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NATIONAL COMMISSION

ON

ACQUIRED IMMUNE DEFICIENCY SYNDROME

HEARING ON

HIV DISEASE IN AFRICAN AMERICAN COMMUNITIES

Monday, December 17, 1990

9:05 a.m.

Curran Conference Room

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COMMISSIONERS PRESENT:

JUNE OSBORN, M.D., Chairman

DIANE AHRENS

SCOTT ALLEN

HARLON L. DALTON, ESQ.

DON C. Des JARLAIS, Ph.D

EUNICE DIAZ, M.S., P.P.H.

DONALD S. GOLDMAN, ESQ.

LARRY KESSLER

CHARLES KONIGSBERG, M.D., M.P.H.

DAVID E. ROGERS, M.D.

HON. J. ROY ROWLAND, M.D.

HON. LOUIS W. SULLIVAN, M.D.

DEPARTMENT OF DEFENSE:

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MICHAEL R. PETERSON, DR. P.H.

NAPO:

JAMES R. ALLEN, M.D., M.P.H.

PRESIDENT OF PEOPLE WITH AIDS:

RON JERRELL

VETERANS ADMINISTRATION:

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C O N T E N T S (Cont'd.)

P R O C E E D I N G S

CHAIRMAN OSBORN: I think we are at last ready, and we appreciate your patience. We had to spend some time getting the sound system arranged so that the recording could be done appropriately for the meeting.

I am delighted to welcome everybody here for the meeting of the National Commission on AIDS, and I would like to take the opportunity to welcome the commissioners as well, particularly Dr. Mendez who is with us to represent the Department of Defense this morning and the Assistant Secretary of Health for Defense.

Later on I think Dr. Sullivan will be with us. For the moment, Dr. Jim Allen is sitting in for Health and Human Services Director of the National AIDS Program Office and Irwin Pernick sitting in for the Department of Veterans Affairs for the Secretary. So we appreciate their being with us.

Congressman Rowland has managed to break away briefly from his busy schedule. So we have got a good set of listeners. I will apologize for hiding in my pack of kleenex. If my voice goes, you will understand that I have an industrial strength respiratory infection at the moment.

We have a very important and interesting set of presentations today dealing with issues of HIV disease in the African American communities. To launch our deliberations, I am delighted to ask Commissioner Harlon Dalton to talk with us initially and give an overview.

Harlon, will you lead us off, please. While you are getting yourself settled, let me comment to any one of the commissioners that apparently, to make these microphones work, it is important to lean into them quite close. Sometimes that gets you an echo, but apparently here it is what you have to do to make them work.

OVERVIEW

MR. DALTON: Thank you. I have learned from Larry, and Belinda and others who have switched positions how truly nervousmaking it is, and it is. Though I don't know whether I am more nervous about the folks in front of me or those behind me. I wish I could face both directions at once.

The purpose of this hearing is to deepen the Commission's understanding of this country's response to AIDS in the African American communities. This hearing could have been devoted to any of a number of other worthy purposes, including giving black community-based organizations and AIDS

service organizations an opportunity to report to the Commission on their many accomplishments and their special needs.

We could have used this time to recognize the contributions of individual African Americans in dealing with the AIDS epidemic or to put the spotlight on the struggle with AIDS in a particular locale or community.

But it was my judgment that, having observed this Commission at rather close range for these many months, that what the Commission needed most was an opportunity to take an in-depth look at a set of issues that are of greatest concern to African Americans.

Similarly, it struck me that black folk who deal with AIDS on a daily basis rarely have an opportunity to come together and to have a conversation particularly in front of our white colleagues about many of the real concerns that bedevil us. So it is my hope that today will provide just such an occasion.

Therefore, we have adopted a different format for the Commission; one that showcases just for issues and that provides a relatively small number of individuals a relatively significant amount of time to engage the subject matter.

The African American community is blessed with extraordinary riches in terms of those people who have chosen or perhaps have been chosen to devote themselves to this epidemic. If the 14 people who will present today had not been able to come, there would have been 14 others behind them, and 14 behind them who would have been quite marvelous.

I say that not at all to slight the people who are going to sit here in just a moment. When you see them and hear them, you will agree with me that they are an amazingly thoughtful and well-informed and powerful group of people, and I am proud to be in the same room with them.

We all are familiar with the devastating impact that AIDS has had on African American communities and I will not repeat the numbers for you except casually. You also know, the ones in front of me, my feeling about slides, so I will not put any up on the wall for you.

But we all understand perfectly well that, if we are talking about women and AIDS, we are talking about black women. If we are talking about children and AIDS, we are talking about black children. If we are talking about gay men and AIDS, we are talking about black men, since roughly half of blacks who are affected are men who have sex with

other men.

If we are talking about I.V. drugs and AIDS we are talking about African American communities, and we are talking about our communities disproportionately, sometimes radically disproportionately.

We also all know at this point that by the time blacks are diagnosed we are sicker and that we die many, many times as fast as our white counterparts.

All of this we know. It is common ground. We also all agree at this point that different approaches are needed to deal with AIDS in African American communities. But the harder questions are which approaches. I would suggest that there is even a prior question, which is why. Why do we need to deal with AIDS differently in African American communities than in the dominant society?

