same thing that prompted the initiation of the -- of the community health center model back in the mid-60's.

And, essentially, the crux of the matter is privatized medical care in this country. And since we cannot transform the medical system, at this point, we can try to modify it whatever we can, creatively anyway. We must try.

We are 22,000,000 Hispanics, of which the overwhelming majority are Mexican Americans, followed by Puerto Ricans, who make up 13% of the total. Together, we make -- we make up 75% of all Hispanics in this country. And the majority of us live in four or five states most affected with HIV AIDS. That is New York State, California, New Jersey, Florida and Illinois.

We almost -- about 70% of this huge population lives in urban areas. So that with regard to access, we are present -- we are at least physically close to health centers and hospitals. So then, why is it that we don't get there or we get there a little too late?

Again, it basically falls on the issue of either no insurance, lack of sufficient insurance to provide full coverage or there -- or many of us who

receive Medicaid, but who cannot get the types of services and the quality of services we actually need.

I'd like to ask Manuel Fimbre a question. That is, that for Mexican Americans, about 37% are uninsured. With regard to recognizing that privatized medicine is at the root of the problem, what is your sense of what the access issues are in the southwest and in the west coast?

MR. FIMBRE: I think they get better services in the State of California. California, like New York, is a very generous state. But I'm not so sure about Arizona. In fact, even though that is my native state, I'm not so sure they're a part of the union.

And God help the poor native Americans. I think they're just allowing them to die. Of course, probably the new governor would probably take issue with that.

But with regards to Hispanic -- especially the undocumented Hispanics in California, they come knocking on the doors of what are the remnants of the old county hospitals and the State of California does pick up the tab.

DR. GUTIERREZ: Dr. --

MR. FIMBRE: Briefly, we also have a large number of Mexicans who have gone through the amnesty process and they -- because they wanted to become

citizens, did not want to put themselves in jeopardy of being a public charge. They have gone into contractual relationships. They've actually established credit with Catholic hospitals.

They -- several of the Catholic hospitals have developed what they call a center for life where they can -- the mother can go get the prenatal care, have the child there. And if they are poor, once the child is born, the child is an American citizen. The child's tab can be paid by the state. Their private -- their own tab, they pay it on a month to month basis little by little over a long period of time.

And so we have also the private care -- the private sector develop -- offering some service to Hispanics. But I would say they are -- they're a small percentage and could be seen perhaps as an exception rather than the rule.

DR. GUTIERREZ: Manuel, just to add to this -- add to the question, there are about 1,000,000 farm workers who live in settlements. Can you comment on their access issues?

MR. FIMBRE: I think that Barbara Garcia will talk about the farm workers.

DR. GUTIERREZ: Okay.

MR. FIMBRE: We have some serious problems with

the farm workers. We discovered, for example, and this relates to services, that a number of them have their social security deducted from their salary, but it has never been turned over to the social security.

It's either the contractor or the farmer who pockets that money. And so when they apply for disability -- lo and behold, they haven't paid enough into their account.

And we would like for this type of practice to be stopped. And we would like for Social Security to truly have an investigating team to put an end to this type of abuse and exploitation.

DR. GUTIERREZ: Dr. Carrillo, a question for -- for you. New York City -- first, you are the president of a municipal hospital system of the largest municipal hospital system in the country. You're also -- it's located at the epi-center of the country where to date it is the leading killer for women between the ages of 25 and 34, and for men between the ages of 25 and 49.

It is a public health system where about one third of the patients who have AIDS find themselves. And generally, they enter the hospital system through the emergency room. To date, there are over 1,350 Latino women identified in New York City and over 6,500 men.

Can you comment on what the obstacles are

regarding this continuum of care model and what it means for a municipal hospital system as large as that to do that kind of work? To actually implement it?

DR. CARRILLO: Yes. I'll be happy to answer that. If there's more information or materials for more specific that the members of the panel would like, I would be very happy to send information afterwards. I came prepared to ask questions and didn't come with -- with prepared remarks.

Let me say that the -- indeed, the health and hospital corporation is the largest municipal system for health care delivery in the country. We have 11 large acute care hospitals, five large long term care facilities, all located in the City of New York.

We are a -- we are a little universal health -- universal health care system. Our doors are open to everyone. We -- we turn no one away. If you have Medicaid, if you are insured, we basically provide care for everyone, with the goal of providing quality care for all.

The problem of AIDS in New York is one that needs to be dealt with in a community based primary care model. It's one that needs to be dealt in the preventive community based primary care model. The treatment -- the education on AIDS cannot be based in

hospitals.

Our system is a system that was built in the first half of the century and in the 50's and some in the 60's, based on the traditional large hospital where all the facilities, all the specialists and all the resources are centered.

The needs of our communities is such that the emphasis in the large hospital has to change to a care that is more accessible, that is more culturally and linguistically appropriate and more accessible in a friendly way so that the people will feel comfortable using the health care system.

Right now, what we have in our communities in New York City, not just for Latino communities, but other communities of color and to poor communities, is a reliance on emergency rooms for care. AIDS is not a disease that is treated in the in-patient services or the emergency rooms.

AIDS is a disease with features of a chronic disease that need to be treated in the primary care setting. Our goal -- our mission -- is to turn around a huge hospital corporation with a budget of close to $3 billion a year -- to turn it from the traditional very acute care hospital orientation to a more of a primary care community based orientation. To be able to meet the

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Latinos. These people are -- are -- these Latinos like myself are just not open -- the doors are not open to us in these medical schools.

So we have a serious problem with personnel. We need to turn to other levels of care. We need to turn to nurse practitioners. We need to turn to physician assistants. But in doing that, we need to confront a whole bureaucracy of state licensing procedures, a whole bureaucracy of basically turf, in a very much turf oriented warfare between the interests of the medical world and the interests of other -- other groups.

So we have a serious obstacle to confront in terms of personnel as we wage the battle with AIDS. It's something that affects all communities, but particularly affects our communities where we have -- we do not have the doctors to begin with.

Facilities -- our municipal health care systems are facing tremendous cuts. We basically face $200 million cuts from the City of New York. We're expecting some $60 million in cuts for fiscal '92 for the state, and with the Medicare cuts, we estimate that we'll be losing another $30 million. So we're basically -- we're losing huge amounts of money.

The money that we will need to basically bolster the defense is the money that we would need to

basically create new programs. To go out there and begin to do prevention, to begin to do outreach. That money is -- is being sliced away fiercely.

So, for example, we had in our capital program a -- plans for $23 million to be invested in creating 12 health care centers around the City of New York, targeting those areas in New York City where we have the greatest death, the biggest lack in health care services. And as a function of these cuts in the City of New York, we are losing that ability to create.

So we are turning to shoestring funding approaches. We're turning to basically looking for churches to do something in a basement. We're looking to do collaborative work with other groups, etc., etc., etc. So we're facing major problems in those areas.

And this are two substantive serious, serious issues that we have. Again, once we get the resources up and running, there has to be still a lot of education. You know, people have been taught for many, many decades because of the lack of adequate facilities to use emergency rooms.

So we need to really educate people very seriously to the use of alternative facilities that are able to provide services in a more comprehensive fashion. Where we can provide comprehensive services around the

case managed system, which we feel is the only rational, the only scientific and the only humanistic way to provide care for Latino communities.

DR. GUTIERREZ: Would you like to comment and tell the Commissioners if you had to fix five things in this system so that care can be much more easily accessible, what would you say?

MS. AMARO: Well, he's talking about that -- okay. About all the different places and how they're trying to build better places. But here in Chicago is real poor. And the services is real poor. Like, the Howard Brown Clinic -- now that's a place to help people with AIDS or HIV infected.

And my sister -- she was getting services there until finally, she didn't have no food at her house and everything was going real bad for her. She called there and they said, well, we can't help you because this is only for gay people. See?

So there's a lot of things that need to be improved here in Chicago. Like, some of the doctors has to be educated how to treat patients, not to be scared of treating patients. And there's some doctors that sometimes they react. I've seen -- I don't want to catch AIDS. You know, and sometimes -- there was one that hit me -- you know, so there still needs to be a lot of

things done here in Chicago.

And like housing for people that could pay low housing because it's real high here in Chicago and it's hard for people to try to understand where you're coming from, what's happening, what you're going through. And so it's real hard for you to try to get through to them.

DR. GUTIERREZ: I just want to say that from my own personal experience as a clinician in a community health center that was affiliated with a municipal hospital that in the seven years of practice, we had an extremely low no show rate. We had maybe five percent of the patients missing appointments. People were "compliant". People were very much involved in taking care of themselves and were very pro-active about becoming educated about HIV and AIDS.

And certainly wanting to get tested. They requested the tests, but at that time, we only had anonymous testing sites that were testing patients on a regular basis. And the patients would not go to anonymous testing sites. They wanted to be tested on-site. The issue of confidentiality in a neighborhood clinic took second place to being walked through that process by someone who they trusted and had some kind of working relationship with.

It seems reasonable and we've all seen the

success of this community health center model in a number of areas -- in prenatal care, in geriatric care so that it seems ridiculous for federal government to make statements about shifting monies away from community health centers and putting them in infant mortality approaches.

It just doesn't make any sense. And I think that if something works, let's keep it. Let's build on it. We have money for patriot missiles. We should have money for this.

With regard to issues of income maintenance which Paula spoke to, HIV and its related illnesses is characterized by an asymptomatic period followed by a period of clinical decline and then fluctuating periods where there's inter-current illness.

The HIV positive patient has, of course, an enormous burden. They lose their jobs. They often have difficulty paying rent and they can't sustain their families.

In your experience, Manuel, as a social worker, what are the essential elements that need to be built into the social service system so that it provides a smooth transition for the HIV positive individual who does not have AIDS?

MR. FIMBRE: Keeping in mind the model that Dr.

Gutierrez spoke about at the beginning, that any community must have in place services in at least four major areas, one of which is education. Since education is our only weapon so far for prevention.

The other one is the health and mental health. A well developed and continuum of care from in-patient to out-patient to community based. And the third quadrant is that of income maintenance. Fancy terms -- keeping body and soul together. Paying the bills. Perhaps this is what this quadrant addresses.

And here basically the Hispanic community is dependent ór inter-dependent on the services that the country provides. Sooner or later, we come knocking on the doors of the welfare department of social security. And here what is needed is a strong advocacy component so that there will be a short turnaround time so that -- almost presumptive eligibility.

Presumed that they are eligible, provide the services and -- and the funds necessary to keep some degree of quality of life. This strong advocacy group, I think, is necessary if we're going to hold these agencies accountable, both Social Security and the various departments of welfare.

So a mechanism to make them responsive is absolutely necessary.

The second point that was spoken about is there is a need for the establishment of emergency funds. There may be funds for persons with AIDS. There are no funds for HIV positive people that may just be showing some of the symptoms. But their bills are just as real.

I admire the State of California -- the State of -- what's your state -- where there is a law there that says that they cannot discharge people from the hospital if they don't have an address. I understand that this puts a burden on the health care system. They should not be hotels. They should not be providing housing for people who no longer need medical care.

But, at the same time, I would like to see this law, I think, extended nationwide so that nobody can be discharged from a medical treatment center if they do not have a place to go to. And for the community to really work in collaboration in providing affordable health care. So there is a need for this emergency funds to be developed.

And the other final concept with respect to income maintenance is we need to think in terms of who is the client? The identified -- the person with AIDS in our way of thinking is simply the identified patient. The client is really the family, whether it be family of choice or family of origin.

And here you have generational issues. You can have, for example, mother being infected, but -- and she will die. Grandmother will take care of the younger generation. So here we -- a number of governmental agencies come into play. Protective services, child protective services, foster care, as well as Social Security, custody issues arise.

And so many of our programs are categorical and fragmented. They are unable to truly conceive as the family -- the care givers -- as truly being the client to work with and strengthen rather than just the identified patient.

DR. GUTIERREZ: Would you like to add other recommendations?

DR. CARRILLO: I'd like to bring up another -- another topic if I may.

DR. GUTIERREZ: Sure.

DR. CARRILLO: We have a very peculiar situation that is taking place in New York City, Chicago, Boston, which I will call the Puerto Rico, New York City Air Bridge. There is a very large incidence of HIV positivity in Puerto Rico, as there are -- as there is in New York City and other parts of the east coast.

And what's happening is very tragic in that in Puerto Rico, the Medicaid cap does not allow for -- for

funding for AZT. So it's harder for people to be able to fund AZT. So, very often in the early stages of the illness, people will travel to New York City in particular, as we have experienced in New York, and I'm sure also to Chicago and Boston and other places in the same access, for the treatment.

Now they leave behind their loved ones. They leave behind their -- their family, their social supports. They leave behind very much.

They come here and basically find their way, I guess through word of mouth -- find their way through the system. Conversely, when people then tend to become more ill in the latter stages of their illness, they tend to go back to the islands. And, again, when they go back to the islands, there's no case manager, there's no doctors, there's no group there accepting them, accepting the medical record, plugging them into a continuum of services.

And we have a real disjointed situation that basically reek havoc on the traditional migration patterns of the Puerto Rican people in the east coast. And this is something that has a lot of implications for prevention, for good managed care, for education, etc., etc.

Besides doing something about the Medicaid cap,

which is something that I think given the situation -- given this problem, it's really criminal that this is not addressed more forcefully by the federal government.

Aside from that, we need to establish case managed programs that basically bridge this gap. We need to set up programs in our cities and we're beginning in New York City to do that with Puerto Rico. This is something that I have spoken with Eunice about and I would like to just bring to your attention that we may need some support from this committee as the politics of doing this international bridging is very complicated and very difficult.

But we feel that we need to have this kind of a case managed approach to basically follow people that travel from one place to the other. We need to coordinate joint prevention programs with Puerto Rico. And we also need to talk about things like creating sister hospital relationships or sister city relationships so that we can better meet the needs of people who are suffering and are being disconnected from their social -- social support.

DR. GUTIERREZ: I'd like to bring up another aspect, which is the aspect of supportive services at this point. It's important for us to know here that the tradition of the Latino community is a multi-service

community based organization making itself responsible for the work and for the building of its community.

These multi-service groups generally have a tradition of about 20 to 25 years. They were involved, and have been involved, over those years in housing and in education and civil rights and in health care access issues. So that when we start looking at HIV AIDS, we look at it differently only because we enmesh it into every one of those problems that have been longstanding in our communities.

Especially the one that I did mention, which is substance abuse, which has been an epidemic in our community for as long as they've been -- for as long as we've settled in this country.

But that's important to say because when we need to make clear that it is not that we do not prioritize HIV AIDS the way that the gay community does. We just look at it differently. We enmesh it into the rest of these issues and make it part of every one of them.

That is why categorical funding doesn't work for us and that we have to use a more integrated creative source of approach so that people can identify what works best for them and permit them to actually do it. Of course, we always have an efficient and appropriate

evaluation tool, but it needs to be done in that format.

The reason why I raised this is because when we talk about supportive services in our communities, we want to say that we want to establish a network of support services internally and we want to work with it collaboratively with city, state and federal agencies.

And I know that, Manuel, you've had a lot of experience in that work. And I'd like for you to address it. And the kind of models that you see are viable.

MR. FIMBRE: With respect to supportive services, again, this is another fancy term. As you well know, that the AIDS HIV is a progressively debilitating disease, even though now it's becoming more of a chronic illness, it nevertheless -- the debilitation continues.

And a person may need help to meet the challenges of daily living, all the way from transportation, house cleaning, shopping -- you name it. And so there is a need for practical home support services to keep that person functioning in his or her home as long as possible. Otherwise, they're going to come into the hospital and run up a bill.

If we can keep them receiving care in their home as long as possible, I think that -- that would be -- that would be the ideal. And that's what they want themselves -- some quality of life surrounded by their

loved ones.

Here, various communities have developed a variety of mechanisms cooperating with -- let's say visiting nurses association or with other nurses that go into the home. We can help the nurses train the care givers so that the person with AIDS will receive the necessary support.

There are a number of issues that enter in here. Some will require things like minor home modifications. Where will the money come from to do these minor home modifications? They are necessary.

But with respect to the Hispanic community, again, what is really needed is an agency that is a family agency whose goal is to help families cope. To continue being care givers to the person with AIDS. And if we do not help them, either financially or educationally, the quality of life for that family will diminish.

A family agency of this nature can work with other professional members of the Hispanic community and develop them into volunteers so that they can also be of help to afflicted family members.

And, here I would urge you to use your leadership, mobilize the United Way, challenge the United Way, mobilize Family Services of America to develop these

family service agencies within the Hispanic community to help Hispanic families cope.

CHAIRMAN OSBORN: I know you have other points you want to raise and I also know we're running short of time and the Commissioners want to interact. So if we can be sure to get to the points you want, and then --

DR. GUTIERREZ: No. No. Ask the questions. Ask the questions. One second, please. Paula, do you have a comment to make in the area of supportive services like housing, supplemental stipends or anything else that has been a problem for you personally?

MS. AMARO: Yes. That is what we need a lot here in Chicago is like the housing and -- and services like child care and -- and be more open so that they could know that we do need all the support that they could try and give us.

COMMISSIONER DIAZ: I have a question for Dr. Carrillo. What percent of your beds now in your system are occupied with HIV AIDS?

DR. CARRILLO: We have approximately 28% of our beds.

COMMISSIONER DIAZ: One of the things that I think piggybacks on what Manuel Fimbre was saying is the need to really educate Latino families to really do greater part or participatory engagement in home care --

home health care. Specifically, beyond the social service functions.

Has your system developed any kinds of plans whereby families that wish to take patients at really at a certain point do not need to be hospitalized, could go -- undergo training and really provide some of that care within the home? Or do any of you on the panel know of any state that has reimbursement for family members or extended others to care for these individuals at home, thus reducing the in-patient load and at the same time providing care that is very much desired by people and can be given?

DR. CARRILLO: That's a very good question. We have a very aggressive program in development -- further development of home health care. Corporation has been attentive to home health care for at least some seven years now and under this administration, we're moving very aggressively to put a lot of resources there.

And we are recruiting, we are training and we basically have in two-thirds of our hospitals have strong home health care programs ongoing. And we plan by next year to provide home health care services in every borough of New York City. We do not have opportunities to have family members reimbursed, that I'm aware. I don't know whether -- we do not. That's not something

that has made its way to New York City yet.

We are also -- the need for development of more long term care beds is something that we're also facing. We were able to salvage the development of two long term care facilities from the budget ax. And we're moving with those in Brooklyn and in Queens -- developing two long term care facilities with about 300 beds each. In each of those facilities, we expect that a fourth of the beds will be people with HIV. And for that reason, the long term care facilities need to be architectural design -- a lot of the conditions are different than the traditional building of long term care facilities that are geared for more geriatric patients that did not care for younger people to have -- you know, much more needs in their treatment plan.

COMMISSIONER DIAZ: I just wanted to express a word of appreciation to Paula for being on this panel. Paula, you and your sisters who are sitting in the audience -- the Hispanic community owes you a great debt of gratitude for sharing your story on the Women AIDS video that has been seen by thousands of communities. And I applaud you for that in a very special way.

(Applause.)

MR. FIMBRE: Let me respond to your question about whether any state helps the family to take care.

Unfortunately not. This is part of our English patrimony remnants of the Elizabethan poor laws which is a responsible relative concept.

However, these relatives are indeed responsible and they want to help. But they need help in helping. And I wish we could change that concept.

DR. GUTIERREZ: I just want to add something to that note as well because it is so important for us to know that our families, extended an immediate -- have been taking care of each other for many, many years. Especially during the heroin epidemic and then the crack epidemic, in terms of caring for their elderly parents.

All of this has been going on and it is not secret information. People know this, but with HIV AIDS, there are an enormous amount of misconceptions and myths within the family with regard to care of that individual.

The whole issue of isolation, of washing things over and over, of bleaching everything down, of treating the individual with a lot of love, but with a lot of distance a lot of times. And that creates an enormous amount of emotional pressures for both the HIV positive individual and the family members. And that kind of confusion requires education.

The community health centers can't play that role. We are simply falling apart with regard to all of

our other responsibilities. But, certainly, in some way, shape or form, we can design programs, the funding, to be able to focus on in-home care.

CHAIRMAN OSBORN: Harlon Dalton.

COMMISSIONER DALTON: I'm very struck by how many times already this morning the concept of family has been mentioned or -- or invoked. And I'm struck by how differently the world of AIDS looks if you start out with the idea of the -- of the client, or at least the affected unit being a family rather than an individual.

To put it differently, I do think that much of our early learning around this disease was in terms of individuals being affected by HIV. Individuals who were perhaps estranged from their families, individuals whose support systems weren't really familial, but rather community -- but a different community than the kind of community that's been talked about today.

So what we're really hearing today is a totally different conceptually -- but also in the real world a different way of thinking about who it is that's affected by this disease and how we set about helping them.

And everything changes if you start out thinking as the family as a central unit. As Professor Fimbre mentioned, the programs in place for helping people are by and large individualized. They're

fragmented. You have programs for young people. You have programs for the elderly. You have programs -- but the programs don't -- aren't really conceived with the family as a system in mind.

The questions of confidentiality are different if you think about the family as an affected unit. As Dr. Gutierrez said, there are lots of people who, in fact, won't go to anonymous testing sites because they would rather have their testing provided by people with whom they have developed an ongoing relationship in the home community.

And now I'm sort of adding family and community as a second sort of notion that's been stressed and stressed, including community health centers as against hospitals. Why? Because community health centers are more -- friendly was the term you used, but I think are more familiar because those are places where the likelihood is greater that there will be cultural competence, to pick up one of the terms from the earlier panel.

Once you think about family as an issue, then reimbursement seems to look a little bit different. Then we begin asking questions like how much -- can we reimburse family members who, in fact, are providing home care? Home care becomes much more important when you're

thinking about the family and the home as the focus for HIV prevention, as the earlier panel talked about. And the family and the community as a focus for HIV care and treatment, as this panel has talked about.

So I just wanted to underscore, or at least feed back, what I've been hearing. Paula talked about child care. I mean, if you're talking about families being affected by HIV, then you need to think about taking care of children while other members of the family are taking care of each other or getting people to the hospital or whatever. So there are a whole set of issues around families that really come to the fore.

I guess I should probably ask a question rather than simply -- but I'm really just repeating back what I've heard. The question I have though is really -- Professor Fimbre mentioned at one point that one possibility is that we maybe need a family agency to kind of put the spotlight on this issue and to help us pull fragmented programs together from a family assistance perspective.

You know as well as I do, that in this political climate, that's not going to fly. That it's the idea of another agency or anther program. But so I guess I want to ask you how I mean, other than you all working 48 hours a day to keep putting out this message,

how can the way in which, not only this disease, but health care delivery or why not just health care delivery and social service delivery?

How is it possible to sort of re-think this in a way that does change our thinking to a community focus and a family focus? How can we do that other than having a family czar?

DR. FIMBRE: That sends shivers up my spine -- a family czar. I think there is a need to conceptualize the relationship between family and community. The family does not live its life in isolation. We believe that families make communities and communities can destroy families.

Think of a concept of a crack house, for example, in your neighborhood and the negative impact that that has on family living. So we conceptualize that the community should be supportive of families. And there is a relationship of inter-dependence and reciprocity between families and communities.

If you start from that point, then it becomes all the more important to truly have an agency that can both develop community, develop the appropriate community resources to truly be supportive of a family.

And we believe that the case managers have a unique role since they are involved in providing the

health and mental health, the income maintenance and the supportive, they are also in a unique role to spot gaps in services and to document gaps in services.

So the -- in our part of the county -- Santa Clara County, San Jose, where I come from, we are seeing that the case managers also have a data gathering obligation, as well as a community development function. They should be talking to the leaders of industry, as well as government and the private sector to begin filling in these gaps in services.

So that's generic -- an umbrella response to your comments, but I think -- I think you've captured the essence of what we're saying here.

DR. GUTIERREZ: Well, I'd just like to -- can I add something to that? And that is that it is important to note that while our experience in general is different, that the gay community has also handled this as a family disease. Except that their family is defined differently by virtue of them being alienated, either by their own families or by virtue of their gender preference.

And so that within our communities, which have a percentage of individuals who are gay, but who are not necessarily public about it for the same reasons, also have the same issues that kind of swing back and forth

from the particularities of the gay communities' family structure and the traditional family structure.

So that just needs to be said so that it's a complete picture.

CHAIRMAN OSBORN: Thank you, very much. I think probably in order to turn to the next very important topic, we'll have to move on. But I think it's on behalf of all the Commissioners, I thank you for an exceptionally important set of testimonies. Thank you.

DR. FIMBRE: Dr. Osborne?

CHAIRMAN OSBORN: Yes.

DR. FIMBRE: May I just make one short comment?

CHAIRMAN OSBORN: Sure.

DR. FIMBRE: If you have the ear of the President, please ask him to declare war on the homelessness. Please ask him to declare war on inadequate health care and to establish deadlines by which these -- you know, these achievements -- draw the line.

CHAIRMAN OSBORN: We'd like nothing better than to do that, but it takes some time. Thank you, very much. Let's move on.

The next panel will be dealing with issues of migrant, rural and undocumented populations. And if they could come join us, we would appreciate it.

I have a feeling our next panel knows how they're going to proceed more than I do in detail. And I wonder if I could also ask you to introduce yourself so I don't do such a dreadful job on my pronunciation. I'm really quite embarrassed not to speak Spanish.

So if you would proceed, we're looking forward to hearing from you.

DELIANA GARCIA

MS. GARCIA: Great. My name is Deliana Garcia. I'm with --

CHAIRMAN OSBORN: Excuse me just a second. May I ask the people in the room to be a little bit quiet because we are running so late that we must indeed proceed. And if you have conversations outside, that would be helpful. Go ahead.

MS. GARCIA: Okay. Let me start again. My name is Deliana Garcia. I'm with the National Migrant Resource Program. I'm the Director of Special Projects there.

I was fortunate enough to testify in front of a smaller group of you in Dallas. And I'm really pleased for the opportunity to be on a panel with these two folks, because I think we need to broaden the issue a little bit.

To my right is Samuel Martinez. He's the Corporate Vice President for Migrant Child Institute, Washington State Migrant Council. And to his right is Barbara Garcia, Executive Director of Salud Para la Gente in Watsonville, California.

I think that we are a nice grouping because you have had folks speak to you about eligibility, about travel or migration, case management access, absence of

services, ethnic variations within the group, alienation from their community.

And what we want to talk to you about are some things that might be considered microcosms of all of this. And that if you were able to do anything to affect the two populations that we'd like to speak to you about most particularly, that these things would have application for other communities that you've talked about as well.

I would like to start by speaking to you about migrant and seasonal farm workers. And what I hope you will keep in mind is that a majority of these three to five million individuals are U.S. citizens, contrary to popular myth. And they have the very important job that none of us could survive without, which is to feed us.

Very little is known about them. Very little work has been done to gain any kind of information about them. What we do know though is that of the folks that we can keep track of, 40% of them leave the migrant work force and go into urban centers.

The ones that you've been talking about now where there is little service, little information, variations in language, and they go to those areas completely uninformed about the disease of HIV. They have come from an environment where they have worked long

hours. They've had low wages. They've had abysmal housing and they've been exposed to things like pesticides and other toxic environmental problems.

There is little government regulation for migrant and seasonal farm workers. They don't get coverage for workman's compensation. You cannot make sure that any of their employers will do their Social Security. So that if anything should happen to them, they don't have the standard recourse that's available to most American workers.

30% of all farm labor is performed by children. Child labor law in this country makes sure that children under the age of 16 cannot work except in agriculture. And then you have exemptions for children 10, 11 and 12 years of age so that they can be out in the fields working.

And even with these few requirements under the law, there is little monitoring to make sure that anyone is complying. You have no toilets; you have not potable water; you have no water for washing your hands. And it is in this kind of environment that we would like to make sure people have some information about HIV.

And it's really important also that on this occasion that you've started to look at children in the Hispanic or Latino communities that we talk about

children of migrant and seasonal farm workers. The rate of parasitic infection for them and preventable diseases really lets us know that the type and amount of education and prevention work that needs to be done with this community is incredible.

If you've got kids suffering from parasites similar to the kinds that you do in third world countries and they are right here working in our labor force, how is it that we anticipate we are going to bring them up to speed on an epidemic that has knocked the socks off of this medical and health community and this country that has so many advantages and so much information available to them.

You've talked about child care. And there is no child care to speak of. There's less now than there was ten years ago for migrant and seasonal farm workers. It has gotten worse.

Exposing them, then, to chemicals and dangers. Every season in every major farm community in this country, there will be a child lost to being run over by a tractor because they were left between the roads because the mother was not able to attend to them anywhere else. Or they'll be lost because they were locked in the car and suffered heat stroke, asphyxiation or fire.

And all of that is still going on in the community that we're trying to educate for HIV.

Services available to this community. While there are three to five million of them, only 600,000 receive health services -- receive medical services. Let's not fool ourselves. It's not health services they're getting. It's medical services that they're getting.

And for that, what Congress has set aside is $100 per person that is seen through that system. Okay? And that's for the whole year for medical services. With that kind of money then, we want to look at affecting HIV and providing them with the kind of health care that we know that that disease requires. Even through a primary health care system, which we know is the best mechanism for treating them with those kinds of dollars.

That -- that, really by the way, if you haven't done a little math on it is 12% of the population of migrant and seasonal farm workers having access to medical attention.

We have been able to do a recent study about them. And we've balanced for ethnic groups, language use, levels of poverty and migrant farmers workers continue to demonstrate an even lower level of health status than what you might see in what is considered an

equivalent counterpart when you balance for language and money and location.

What we know if, for example, that women who are migrant and seasonal farm workers -- when they come into the clinics and they're between the ages of 20 and 29, most of them are coming for OB care or a sexually transmitted disease.

Men of that same age group are also coming in because of STD's or something like scarlet fever. So that we're not seeing people come in for anything but really exaggerated and now fairly extensive health problems.

And the other thing that we can tell you from migrant and seasonal farm workers is that if they don't access one of the few migrant health centers available to them, they go directly to the emergency room.

And emergency rooms, we already know, particularly in rural settings, are being closed because there is no money to support the hospital in that area. So one of the few health resources available to them is starting to drop off.

Not considering the fact that it's now, because -- while the National Health Service Corps has been re-upped, we have lost that as a resource for physicians who were willing to go out into these -- you know, hard hit

areas because we couldn't get anyone once they'd done their commitment to the government, to stay in those communities.

They'd go off where there was a change to do less harsh, perhaps more financially rewarding, medicine. And not stay in rural communities.

But as far as HIV in the migrant and seasonal farm worker population nationally, the sero prevalence rate is really low. What -- what we know is that it's a window of opportunity right now. That they're engaging in all the same kind of high risk behaviors that we've talked about for years now.

And they're even doing some that are considered positive health practices. Okay? They share syringes to inject vitamins and antibiotics because they want to stay healthy. But that, in and of itself, if we cannot talk to people and have not in the last few years been very successful at educating people about risk behaviors that we are wanting to consider negative and jump up and down on the group bench about how bad that is going. And whether or not someone is willing to use a condom and whether or not we make condoms available to them.

How is it though unless we are more specific and more particular in our work that we educate people about positive health practices that also endanger them

of HIV infection.

But the other thing that we need to keep in mind is for migrant and seasonal farm workers, the ratio of male to female for infection is one to one. As many men and as many women are being infected. And this group is -- is like a petri dish. It's a group that's alienated from its communities because most people do not want to accept farm workers.

For example, there is the community in the northeast that relies on them tremendously. And they just passed a law that there will be no farm worker housing in their city limits. And this is still the same sort of thing that's going on. Okay?

And we -- and I'm sorry. So I'm getting kind of wild eyed now. So that I would like for us to consider them an opportunity to make things happen in such a way that we know that they could translate for other special communities. If you have such a low infection rate, but in one year's time we have seen such radical rate increase.

For example, as you see in the northeast in the Delmarva Peninsula, where from one year it was in the point something range, and it is now in the positive four to five percent range. And I don't mean that it jumped that radically. Perhaps our testing got better. Perhaps

our reporting got better.

But I also think it demonstrates that it's starting to explode and we're losing our chance with this particularly mobile population to get in there, to educate, to test, to provide them with treatment, to look at things like case management.

When I testified before you in Dallas, I spoke to you of a young woman who was in this country working. Was infected at a hospital when she had her child. As she migrated, nobody would treat her. No one would do a T-cell check because no one wanted to be responsible for her care.

And so those folks then, if we are able to come up with a system of case management, which is something that you've heard about. Where we've talked about breaking down the eligibility requirements across the states. Where we could make people then not overly responsible if they didn't feel like that person was a member of their community, but we had some way of easing their access into care. So that as they continued to travel up and down, continuing to labor, they could get back home.

So I would ask you then that we integrate prevention services, that we look at community based organizations, that we look at the existing services that

are already in place. For example, the migrant health centers. That we not see the need to create a new agency or have the family czar. But those things that we've heard about working in other communities are already in place.

And that we extend their ability to help beyond the limited constraints that they're involved in right now. I would like for you to hear some of what is going on in Washington State and -- and Sam can also talk about what is going on in some states surrounding him about what has been effective in trying to work with migrant and seasonal farm workers.

SAM MARTINEZ

MR. MARTINEZ: Deliana has given our report pretty much.

CHAIRMAN OSBORN: And very eloquently.

MR. MARTINEZ: So I'll try to fill in a little bit more.

I want to thank you for inviting us here. Thank you Eunice Diaz. Of course, she is one of our champions throughout the country. So I'm very appreciative that I was asked to participate. I want to be able to give you a little bit of rural America, particularly those areas of the northwest where the migrant farm workers work, live and raise a large family.

In the States of Montana, Idaho, Oregon and Washington, we work the four states. I must first commend you for the work that you've already done in the areas of the rural America.

Your Report No. 3 speaks of some horrors. And I want to let you know that they are still alive and well and expanding in those areas.

We -- like I said, we work in the four states. And the difficulty of working in particularly those four states is the -- is the rural -- the scarcity of populations and resources.

In Montana, for example, we have a project in Billings. And in order to get to the west side of Montana, you need to get up early and cross over to deliver -- you know, seminars, talks, information to the -- to the farm working population in that area.

So in Idaho it is pretty much the same way. We have an over population of skin heads that make it rather difficult for us to work in that area. So we kind of stay away from there and work in the southern part of Idaho where there's -- you know, more of the farm working community.

In terms of services in that state, it's not one of our more progressive areas that we work in. Oregon is pretty much the same. In Idaho, we work

through the family and child care centers. What we do is that we meet with the parents at each one of those centers as a parent advisory committee. And we attempt to make with them and to deliver the kind of information that is relevant to them.

In Oregon, we work through the clinics pretty much the same way. The clinics, the community meetings -- wherever it is that we can meet -- meet with this population, we do so.

We have had the problem of, you know, lack of cooperation from the schools. Schools have always looked at us at outsiders, especially in the area of health. They've gone to the health departments and they are quickly finding out that the health departments are not equipped to provide the services to a mono-lingual community. So now they're calling us in. Now we are partners with the public schools.

Washington State -- we have both the clinics and the day care centers in which we work. Again, one of the most difficult aspects of the work -- prevention work that we do is the lack of a credible information system that we can deliver messages to our folks in the language that they can understand.

So, a few years ago, we developed our own radio station. It's called KDNA and it's known as Radio Carena

but it's now rapidly being recognized as Radio Sida because of the amount of information, not only the sexually transmitted disease, but the substance abuse and the AIDS.

We have a twice a month, we have talk shows -- one hour -- in which we talk about -- about the problem, prevention, etc., etc. And we get a lot of calls. A lot of calls about people who want to know do I have the symptoms? Where can I meet with somebody? There's -- there's still a lot of denial, a lot of reluctance, in taking the test, for example.

I mean, I personally had that kind of problem. I will admit that only last December did I decide to go through a testing at the University Hospital in Seattle. And waiting for two days for the answers was extremely -- my wife began to question why I wanted to take it. And so I can understand what kind of problems folks go through.

However, we are now beginning to experience -- we are now beginning to experience a change in attitudes. People are beginning to understand that this is not -- it doesn't necessarily mean that they have the disease and they understand that through the messages that we provided -- we provide to them like transmission by shared needles and syringes is increasing among the IV

drug users. We tell them that the transmission by sexual intercourse is increasing in the heterosexual population.

They begin to hear the message over and over and over. And they're becoming more comfortable with that kind of -- with that kind of a practical chat or talk. So -- so it's a little more -- it's a little easier for us to communicate and to have these talks with them.

Let me see what else I can -- the churches -- we are just impacting the churches. We have just met with the bishop, spent a whole day with him. A new bishop in this particular region. And he's opening up the doors. He's letting us talk from the pulpit, much like the recent war. The priests determine what it is that we can say. And what it is that we can't say.

Recommendations -- let me just briefly recommend that I know that some have spoken against a national approach to the problem. Let me tell you, when you're talking about a mobile community that moves from -- from the state of Coahuilla and Tamaulapis in Mexico, into Texas, into California and into Washington State and those western states, we look at the situation much the same way as the national migrant head start looks at dealing with this particular situation.

We have a project right now. It's called Even

Start, in which we work with 40 families in the State of Texas and 20 of them move to Michigan and 20 to Washington State. And we follow those families, providing the case management approach to -- you know, to dealing with their issues from illiteracy to child care to resources and etc., etc.

So I'm suggesting that we begin to look at -- especially in the migrant community -- that we begin to look at a national approach to this partiular situation.

Dr. Carrillo spoke about the international issue. I think we need to start looking at that very seriously. Especially like I mentioned in Mexico, the different states, we get a lot of populations from those states. So we need to make that connection and work jointly with those folks.

Thank you very much.

BARBARA GARCIA

MS. GARCIA: Okay. My name is Barbara Garcia. I'm the Executive Director of Salud Para la Gente. Salud Para la Gente means help for the people. Talking about a family model, community health centers -- I can't emphasize enough as a model for mainstreaming the AIDS issue, especially in the Latino community.

Our agency provides primary care services, mental health services and social services. And when the

AIDS epidemic hit our community, we integrated that issue into our regular system. In fact, we had to be more sensitive to the issues of gay men. We had to be more sensitive to the issues of IV drug users through the staff through our policy boards.

But we can do it within those kind of models. The issue at this point is that our monies are being taken away from us. And I think that we need to be looking at increasing monies to community health centers. We are the safety net for communities, the county health system. We are the safety net for those hospitals.

We keep the people out of the emergency rooms. We keep the costs down for those hospitals. And we're probably one of the most cost effective health systems there is in the country.

But I'd like to talk to you today about the issue of one of the most fragile populations in the Latino community, and that is the undocumented population. And also how the HIV infection impacts that community.

But, in order to understand the community and the dilemmas of the undocumented population and Latinos in our country, we have to take in consideration the historical contribution that this population has made to the labor force in the United States.

The undocumented worker has fulfilled tremendous gaps in the labor force fluctuating in the times of war, recession and to the need of particular industries. This labor force has gone where no other labor force will go. The picking of strawberries, grapes, and closer to home, building a railroad to Chicago.

In exchange for this labor, workers were promised legal status, temporary status and many times forced and exported out of the country once their labor was not needed.

The guest labor program Busaro program, and the newly executed -- one of my favorite programs -- Immigration Reform Control Act -- IRCA -- have recognized the undocumented population, have federally legislated the undocumented population. And even in the 1990 census have counted the undocumented population.

To say the least, this population is legitimized. The IRCA program provided millions and millions of dollars to government entities. And I say to government entities -- not to the people, but to government entities. For medical, education and public assistance access, but failed terribly.

They failed because of the historical mistreatment of the Immigration and Naturalization

Service and the distrust of the community and the misinformation that the INS programs gave to that community. And basically, they told them, do not receive any type of care from anybody at any time.

Those today who remain undocumented still work because the labor force requires it. So the access to medical care and social services to this population are at risk. The fact that if they'd access any type of this service, they can be deported and separated from their families.

Testing sites and medical services that are supported by the government and given by the government are not trusted. And the fear of deportation is extremely high. Those who become ill with HIV infection have little access and many return to Mexico to their families where, as we know, the HIV service are even more scarce.

A good thing is, and one of the positive notes, are the fact that community based organizations who provide education, medical services, social services, support groups, are the most successful with this population. They have the trust of the community and they have been coming to our community agencies for years and years. And will continue to come.

But the need to continue a bi-national

perspective on this issue is very important. We have to be able to link the country of origin of the person and really follow that. In our community, Michocanas is a place where many people come from and then they go back when the season's over.

And it's been on my wish list to be able to follow that migrant -- people who go back and be able to send back the messages of information to them.

So we have to implement programs that are border programs. And we have to continue to support programs that follow those migrant trails. And we must continue to promote and support compassionate legislation that's not based on a needs test of legality, but on legitimate need.

Like I said before, community clinics are -- I think one of the best providers of these -- this type of care. And we do not distinguish whether people are undocumented or documented. Although we are now forced, because of the IRCA program, to ask for some type of identification if they are an amnesty client.

But the implementation of the IRCA legislation will be more prefaced on this population and they will be forced to go further underground and further away from our educational messages and our medical services. So it's imperative that we advocate for this population.

And -- and also protect these workers and their ability to access care.

Thank you.

MS. D. GARCIA: What we can do is we can go back then and give you our recommendations in a chunk. We can also accept your questions now and broaden and flush out what we were saying for you a little bit more. I mean, that is an option. Whichever you would prefer.

Can we address any questions that someone might have right now?

CHAIRMAN OSBORN: Sure. Are there questions? It looks to me as if -- as if you've been hitting -- Scott.

COMMISSIONER ALLEN: Ms. Garcia, I have a question about -- do you folks work with the Caribbean workers that come into Miami -- into Florida?

MS. D. GARCIA: Right. You're talking about the H-2 program. Yes. Uh huh.

COMMISSIONER ALLEN: One of the things that we heard in Florida recently was that the sugar companies were testing individuals and sending them back or being testing there before they come over or that kind of record keeping.

And it was unclear whether it was forced testing or how that works. And I'm wondering along the

migration route what type of relationship the industries have to the one being responsible for health care, which sounds like very little. But also being detrimental to the individuals as they pass through.

So, if you could --

MS. D. GARCIA: Sure. When you talk about forced testing, I think when you look at the economic system that these people are participating in, anything is forced.

Because they're trying to get a job and the sugar industry, and then also some of the northern industries that are -- that are fruits -- orchards, what they do is through the program, they say that they have offered these jobs at a wage that they think is reasonable, which, of course, no one in this country wants to take cause they're trying to force an increase in the wage. Then the growers or the companies can say, well, no one in this country took it.

We're going to invoke H-2 and we're going to bring somebody in. And we'll fly them in, clearly with the understanding that they can only stay here and work. And as soon as they're done, they're even flying them home from the northeast. So that anything that they put them through really is forced.

Even if they say this is at your own option.

What they say is if you want a job with us, you will do this. And folks want those jobs desperately, so they will.

But the other part of what doesn't get said is that many of those folks are infected in this country when they come to work. And many of those folks are being used to mule drugs by crew workers from Florida up the northeast coast.

And they get told, look, you're going to take these and you're not going to say anything. And this is part of the work that I want you to do if you want to keep your job cause I'm your crew leader and I can send you home in a second. And it's true. Those folks have absolutely no legal recourse. There is no way to complain. There is no way to come before any kind of grievance group. I mean, it is strictly at the whim of the grower and the person who acts as your sponsor that you get to stay.

Another example of that would be if you have an H-2 worker who comes into the sugar cane fields in Florida, and happens to machete his ankle, he gets sent home without medical services being provided to him other than absolutely necessary at that moment to perhaps stop bleeding.

And he's sent back without any kind of

workman's compensation for what has happened to him. He is now incapacitated and for the most part, will not be brought back by a grower next season because they're already weary of someone who's hurt themselves and they want to make sure that they don't bring them back into the country and give them an opportunity to start any trouble.

So then what you have is folks who will not declare an injury. So the companies are not behaving responsibly. And this activity is just one of those mechanisms that I believe is in place to keep people quiet. And to really force them into a position of not demanding what would be compassionately deserved to them for the work that they're doing.

COMMISSIONER ALLEN: Could you expand on the migration within the southwest? Do you find that same dynamic happening there or less abuse, more abuse -- or how is --

MS. D. GARCIA: Within the southwest, which is very different than the northeast, you have many more families. Certainly on the northeast, you have crews of single men while you do also have women working. A majority of those in the northeast or in the eastern stream are single men working in crews.

What's very common in the midwest is that that

stream begins in the lower Rio Grande Valley in south Texas. And they are families who migrate in cars and trucks as a unit north. And many of them go back to farms where they already have a relationship in the midwest.

It is not as abusive and certainly, those folks know that if you can make it out of Texas, you can get to Arkansas, where there's a little bit more money to help a migrant on his way to Colorado or Michigan. And Michigan, of course, has done so many great things that people are anxious to get to Michigan.

And one of the problems becomes that they don't have any money in Texas. There are no services. They can't get into a clinic who's not taking any new clients. So they pool what little money they have for gas to get to Michigan and they'll come way in advance of crops being ready for them.

And then that state is knuckling under and running out of money long before the season is over. And so we have this huge cycle of folks who are really trying to learn the system -- you know, and not being able to get anywhere with it because it's going to run out of dollars.

COMMISSIONER ALLEN: Thanks.

CHAIRMAN OSBORN: I'm sorry. Harlon. Excuse

me. I'm -- I'm --

COMMISSIONER DALTON: Scott says I have a statement or a question.

CHAIRMAN OSBORN: We've been talking about family. Harlon is part of our family and we know him well.

COMMISSIONER DALTON: This question is for the other -- Ms. Garcia. By the way, to preface the question --

CHAIRMAN OSBORN: The preamble.

COMMISSIONER DALTON: The preamble is I like your preamble that is putting the question of undocumented workers in the sort of broader context of undocumented workers throughout the history of this country. And that's really quite useful for people to hear.

My question had to do with the immigration so-called reform act -- the IRCA Act. You indicated that it provided money to governmental entities to provide health care to those who took advantage of amnesty. But that the money -- by and large, that program had not been successful because people were afraid to take advantage of it.

What has happened to that -- to those funds?

MS. B. GARCIA: Let me just say that the way

that the IRCA program was administered was the fact that it was given to mostly state -- it was given to the states. Then it was also given to county entities. And then a trickle down effect to the community based organizations.

And what happened was that -- for instance, four years after the program, we just barely got outreach money. So we were not in -- we were not given any type of money to be able to go out and do the outreach to bring people in.

There was a lot of misinformation, even to the legal aid societies and there was a lot of confusion through the process to when was somebody ineligible because they became a public charge? They finally, three years later into the program, distinguished it between money in hand -- say they were not eligible for AFDC, food stamps -- but they were eligible to go to a community clinic or to a county. And the counties and the community clinics would be reimbursed for providing services to them.

But there was a lot of fear in that population and a lot of misinformation given to that population that they were not to go to any type of government agency and ask for any type of assistance. So that a program now going -- is going to be sunsetting in '92 leaves many

people with no -- thinking that they have no ability to access any type of assistance.

The money was really a stop gap measure between the time they came into the program and the time they would become legalized. And I am afraid to say that it was severely mismanaged by the federal government.

MR. MARTINEZ: In the State of Washington, we had a -- a similar situation. The money was coming into the state to community colleges. Why the community colleges still -- but that was the system that they used for the distribution of funds and resources.

Today, the State of Washington doesn't have a plan. It doesn't have a plan for distributing those resources. So -- so it keeps them. And we have met with them; we have pushed them; we have coerced them. And they're saying that we're not sure that if we do this the Feds are going to come down on us. We're not sure that the kind of plan that needs to be -- you know, put out in the state so we continue to wait.

MS. B. GARCIA: Just one other point on that was that through the amnesty program, you're required to have an HIV test. And that was another issue for many people. Today, there are over 100 cases in Los Angeles that are still have -- people do not know whether they're going to be deported or continue to be able to stay in

the country due to the HIV positivity that came out of that test.

So you can imagine, word gets out like that and people are not going to be coming -- rushing into our clinics to get tested, thinking that we may be reporting them to the INS. And that continues to be so. Today, undocumented people feel the same way. That we have the ability to report them to the INS by coming in for an HIV test.

MS. D. GARCIA: And something else that was brought up was the need to maintain a bi-national perspective on all this. And it's been pleasing to see some of the efforts that are being made around health issues.

But what winds up happening -- and on one of the few occasions that I got to participate -- is as they look at bi-national labor issues, people are focusing on "machilas", as if somehow agriculture has disappeared from the face of the planet. And hasn't been the major source of economic growth to basic communities along the Mexico border.

And I -- and my fear is that as we talk about migration and folks that are migrating, we're really just looking at those folks who stay right along the border and go back and forth, and really don't take the time to

look at the folks who are going to migrate all the way across the country and now are crossing paths east and west.

What we've heard -- and this is strictly scuttle butt -- is that folks in Florida who've been convicted of possession or intent to distribute, are being advised that if they'll go to Wisconsin, out of the eastern stream and into the midwestern stream, that they'll get off their backs. They just want you to take that problem and shift it west one stream so that they don't have to deal with you.

This is the kind of work that's being done to try and reduce the problems that folks are having within specific streams. And so you're going to start having cross-migration in a way that we've not considered before.

And what's going to happen is folks from predominantly one stream crossing into another, that it's predominantly families on the road and barely able to keep connections going anyway and really struggling to survive, are going to be faced with a whole new set of problems. That their system, as precarious as it is, isn't prepared to take.

COMMISSIONER ALLEN: I have one more. This is a question. Ms. Garcia, you mentioned in Dallas --

MS. B. GARCIA: Garcia B or Garcia D?

COMMISSIONER ALLEN: Contestant Number one. You mentioned the -- the use of a system in Dallas when you testified?

MS. D. GARCIA: Right.

COMMISSIONER ALLEN: The use of a computer system that would follow the individual. That they could be hooked up in that kind of care and not falling through the gaps. Did you mention that this time?

MS. D. GARCIA: I tried to speak about it a little bit. I was trying to talk about a network of case management.

COMMISSIONER ALLEN: Okay. All right. And that's out of that computer -- I just wanted to put that in the record for this time because I think it's very important. And I appreciated what you had to say in Dallas and I thought about it a great deal and would like to see that implemented.

MS. D. GARCIA: Absolutely. If we just had a way to keep track of folks.

COMMISSIONER ALLEN: Right. That's all.

CHAIRMAN OSBORN: Now, you mentioned recommendations and you've made some, and I know we'll get to hear a little bit more from you in the final panel. Since time is pressed, if there are things that

you wanted to -- to make sure got said in this session, fine.

And otherwise, we'll try to get back to that as we -- as I think you will join us again Deliana in a few minutes after the next --

MS. D. GARCIA: I think that what would be important to take away specifically from this group then are the things that we've talked about in using the existent system of community based organizations, of migrant health centers, of community health centers, that they're already in place. That people already trust them. That it's a network that already works, if we could just extend it to provide case management as people move up and down the streams. And then we'll just talk broader of that.

But I just wanted to make sure that we focus on the fact that we don't need a -- you know, a family czar, and we don't need a new program. We just really need to maintain and enhance the existing program that people trust and that have inroads into the communities that we're trying to assist.

CHAIRMAN OSBORN: Thank you, very much. We really appreciate your rich testimony. And admire your work, I might add.

The panel-next panel will talk about policy

and leadership issues will join us. And after they're done, we'll have an opportunity, as I just inferred, for summary discussion with the leaders of each panel.

Dr. Helen Rodriguez-Trias, welcome again. And let me put the control of things in your hands. You're aware of our time constraints and our sense of regret for having such a constraint. And -- but I would ask you to have others introduce themselves. And proceed. Thank you.

V. POLICY and LEADERSHIP ISSUES

DR. HELEN RODRIGUEZ-TRIAS

DR. RODRIGUEZ-TRIAS: Okay. We'll do our best to be brief in the presentations because we really think that what enriches this is the exchange with you, Commissioners, but perhaps also we talked about not having the last session of the recap, but allowing that to be open to the audience.

And so, we'll try to make the best of time.

Briefly introducing myself, I'm a pediatrician. I am currently engaged as an independent consultant in health planning. My previous experience has been in primary care, the direction and the creation of programs in inner city areas for children. And, of course, that took us right into HIV when HIV came into being in those communities.

So that -- and my most recent full-time job was with the AIDS Institute as Medical Director in New York State. I think that experience took me into the field of policy and made me realize -- you know, that all those years, I had been a clinician in directing programs and doing all these things. I was being an agent of many policies, some of which were explicit, others which were implicit. Some of which were very understandable and some of which were extremely obscure.

So I am committed to the notion that we should de-mystify policies and we should de-mystify policymaking so that it can be more of a participatory process than it currently is today. Because I think that relevant policies directed to our communities can only happen in the context of the reality of those communities and your having the input from the communities.

Having said that, I would like to very quickly introduce my panelists here. And to say that it's been a pleasure working with them and to thank the Commission for facilitating this kind of exchange we've engaged in.

First of all, by Miguel Gomez enabling a very long telephone -- teleconference we had prior to coming here and our meeting last night, and our meeting again this morning. It's been very rich and I just want to thank you now.

The first speaker is to my right. And that is John Zamora, who is -- I'll let you introduce yourselves. I think that will make it briefer.

So, John, go to it. And each one in turn.

JOHN ZAMORA

MR. ZAMORA: Okay. My name is John Zamora, and I'm the Minority Education Specialist for the State of Texas. And out of respect to you as a group and individuals, I will move quickly because I admire timeliness and move directly to the point, if this is okay with our -- okay.

My comments come from my experience as a project author in Texas. And what I want to first share with you are what I feel are some successes in Texas in engaging the community and responding.

In '90 -- in fiscal '90, we went from 21 contractors in '90, to 28 contractors in fiscal '91. And I view this as a direct demonstration of our ability to engage the community in responding to the issue and in providing programming by Hispanics, directed to Hispanics and directed to gay and lesbian Hispanics.

Other successes that we have are supporter/mentor programs in the state, so that there's a sense of continuity. I view myself as a good example of leadership development in Texas as an HIV positive

individual involved in leadership roles.

Some needs of the Hispanic community are training and development of Hispanics, with an eye toward layering or staggering within the CBO's for a sense of continuity of presence. We invest a lot of money. There needs to be a sense of continuity. What's going to happen if some of the money is pulled out?

We need to designate monies for technical assistance. It's okay to make policies, but if we don't provide the funds for these agencies to be able to do networking, to do skills development or empowerment, to take a more active role, then we will have lost something there.

The issue of inclusion -- the need for a sense of ownership on the part of the community. A full partnership. Hispanics need to be fully involved, not just tokens. Hispanics must be involved in greater ways in planning, collection of data, analysis and implementation. So that this reinforces our recognition of leadership within the community.

This is also to include gay and lesbian portions of the Hispanic population. The policy coming out of this? Leadership development goals should be included in all policies affecting Hispanic communities.

Fully developed leadership will allow CBO's to

more directly and fully address issues such as bisexuality and sexually explicit materials. There is a real need to integrate bisexuality into present prevention messages and health education activities.

Our message is not fully effective at this time. Lack of strong leadership has prevented CBO's from discussing bisexuality and, in some instances, sexuality as a whole. Unable to overcome the stigma and unable to educate women who are at risk due to their male partners.

The policy implication for this related to bisexuality is anti-discriminatory legislation and education at all levels of community and government. The need to help communities and individuals come to terms with their own cultural homo-phobic beliefs.

The need to earmark resources -- allocations specifically towards persons engaging in behaviors which put them at risk. The need to help communities avoid labeling and judgment.

And, again, I apologize for reading to you, but with an eye for speed, I do it to insure inclusion.

On the role of private foundations -- entities such as Robert Wood Johnson and Ford have helped in enabling projects which maximize community development and participation. As they begin to withdraw their support, what or who will follow to fill the void?

This is a valid concern that needs to be addressed.

Policy recommendation is that public health entities and governmental entities must expand roles to support community development. There needs to be an emphasis placed on more flexible and relevant ways of engaging communities. Ways of engaging communities in program developments and implementation.

Something else I see as related to the support of leadership is recognition of main Hispanic populations. As pointed out earlier, the term Hispanic is not a monolith. There is -- it is made up of components. And I see a need for the recognition of these main Hispanic populations to monitor funding activities, cultural issues and dissemination of information.

Issues have been brought up about language. What one word means to one group may not mean the same to another. The need to insure the policy is developed -- that policies developed reflects the recognition of major Hispanic populations to insure successful intervention, materials, policies and practices. As has been cited, the Spanish version of the American response to AIDS is a good example.

And I think that's my five minutes.

DR. RODRIGUEZ-TRIAS: Thank you, very much for

keeping to your -- to your time. We really will open up. We have many issues that we want to bring forth which will come.

MIGUEL GOMEZ

MR. GOMEZ: My name is Miguel Gomez and I work in Washington at the National Council of La Raza. And I know many of you, which I think is -- gives me an advantage because I know that you are good folks and work very hard. And I laud you for still being awake right now. It's been a hard, long day already for you.

But what I do primarily is I work with Hispanic community based groups throughout the country, over 100 of them. But, in reality, I only work closely with 20 of those organizations helping them augment their programs.

And by virtue of being in Washington, I advise a lot of the public health agencies about how to reach and educate the Hispanic community. And one of the things that I think is real, real important by virtue of my experience is that the Commission, regardless of the fact that you're here til 12 or 1, or you're here til 5, is that you have a gift.

You have learned about the Hispanic community. Not only here in Chicago yesterday, but weeks ago in Miami, weeks ago in Puerto Rico, New Jersey, etc. You started off in California learning about the Hispanic

community.

And of the things that's real important to me seeing the groups is they value what you have learned. And my first recommendation, is that you take the information that you have learned in your observations about our communities back to our communities. Not just to the -- not just to member of Congress and the administration who you have an obligation to report to.

And that is the first recommendation.

And have recognized your commitment to the Hispanic community. I know Commissioner Kessler has made sure in Boston that community research and institutes targeting the Hispanic community have worked. Commissioner Osborn, years ago, made sure that dollars were coming to the Hispanic communities through federal legislation.

But when you think about the Hispanic community, think about what we talked about today. And it's important to me -- for you to think about the Hispanic community, not just what you saw in those various pockets. But who is able to serve and reach that community.

The ones have been told to you before have been around for thirty plus years. But they've been responding to the epidemic for about three years. And

this is leading to recommendation number two.

These entities who are part of programs -- part of a larger group, are just beginning to respond. Year three -- they've already had staff turnover. But they've also had to learn some important things. And that is that they have to diversify their funding base. And they have to learn about the epidemic.

They have to learn about the sexual health behaviors of our community. They have to learn about men who are having sex with other men. The fact that there is women to women sex. And there's no place to record that. They have to learn about the issues of incest. And for them, we don't have a hard to reach population -- real important.

We know how to reach that community because we have their trust and we're in their community. And these programs, which leads me to recommendation number two, need to be supported in the future, which means more dollars. When you hear from folks in Washington saying more dollars, direct it to those who can reach and educate a target community.

It has -- for our community -- augmented, meaning Hispanic focused or Hispanic run community based organizations. If they have the ability and trust in the community. In our community, we don't have traditional

colleges and universities. We don't have a number of elected and appointed officials.

And the one thing that's really good to see around the country is our groups are starting to become involved in the policy and leadership positions. In Title 1 of Ryan White, it was real exciting in seeing in most of the 16 cities seeing our groups at the table. However, there are demands for continued funding.

The fact that they don't have time and money to be able to do policy work, networking -- means that when funds go to these community based groups, funds have to allow time for networking and technical assistance to run these programs.

I just had three groups that ran -- called me within the last two weeks to tell me that they were going to go out of business -- their programs. And I said, well, maybe it's not a good idea. And the reason why is that they didn't know how to diversify their funding base; they didn't know how to evaluate; they didn't know how to work with their funder.

And these were groups that were working in a midwest group that was in schools during -- during a week -- over 50 times a week in the schools.

America, who was quite boisterous this morning, is a model program for us. She told you that she had to

lay off one of her few outreach workers. And she's a model for the Hispanic community because she also -- her group understands the link between learning about the link between substance abuse and HIV.

But, going back to Ryan White, we've been able to be in the Title 1 planning councils. But we haven't had the time. So we're building -- when giving dollars to those groups, building the time necessary to network is real important.

In addition, is that when Title 2 and Title 3 move forward, making sure that not just the Hispanic community, but all communities know what is happening with that. And I know that through your talks and through your positions that as we move through implementing Ryan White can make sure that the information distribution is happening so there is full involvement.

And lastly, just for you to pose the question. We talked all day about the strength of our community and the ability to reach. But in the future funding, it's going to be categorical block grants. Where is the Hispanic community going to fit in there? Lots of questions. Good luck.

Thank you.

MIGUELINA MALDINADO

MS. MALDONADO: My name is Miguelina Maldonado. I'm the Executive Director of the Hispanic AIDS Forum in New York City. Our organization was established din 1985 and was the first Latino based community organization solely addressing the impact of AIDS in the Latino community.

What I'd like to do is to address some issues specifically related to -- to Latinos and AIDS. Some of these issues are specific to all women, yet I'd like to highlight how the issues are of importance to Latino women because of what you've heard this morning and this afternoon regarding the socio-economic, the health status of Latino women.

And also the lack of access to care. I think that a lot of the issues become more pronounced within Latino women because of this.

First, in relation to prevention education, you -- you had a panel very well identify what needs to be done. I think added to that, we need to begin to integrate into prevention education efforts when we're focusing on women. Also focusing on the fact that when we're talking about hetero-sexually transmitted AIDS that -- that women do not necessarily have power to control sexual relationships. And that the programs have to also focus on empowerment issues that -- and behavioral change

issues that will take time over the long course of time.

So that funding for prevention education cannot be seen as short term. Because we're talking about changing behaviors. And we're also talking about changing attitudes and conditions that place women in less than equal position to men that will take a long period of time to change.

So that we have to have more intensive, long term prevention education dollars. It can't be dollars that are allocated for one or two years and then the programs are cut. And the dollars are located elsewhere. And I think that's very key.

In addition to that, the programs have to focus on the range of sexuality. As John related, we have to look at women who are lesbians. And I think that there has been an absence of focus on lesbians because of the entrenched homophobia in our community. But also because there's been a lack of recognition that lesbians are -- can be at risk of HIV infection. In fact, many lesbians are HIV infected.

And they are categorized in different groups because there's a lack of attention to lesbians period. Lesbians are also mothers. They have children and they're part of families. So I think that it's important to -- to focus on including the range of sexuality,

particularly for women.

The other issue is bi-sexuality within our community. And the issues related to the hidden bi-sexuality within our community and the need to target that more effectively and to raise consciousness more effectively regarding bi-sexuality within our community. Because many, many women are becoming infected. Not because they are IV drug users themselves, but because they have sexual partners who are not IV drug users either, but are bi-sexual. And they don't even know that. And I think that that's a key.

And the -- the -- there's an underreporting in that category. And I think we need to look at that more effectively for all women, but also in the case of Latinos where we know that bi-sexuality exists. We don't talk about it, but it exists within our community.

One of the other issues that I think is important in terms of access to care, and it's been said time and time again, is that Latinos as a group have less access to primary care than other women period. We can look at the little, no or late prenatal care. The high instance of low birth weight babies, the high incidence of infant mortality and also maternal mortality that point to a lack of care prior to giving birth.

And, in many instances, the focus has been on

getting mothers who become pregnant into care. I think we need to focus also on getting women period into primary care. And the health of women in and of herself as a woman needs to be focused on more.

And, as you've heard -- you know, the role of a family is very important in our culture. And I think that we also have to see that the role of the woman is very important in our culture and is a centerpiece to the family. And if the woman is not healthy, and we know that women -- the primary care givers for people who are HIV infected in families where there's more than one person infected. And very often, the woman who is HIV infected herself is the one that's caring for the others as well.

So that we need to focus on the woman's health as well as the health of the family as a whole. And access to care is key. It has -- care has to be provided within the context of community based clinics in places that are accessible to women. And there has to be a revisiting of public health models that have worked in the past where people visit homes. All right -- to teach people how to take care of themselves and where there's a real ongoing connection with people in the homes and in the communities, rather than having people always go to very far large medical centers for treatment.

And I think that we have to take a look at how health care is organized and also how the organization of health care is a barrier to access. And look towards what Emillio Carrillo amd Nilsa Guiterrez talked about in terms of community based primary care and community based, neighborhood based care for people, rather than hospital based care.

Clinical trials and the access to clinical trials is a critical issue for women period. For Latinos, it's more critical. The Latino community as a whole has had very little participation in clinical trials and has been excluded from clinical trials for a variety of exclusion criteria of the actual trials.

In addition to that, the location of clinical trials in large university and medical centers, I think, also places a large barrier on access to trials. And one of the recommendations that I would make is that there be more -- an expansion of the movement to clinical trials in communities. That Latino physicians who are providing primary care be recruited and trained to become involved in clinical trials.

And that clinical trials be attached to care, treatment and services for people. People who have lack of access to services are not likely to engage in a clinical trial where the likely benefit of the trial for

them is far fetched. So that there has to be outreach that's aggressive.

There also has to be a movement of trials into the communities using community physicians. And there has to be a connection of trials to comprehensive treatment in order for them to be more accessible to our people, and particularly our women.

Another issue that I think is very important in terms of women is the issue of reproductive choice. And a lot of programs and a lot of studies that have been done regarding reproductive choice have indicated that women who are HIV infected may very -- and are pregnant -- may very often choose to carry pregnancy to term and have the child.

And one of the issues that I think is of concern is the trend among health care professionals to view that in a negative way and not to accept the woman's right to reproductive choice.

I think that coercive types of -- and covert types of counseling programs where the bias of the provider is clearly towards termination of pregnancy has to be looked at. That there has to be a way of monitoring for that so that women have actual right to reproductive choice.

And women -- Latino women are concentrated in

the reproductive ages. They have high fertility rates and they will continue to have high fertility rates. And the cultural emphasis on children and on family is very strong. And I think that there is at times this continuity between those cultural elements and the public health goes.

And that needs to be looked at from a positive point of view. And the insurance of actual reproductive choice has to be integrated into programs. And that may take some retraining of physicians and health care providers, as well as really providing women with the tools to be able to make the choices themselves and not to be coerced within a system where they feel that the push is towards one choice, as opposed to another.

Finally, I'd just like to highlight that of particular concern is the possibility of criminalizing HIV transmission and as it relates to women in terms of prenatal transmission. In some states, for example, we've seen that where there has been a focus on criminalizing mothers who use drugs. And we may see extending of the same trends.

And I think it's incumbent on this Commission to really guard against that. Women will not go forward to be tested. Women will not go forward to get primary health care if they feel that they're going to be

identified if they're HIV positive as possibly transmitting HIV to their children -- their unborn children, and then lose their children.

So I think that that's a real important issue. From a policy perspective, that has to be looked at carefully. And there's already precedent for some of the criminalization in some states. And as a national commission, I think that there has to be a strong position against that.

I'll stop there.

DR. ALBERTO MATA

DR. MATA: I'll keep mine even briefer. And I'd like to address two particular issues. The meaning of HIV, particularly as it impacts on the Hispanic community, will rest on us getting rid of a notion that there is a single source or a silver bullet that's going to take care of this problem.

I have yet to see a community or a group or a state or a commission that doesn't take on that singlemindedness and -- somehow, we need to think in terms of a long term campaign.

Drug addiction is a life long problem that is at once chronic and acute as we start to look at the impact that crack cocaine is having in our community.

Second, HIV parallels that very much. The

second thing that I think is very, very important that we need to do is that the world is getting much, much more complex. And every time I hear of instant solutions, silver colored condoms, a particular case management system, empowerment. If I hear cliches like that anymore -- it takes away from some meaningful approaches that people who have really struggled with this issue.

I remember Don De Jarlais back in 1986 talking about going out to talk to addicts and pass out these little damn cards. And I looked at him and I said, you must be crazy.

Eunice Garcia raising this issue with National Council De La Raza before 1,500 other folks.

A friend of mine named George Beshner who put together programs that are now in 64 cities across the United States that have moved the AIDS agenda, not as an AIDS problem stigmatized folks, but as a public health model and concern.

The last issue that I think that is very important is that you as a national commission play a very, very important role. Many of the issues that are here would not be taken on anywhere else, regardless of how well some of our governors are, some of our mayors are, some of our public health officials.

We need a national forum. And a national forum

means a national partnership. A national partnership with a private and public arena. If you look today, we're going -- we're seeing the foundations move away from this issue. We're seeing the United Way being overtaxed with a lot of the systems. A lot of the demands that are being placed on them.

And so the role that you could play for us is very, very important. One is give voice and keep the dialogue going because I don't think that there will be any special solutions that will come out of this meeting or the other ones. But a series of trained, reasoned, balanced judgments that our communities can, in the long run, benefit from.

We need to have some balanced discussions. Each time, I don't care whether it's the issue of needle exchange or condoms in the school or go turn the Catholic church on its head -- those are not solutions. We need balanced discussions in our communities because what works in one community will not work in the other community.

And irregardless of you -- of us finding a particular model, these folks have to take it on as their own. And they will take it on their own when particular leaders in the community adopt it. And they allow for some type of discussion in these communities.

They will come up with answers that many of us will not agree upon. That's tough -- you know, we're going to have to live with these communities as they struggle to get an identity and to fend for themselves.

So the last thing that I'd like to recommend is at some point, this dialogue continue with the black, Hispanic, gay community, with our professional community -- that somehow assesses what we have done in the past. There are some hellacious plans that -- I was just discussing with Don -- I doubt that we've had time to really think about a number of these issues.

We've had a full meeting. We've seen the foundations have meetings. We've had Latino this and that. But to really take ourselves back and look at what some of those solutions that we recommended. And some of the recommendations, we'd probably go, I didn't say that. And another one, Jesus Christ, I said that. When am I going to do it?

And so, there has got to be a place for us where we build on past the current and begin to address the future problems that are going to be facing our communities. And they're not just going to come from federal legislation and programs. They're not just going to come from mandates.

They're going to come from looking at that

private sector arena. They're going to be looking from how do we somehow figure out a way to bring back those foundations? How do we wind up finding the United Way to make meaningful incursions in communities where they have not?

There have been places where they have. How do those solutions get diffused and disseminated to those Hispanic communities, those black communities, those poor white communities? All you have to do is go to West Virginia where they're just -- they're needed there just as anywhere else.

So what I had wanted to recommend is if you can find models of cooperation and collaboration on research and service and policy making, then please highlight those and share them back with the community.

I think the dialogue, particularly in a democratic society, are very important. Many of the problems that are going to come are going to be very, very difficult down the road for people are going to be making choices between different health policy and different health concerns.

And those aren't numbers. Those are going to be individuals. Those are going to be people who have particular health conditions. And we're going to have to make choices.

The second thing is federalism. I've been -- in my real life, I am a field worker. I'm not a bureaucrat. Okay? And I've had to learn the ABC's and you almost need a Ph.D. to figure that out.

But the new federalism -- that's what we have. We have a state, we have a federal and we have a private arena. And if you're going to be effective in that arena, you're going to have to learn that we need to figure out a way to get those models out and those informations and those internships.

20 years ago, at the University of Michigan, I discovered 75 Latinos who happened to be Hispanic, Puerto Ricans and Cubans. They were here in northwestern; they were here in Chicago. If I go back to those same schools, those folks are not there.

They cannot be providing the services to our folks if they're not there. A recent chronicle for higher education report came out. 80% of the Hispanic women who started Ph.D. programs did not complete those programs. Okay?

There -- it's something -- I can't recommend to Mr. Allen or to Mr. Mason, folks whom I don't have yet. Now, I can tell you that I still have a list of folks that I will always recommend. But we need to somehow get into a partnership that allows us to create the next

generation of MPH's, M.D.'s, nutritionists.

By the way, I have lost 32 pounds and I have gotten into a program of weight management and behavior control. And it is not unlike many of the other programs. There is no simple solution to this thing. It's going to be a lifelong condition.

And somehow, we need to get messages about how successful behavior change occurs. Brown ones, black ones and white ones that's put in people terms. And that's going to come when we train community based intervention. That's going to come when we train commission corps officers. That's going to come when these people go back to Aetna Insurance and become the voices and the links to these.

The last, we need to still come up with innovative ideas. Five or six years ago, we flew up all kinds of trial balloons and everybody now takes them as their own. But we need some new trial balloons. And they may mean -- for Hispanics, you've heard today a large -- about the lack of insurance, but there's a large number of them who are in the work force, in sheltered employment. And we need to get the AIDS and drug abuse messages through EAP programs to them.

And it cannot just be the federal government doing it. It's got to be the state; it's got to be the

private partnership. And so to return, your role for us is to continue to voice some of those concerns. And I really do applaud the Commission in terms of the reports that you have put out. Please continue to do that.

In terms of balance, the issues have got to be put on the table and the American public has to discuss them. I don't care whether it's health education, sexuality, drug abuse treatment, treatment on demand. Those are issues that the American public needs to discuss at some point and you folks may be one of those forums.

And the last -- at some point, for yourselves, if you have time -- which most of us don't -- a retreat that gives us a plan that says what we have done in the past. What we are doing currently. And allows us to address some of these future issues in a way that gives us options.

And the options aren't just for congressional folks. There are communities -- there are people in these communities that need to know that we are working and things are being successfully done in their communities.

So if you find these diamonds in the rough through your hearings, please, get them back to people.

Thank you, very much.

DR. RODRIGUEZ-TRIAS: Thank you, very much. I would just to highlight maybe just two issues that are sort of near and dear to me.

One is -- was raised by Miguel is getting the information that you gather back to where you gathered it -- the community. I have, in working on the draft report for the Commission on the hearings in Puerto Rico, I have come across a tremendous -- a tremendous richness of hope that people have that they were heard.

And I think what you can do for people is to insure that you are saying to them, not only were you heard, others can hear you and you can use your participation in a way that serves as a tool in your struggle against this epidemic.

I really feel very strongly about that as a commitment for the Commission.

In that area, too, of sort of feedback, I think in research policy, many of you are researchers and many of you are attached to schools of public health. And many of you are on review committees and have the opportunity to guide research.

That, again, there's a common feeling out there in communities that they are somehow being robbed when research is being done because the results of this don't necessarily come back to them in ways that they can use

in pushing for programs and specific -- you know, for their own use as they may set priorities.

So that I think this is also a very important part of commitment.

And my last point is in relation to leadership development. And I note that -- you know, the panel has had much more to say about that. But that I really because I guess my experience in New York State taught me the following. That although it was AIDS that made it happen, the fact that it happened was impacting on other things. And that was this participatory process that I mentioned before.

For example, great concern about the high sero prevalence in the blind study in the hospitals -- you know, in New York State. How to get that information back.

A committee was created to look at policy and it was just fascinating for me because as an educator, I'm committed to the notion that people do grow and learn. That to see epidemiologist who had not been out of their labs for a long time really become interested in going into the delivery services at Harlem, at King's County to say, well, how do we get this information back to people in a way that's going to result in counseling in that setting?

And maybe coming back to the committee meetings and saying, hey, it was impossible. There's nobody who can talk to anybody there because that's in and out with the number of deliveries they have. And maybe that's not the appropriate setting in which to place this counseling.

Hey -- touch or feel -- a touch of reality. A touch of learning how to make policies that really are going to work and are going to implement programs that really are going to work because they have talked to the people in the field.

So that kind of input -- it's happened as a result of AIDS, I'd say. But it has had an impact on the way people think, in the way they participate at the state decision making level in New York and in other programs.

So I will put before you -- you know, can the Commission become very committed to this kind of approach?

MS. MALDONADO: I'd just like to raise one other issue and I think you've heard it before. When the other panelists talked about migration and other panelists talked about the average between Puerto Rico, the northeast to midwest. I think that we need to really take a look at the federal policies regarding Puerto

Rico. Particularly in terms of limitations and Medicaid funding.

And that if we're really truly addressing the needs of Hispanics, we also have to consider that beyond the fact that Puerto Ricans who are Puerto Ricans in Puerto Rico come to the northeast and to other areas. And they have an impact. And they come for care and services. That they're also citizens of the United States and then in the same way that they can go to war, that we need greater access to care and treatment on our own island.

And that this Commission really has to put that forward in a very strong way to the federal government.

CHAIRMAN OSBORN: We are so badly out of time that I'm a little nonplussed. But I want to make sure that we have at least a little bit of chance to interchange with this very important group of witnesses.

Harlon, I know you had a quick one and Don Goldman.

COMMISSIONER DALTON: Well, this time I won't pretend to ask a question. I just wanted to -- to reflect back again a little bit of what at least I have heard. Because I was struck by the connections between what this policy panel has had to say and what the earlier panels have had to say and it's no surprise.

Miguel, I was glad that you just put exclusively on the table who is able to reach and serve Latino communities the best. Because I think that was really the hidden message of the first panel on prevention.

I mean, they never quite closed the loop and said -- you know, rather than trying to train Harlon Dalton or Irwin Pernick to be culturally appropriate, let alone culturally competent, there are people out there who've got these skills. And those are the folks who ought to be doing the job.

And it's often hard for people to say that because it sounds self-serving. It sounds like give me some more money. And Lord knows, we've heard more people say, give me more money. And sometimes, the person asking that is the executive director who either appears to be out of touch with his or her own community or is just simply showing this group that they know how to use the right fork.

And so we see the anglo side or their white side. And, in fact, they are perfectly culturally literate in their own communities. But there's this funny kind of sense of disjunction.

So I'm glad explicitly that that message was there. That there are people already who can knock on

the door and somebody will say, come in. And that's the test of who can provide prevention and education services.

Secondly, there was a strong message from this panel and earlier in the day about the need to be engaged in a long term campaign. Not simply in terms of treatment and care where it's fairly obvious. But in terms of prevention as well.

As America Bracho said earlier, I mean, part of the point of treatment is to engage in an ongoing process of helping communities change in ways that foster behavior change and helping individuals and families find out what, for them, will result in sustained behavior change.

Miguelina and this panel pointed out specifically with respect to women, that part of what we're talking about with respect to prevention is helping to empower -- sorry about that word -- women to take a measure of control -- exercise a measure of control over their own sort of bodies and sexual lives. And that, in fact, is part of an ongoing interactive effort.

And what we've heard from people is a sense of frustration that prevention dollars may be fleeting. People feel, well, we've done that. And, in fact, it's not a one shot or two shot deal, especially for

communities that have gotten into the game three years ago, as is often the case with Latinos and blacks.

And finally, from this panel, from a couple of people and from some earlier people, we've heard about the need to kind of focus on a range of sexualities, to use Miguelina's phrase. And sort of between the lines, we've got a sense of some of the complexities of doing that.

The categories sometimes get in the way. Several folks have said, for example, gay man -- that phrase doesn't really capture the way people self-identify. And we've certainly heard that before.

But also when Miguelina talked about lesbians and the need to sort of focus on transmission among lesbians. And we don't often hear the "L" word; you're right. It's for some complicated reasons. In part, because early on in this epidemic, the organized lesbian community felt quite appropriately that since as a group, they were among the group least at risk, to somehow be assumed to be at risk because they had the same sex orientation was doing them a disservice.

But with respect to lesbians, you have to ask the question not whether there is a label, but what do people do? That is -- a woman who has sex with women can also have sex with men and be at risk by virtue of that.

Or by virtue of drug use.

But she's also in the position of transmitting the virus to other women. So, again, the focus has to be on what do people actually do?

And, now just tying it back to the first point. Who can sort of ask these questions? Who can talk about sexual behavior? We've heard several people say the idea of the Latinos can't talk about sex or don't is a myth. But the question is how and where and under what circumstances do you talk about sex? And that gets us back to who can best do the job -- Miguel's point. I mean, who knows how to sort of talk about sex -- not only sex but the varieties of sex.

And we really do need to go to those folks who have been for 20, 30 years working in their communities -- not on AIDS -- have now added AIDS to their set of concerns.

In some ways, we're still learning the epidemic and we have to recognize that. And sometimes we'll come up with solutions we don't -- whoever we are -- don't recognize or maybe don't like. That's just part of the game.

Anyway, I just wanted to sort of feed back what -- at least I hear to be a somewhat consistent message across the panel.

CHAIRMAN OSBORN: Don, quickly. We are really very far behind. And we have some other things we need to do before we break.

COMMISSIONER GOLDMAN: I have two quick questions. One of them is that I was just curious. Dr. Gutierrez, in her earlier panel, suggested that categorical funding does not work for the Latino community.

And, yet, I think Miguel indicated that the reality is that's where funding is. And I'm wondering whether or not the suggestion is a categorical funding is not appropriately used in the Latino community and how you deal with the issue if categorical funding is where things are and categorical funding doesn't work for the Latino community, what do you do about it?

The second question I have is to -- why don't I just leave that one question and I'll deal with the other question on a more private basis later on.

MR. GOMEZ: Two points. One, I think Nilsa can also, if you are still here, respond. But what's real important is that when we're talking about funding, the recommendation put forward was direct funding as what is the AIDS community in Washington doing?

Two groups who can reach and educate a target population. And what is real important is that with

these funds, we are scared that in future funds, are not going to be -- there won't be the future of direct funded programs. We have seen them work throughout several of the CDC and the public health service programs.

What my call is for is a continuation of those type of programs. I'm not sure if I'm answering your question. But I think the point that has to be taken a step further is that any continued funding of programs, as Harlon pointed out, is that the groups can reach and educate, as I pointed.

But my concern is their continued survival. And not downsizing -- survival. And so they just don't need funding. They need technical assistance to be able to network, to do policy work and to work with others in their community and to build their programs.

DR. MATA: Let me give you a sharper answer, too, in terms of in some states, the monies will come down the HIV testeing and counseling and in some lines, they'll come down to drug abuse. And in some lines, they'll come down the HERSA track.

And the problem with that is that we have well meaning programs, but in some communities, until a Fed shows up or a commission shows up, these folks have not talked to each other. And in other areas, they have begun to put it together.

And even where they have begun to put it together -- an example is Miami. Miami, we have a case management program with the South Florida AIDS network and the with the drug abuse community. One AIDS case management case to walk through the system takes three weeks.

And then, that person's HIV status and health status is going to change. Entering that data, following that person, becomes a responsibility and can overwhelm systems that have just begun to talk to each other. So the categorical grant not that they're working in some areas and not working in others. And that's what has to be discussed.

That's when we say partnership and collaboration is very, very important. And when we piece these things together, the cliches make things sound right, but when you look to see what's operating and how to make them operate, that's another.

And that's why I keep saying we need to highlight those examples where they are working because we need some more success and a can do attitude in this area.

MR. GOMEZ: And I think another important example is what's happening with the Ryan White Care Act and participation and is the money going to reach the

populations that the legislation targeted?

DR. RODRIGUEZ-TRIAS: Yeah. I think another issue and I don't know how to tackle it at the federal level, but it which certainly does not fit into the HIV model because, you know, the woman may cease to be a mother, or simply the child may be out of the program and die, and then the mother gets disqualified in terms of the services. And I think we have to make a commitment to broadening those categories that are addressed to women and children, and not necessarily to women just when they're mothers. I mean, there are programs like that, that sort of boot people out when the child dies.

CHAIRMAN OSBORN: Well, let me express the thanks of the Commission for your -- your input. We value it very much and feel a little frustrated when you talk about taking the message back, because we shout as loud as we know how all the time as Commissioners, and as a Commission. And it's hard.

We need your help in making sure that it gets back. We will continue to make reports and so forth. But I hope you recognize that we have a level of frustration too, because some of us have been shouting as loud as we know how for a long time about -- including some of these issues, and will continue to try. Thank you.

throughout the country, and when we talk about getting the message back, it's because you have established trust in our community. And that is a real important idea to recognize and grasp.

CHAIRMAN OSBORN: Thank you. That's a very kind comment, as well, and we appreciate that.

I knew informally that the final panel -- thank you very much to this panel, and I knew informally that the final panel had agreed to defer formal recommendation type comments, and so the staff has solicited the interest of people in speaking briefly.

I have five such people, three being the Amaro sisters, and I wondered if they'd like to come forward to talk to us, or however they'd like to proceed. These will be very brief inputs.

Then Dr. George Rivera.

CHAIRMAN OSBORN: -- Rivera, thank you. And Mindy Rice. So if I could have the Amaro sisters, Marta, Paula, and Brunilda. We appreicate you being with us, and I hope you understand how short the time has become, but we're very happy that you could spend a brief time with us.

PAULA, MARTA, and BRUNILDA AMARO

MS. PAULA AMARO: As you know, I am Paula. These are my two sisters, Marta and Brunilda.

Dr. Gutierrez, I think you had a comment you wanted to make. Perhaps you looked as though you wanted to comment and --

DR. GUTIERREZ: Oh, no. What do you --

CHAIRMAN OSBORN: Well, I'm getting a series of signals here which converge on the fact that you'd like a couple of minutes at the microphone. Why don't you say what you wanted to.

DR. GUTIERREZ: Simply that the panel discussion on the policy summaries. We're going to forego on that and open leave that time to the floor if there are any questions or comments, and then we can put it in writing for you. Mr. Pernick suggested that we use -- that we have some things ready for you no later than the first -- the week after Easter. A week, I believe.

CHAIRMAN OSBORN: Well, we will welcome your input when you get it to us. Thank you.

DR. GUTIERREZ: Okay. But in about three weeks or so we can get that to you. And I think that that would be better.

CHAIRMAN OSBORN: Good. That's very helpful. Thank you.

MR. GOMEZ: I know, June, you're trying to finish, but one thing I think is a real important message I want you to leave with. As you have traveled

CHAIRMAN OSBORN: Welcome. Thank you for coming.

MS. MARTA AMARO: We're open to questions.

CHAIRMAN OSBORN: Well, you heard some -- I don't know whether you heard the questions that Paula was asked. Perhaps you'd like to add. I think one of the better questions to focus things in such a short time is what -- we recognize that you've got serious problems with very general -- in a very general and important way. But are there specific things that would help a great deal in your present situations that you could tell us about in just a minute or so? Particularly in terms of health care, where our focus tends to be, and recognizing that the housing and employment circumstances are very difficult now.

COMMISSIONER DIAZ: I think another thing I would like to know, which you covered somewhat before in the video, is how you feel that education might have reached you at a very important point in your life, in terms of preventing HIV infection.

MS. PAULA AMARO: Well, I think that for me, it was quite an experience, because that showed the community how to accept when someone in your family is HIV or somebody has AIDS, because it would be educating people how to accept them, how to treat them and that,

because there are still a lot of people out there that when their family finds out, they don't want nothing to do with them anymore. "No, you're not my son, you're not my daughter."

See, and that movie, like each time I look at it, because we got a film for ourselves, and it would be showing us how to be more open with people. And I say that some other people, they learn from that movie not to reject the person who is infected, or whatever, because that's when they more need their families.

And that would help them out, because while they stand by them and help them out. They say, "Oh, so they don't reject me like I thought they were going to reject me," you know.

MS. MARTA AMARO: I think it was an experience for me, too, to let everybody know that like me and my sisters all are infected, you know. And it's -- we've become closer, always there for each other, my mom's always there for us, my dad, and they've been giving us a lot of support.

And, you know, it's an experience to show the other people how we're living, how we accepted it, and what we're doing with it. It could help other people with the same thing, their mothers, their fathers, help the children, you know, the kids that are infected, not

to reject them, you know. So I think just showing us three, the way we live and helping each other would help a community, too.

MS. BRUNILDA AMARO: Yes. Because I feel that it's bad enough that you have the -- this disease without having to be rejected by peers on top. I mean, you know, you feel like -- I just found out about seven months ago.

And I was very grateful for my sisters. They're there for me, and my parents.

And I think that the public should be more educated on how to deal with this, because it makes me think of in the times of Christ, the lepers, you know. You were just outcast, and I ran into a few people that made me feel like an outcast. When I say now I have the virus, they talk to me from a distance, they won't touch me.

I was even in a bar where they served me with a little cloth around the glass, and then threw the glass away when I finished. And yet, I'm going like (demonstrating). So these are ignorant people.

So the medical people and the community have to be educated, and make them realize that it's just like cancer or leukemia, or any other disease that you can deal with. And we're making it.

MS. MARTA AMARO: Hope for the best.

COMMISSIONER DIAZ: Are you all under treatment now?

THE AMARO SISTERS: Yes.

COMMISSIONER DIAZ: AZT?

THE AMARO SISTERS: Yes.

MS. PAULA AMARO: No, because the AZT would bring my blood count real low, and I'm anemic. So I've been two times already and had blood transfusions. So he's going to now, this month, he's going to start me in DDC.

COMMISSIONER DIAZ: You're all mothers?

THE AMARO SISTERS: Yes.

COMMISSIONER DALTON: I think Paula mentioned earlier that -- of having an experience, I think, with a doctor who was afraid to -- to deal with you. And I guess I want to ask of all three of you if you've had experiences of that sort with health care workers, or have things gotten better, in terms of the field level of doctors, nurses, and other people at the --

MS. MARTA AMARO: All three of us have the same doctors. We go to the same clinics. They know us there already. And I like to doctor we have now. He's not scared of us, he treats us like we don't have nothing.

MS. PAULA AMARO: He takes blood tests with no gloves.

MS. BRUNILDA AMARO: We miss appointments, he calls us.

MS. PAULA AMARO: And he explains things to me. And there are some people, like Welfare. As soon as they find out you're HIV -- they stand back, cover their mouth.

MS. BRUNILDA AMARO: They give you the runaround. That happened to me when I went to apply. When she learned I was HIV, she rolled her chair back to the corner and spoke to me from a distance, and kept covering her mouth and stuff when she spoke to me. And that was a frustrating experience. It's --

COMMISSIONER DIAZ: Where are you all getting care? Cook County?

MS. MARTA AMARO: University. University of Illinois Special Medicine Clinic.

COMMISSIONER GOLDMAN: Is your doctor Hispanic?

THE AMARO SISTERS: No.

COMMISSIONER GOLDMAN: Is that important to you?

THE AMARO SISTERS: No.

COMMISSIONER GOLDMAN: Does your doctor speak Spanish?

THE AMARO SISTERS: No. Yes. A little bit.

MS. PAULA AMARO: Sometimes when I go and I

start speaking to him in English and I cannot finish it, I tell him in Spanish.

MS. BRUNILDA AMARO: And he understands.

MS PAULA AMARO: And he understands.

MS. BRUNILDA AMARO: He speaks Spanglish.

(Laughter.)

CHAIRMAN OSBORN: Thank you very much, again.

THE AMARO SISTERS: Thank you.

CHAIRMAN OSBORN: And it's quite clear that you're helping a lot of people with the work that you do. So, thank you.

(Applause.)

GEORGE RIVERA

DR. RIVERA: I'm George Rivera. I'm the Director of the Charlie H Project at Our Lady of Guadalupe Church in Denver, Colorado. And we have the privilege and unique experience of working within the Catholic Church.

And I want to focus your attention just for a few minutes, that's why I wanted to make some remarks on the Spanish who live in non epicenter cities, because there's very, very limited resources, funds available. We're merely working through fund raisers that we do there at the Church, et cetera. And we were burying two there per month.

There were two Hispanics a month there who were dying -- who had died from AIDS there at Our Lady of Guadalupe Church. We found a need to form something to help the infected individual and their family. So we work with infected individuals and their families before -- before, while they're infected, and during their death, and in the aftermath of all that.

We deal with families because we can't deal with the individual in isolation. There's -- there are families who need help, adults who need help, even beyond the infected individual. They're trying to deal with all this in their families, there's children who need counseling and help because they're dealing with that, and they certainly need help with that even after the death of their loved ones.

There at Our Lady of Guadalupe Church we have a priest who is very, very supportive, and out of that we've been able to form a coalition called the Colorado Latino AIDS Community Network. And out of -- and that is coalition of the Charlie H Project, which provides spiritual and educational programs for those who are infected and for the community.

And Los Alamos Adios, which we had to form up then, was formed up there by Linda Mucero to help with -- as a support group for the families and children. In

fact, the children's group grew so large from all the extended families that we had to form a separate support group for the children that come from these families, and it's called Puzzles.

And we also work very, very closely with GALLA, the Gay and Lesbian Latino Alliance, which is the Latinos in the community who are -- work very, very closely with us in the Church as we try to put these programs together.

But I just wanted to focus your attention just for a moment on the fact that those of us who are beyond San Francisco and are not located in New York City and Miami, and some of these epicenter cities, that are needs are great, and we've had to work with institutions that already exist in order to try to meet the needs that are very, very real for us in the community.

So we work with families because we see the individuals embedded within the family and extended families, because extended families make up the community as a whole. And so we try to work with them in an effort to try to bring education to them, to try to bring support to them, to try to bring some show, and even economic help to them that's not gotten elsewhere. So I just wanted to bring that to your attention, if I could, please.

CHAIRMAN OSBORN: Thank you very much, Dr. Rivera. I appreciate you being with us. Now, Mindy Rice?

MINDY RICE

MS. RICE: My name is Mindy Rice, and I'm with Act Up Chicago, and I'm sure you've all heard several things about Act Up, probably two-thirds of them aren't true. I work with the women's caucus of Act Up Chicago, which is a group of about twenty women who work together to address issues specifically of lesbians in AIDS and women in AIDS, and are specific issues.

And like you said before, there have been several things thrown out, but no one's really pulled things into a circle. And I'd like to take my few minutes and talk to you about lesbians and AIDS.

There's an idea that lesbians and AIDS aren't at a risk for HIV infection, and it's not based on medical fact in any way, but rather on a number of deep rooted misconceptions about the way lesbians live and about how we have sex.

It's very difficult to talk to straight people about a lesbian culture, because there really is no way for you to have any concept of what it is like to be a lesbian, especially if you're a man. It's just one of those things that can't be done.

And a lesbian culture is very different from the gay male culture. The way we socialize, the way we love and the way we live are very different.

And just as an example of some of the misconceptions that are perpetuated through the institutions, Dr. Charles Shabel of the CDC told Visibilities, which is a lesbian magazine, that it isn't necessary to study lesbians because, and this is a quote, "lesbians don't have much sex." I don't know what lesbians he knows, but they aren't any that I've ever come into contact with.

There there are so many myths about lesbians, that we're the lowest risk group, and a lot of people when, you know, people come out with the religious standpoint that AIDS is God's wrath. I've heard the retort, well, what are lesbians, God's chosen people? And there are so many things like that that are perpetuated through the AIDS community.

A lot of people think that women who are self-identified lesbians don't sleep with men. It's not true. And a lot of people say -- have the impression, not in my back yard, but lesbians are already your next door neighbors, your coworkers, and your family members, and you love us already, so why can't you work for our issues.

I mean, the biggest problem I face in working the lesbian communities is that lesbians don't believe themselves to be at risk, because of the institutionalized disinformation. Lesbians have a viable lifestyle. There are many happy, healthy lesbians who are in love and having sex, and getting HIV and dying.

The current outreach programs list lesbians. We are not in the "high risk" category, unless they happen to fall into the injection drug use category or are bisexual. And we're not part of a specific community's mass target plan.

And Latino lesbians, especially, have a tendency to ignore their own self-identity, to sort of "grease the family gears," to make working with your parents more comfortable, a woman will ignore her own self-identity as a lesbian, and work with the family in a different context, which is -- it promotes another problem, because if you have to deny who you are to your family, how can you really get support from them? And how can you get support concerning HIV issues and things of such a serious nature?

And then there's the problem that there is no research done about woman to woman sex, there are no statistics. We're totally statistically invisible, because any woman who has ever had sex with a man in her

entire life and has contracted HIV, whether from a woman or not, it's heterosexual transmission.

There is no bisexual category for women, there is no combination category of injection drug use and homosexual contact, or injection drug use and bisexual contact. I mean, lesbians aren't modifying their sexual behavior.

It's very hard. I work -- I am the safe sex slut of Act Up. I am the one that goes out and sticks dental dams in people's faces and says "Do you know what this is?"

And, you know, lesbians are discriminated against in every way. And it's so hard to fight against all of that discrimination and try to inform them about the HIV issues that are a factor in their lives.

And lesbians do shoot drugs. Lesbians do share needles. They have been married, they do have children. They're in prison. They have sex for money, and they get raped.

And these are all things that seem to be invisible. And I've felt very invisible for the last couple days, and I thank you very much for letting me speak to you.

Are there any questions?

CHAIRMAN OSBORN: Mindy, I'm going to ask

Commissioners to ask you questions individually, if I could, because we are now almost completely out of sync, and while we're very eager to learn more from you, I think we may need to do so informally, because we have important work to do in that communication mode that was talked about earlier in the afternoon session.

So thank you very much. I, personally, have learned quite a lot from getting to know you the last two days, so I hope you didn't feel completely invisible.

MS. RICE: Included in all of your information packages is an excerpt from this book, Women, AIDS and Activism. It was published by the active New York Women in AIDS book group, and I encourage all of you to read it.

It has the most -- it was copyrighted in 1990, it has the most up-to-date information about women, and lesbians, and safe sex, and the information, and the statistics, and the disinformation as well. And it's from sort of my generation and my activism perspective.

And I think it would give you all an interesting perspective. There's only one thing wrong. You can't use Sarann Wrap for a dental dam.

CHAIRMAN OSBORN: Thank you, that is particularly useful. Thank you very much.

We need to adjourn now -- we will take an hour and

return to Commission business at 2:30.

Thank you all for your patience. We ran a bit late, and thank you for your forbearance in this fact that we had to be so pressed sometimes. We appreciate you're being with us.

MS. BYRNES: I've been asked to make the announcement that for any of the witnesses who have participated in the meeting today, as well as the Commissioners, we've made arrangements for lunch. If you check with Frank, he'll let you know where that is.

(A luncheon recess was taken.)

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In the Matter of:

HIV DISEASE IN HISPANIC COMMUNITIES

Docket Number:

Location: Chicago, IL

Date: March 12, 1991

Presiding: Chairman June Osborn

were held as herein appears and that this is the Original transcript thereof for the files of the Department.

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