There is, I think, in all of us, on both sides of the table, an irresistible impulse to focus on those things that we have in common as human beings. It is perfectly natural. We are, after all, all the same species, at a minimum. We all prefer pleasure to pain. We are all, for the most part, pleasured by the same things and pained by the same things.

Emphasizing our commonality across race and other lines is often a useful antidote or useful response counter-weight to those people who wish people ill on account of their race or sexual orientation or what have you.

All of us on the Commission have had the great good fortune of seeing our Chair hearing our Chair from time to time invoke the metaphor of the human family as a way of dealing with certain retrograde members of Congress. Part of what gives it such power is that it is not simply a metaphor when Commissioner Osborn uses it, but, in fact, a deeply felt sense of reality.

African Americans are especially fond of invoking our commonality; blacks and whites together. I think of some of the versus of the song "We Shall Overcome." Invoking that commonality, even at those moments when internally we are feeling most separate, most alienated, when indeed we may be seething on account of race.

I want to suggest that that sort of the invocation of commonality is, in many ways, a two-edged sword. It is often used by the "bad" guys, and I use that term loosely, though I could name names, and indeed I will in just a moment. The U.S. Supreme Court has taken lately to emphasiz-

ing colorblindness even as it undermines decades of progress along race lines in the name of "colorblindness."

More recently the Assistant Secretary of Education for Civil Rights invoked the idea of our commonality. We really are all the same. We want a colorblind society as he promoted a policy that would be extremely detrimental not only to African Americans but to the entire nation.

The problem with colorblindness with treating us all as if we are the same is that it locks in the status quo; that it freezes existing imbalances of power and resources. But even when this notion of our common humanity is used by the "good" guys, it sometimes leads us to deemphasize differences that truly matter; differences along such lines as race.

There is a real kind of psychological drive in all of us to deemphasize differences because they make us extremely uncomfortable. To talk about race differences puts whites and whites of good will in an extremely unattractive position.

It also is discomforting for blacks. We fear that if we emphasize the differences in our society we will simply reinforce stereotypes. We fear that we will be accused of

playing the "race game." We feel that we will be charged with arguing on behalf of "special interests." We fear that we will be accused of guilt tripping. So as a consequence we are silent and instead we focus on what we have in common.

My hope is that on this day we will not be silent and that we will do the uncomfortable thing and talk about race differences in America.

I am a little nervous about the clock because I want to model for those who follow of paying attention to the clock. I also have a million things I want to say. Let me see if I can say them quickly.

Three points: The first is the touchstone of race in our society is not blood or pigment or physiognomy, rather it is history or more precisely a historical relationship between blacks and whites. That relationship in this country is one founded on domination and subordination. It is a relationship born in the peculiar institution of slavery.

In 1990 we are still living out the legacy of that history. It is a history that is passed along from generation to generation in the black community in stories like the ones my father told me about meeting his grandmother the slave, in "Afraisms" like if you are white, you are all right. If you

are brown, stick around. If you are black, stay back. In lived experience, like my own experiences driving across the country with my family as a young man and having to get off interstate highways and go into colored town at various points across the country to find a hotel, and lived experience like the experience at Yale Law School, bastion of liberalism, this fall in which a number of black students received in their mailboxes a letter which said, "Last week one of our classmates was sexually attacked by two black men. Now do you know why we call you nigger? Signed: Yale Students for Racism."

So race is about history, about an historical relationship. It is about a relationship that exists into the present. Until and unless we take into account that reality, we will not truly understand how to deal with AIDS or with anything else insofar as it differentially affects a people of color and in particular black folk.

The second point I want to make is that all of us experience everyday life through the prism of race. In other words, blacks and whites experience the same event differently simply by virtue of our race or simply by virtue of which side of the historical racial divide we fall on.

Let me illustrate with just two examples. Some people have heard my cash machine story. You will hear it again. Not so terribly long ago I was using a cash machine at night in New Haven, and it was one of these machines where you need a card to gain entry into an enclosed area. I did that, and I was taking out my rather paltry sum of money, and I heard a tapping on the door, and there was a white man about my age indicating he wanted to come in.

I kind of waved him off with the universal I am using the machine, not now gesture. I returned to my business. This was a very slow cash machine. All of a sudden I heard a rattling at the door, and he was rather more vigorously trying to get me to let him in. It was cold. It wasn't that cold. I turned around and gave him a somewhat different don't come in gesture, still universal.

When I finished, I opened the door, and he came in. He looked at me as if I was crazy, at which point I became, indeed, a crazy man, and I began to sputter and stammer. What came out actually was really very kind of arched. The Yale part of me came out rather than reaching back to my roots.

What I said to him was, if the situation were

reversed, you wouldn't want me coming in. This didn't help. He looked at me as if he still understand what had just happened. What had happened for me was a profound racial experience, which is to say that I knew full well that if he had been in that machine and had turned around and seen a black young-appearing man dressed casually, as I was, wanting to come inside, he would have been scared out of his mind. He would not have wanted me to come in there, and I wanted at least the same respect from him. That was the experience that I was having.

The experience that he was having was that he wanted to use the cash machine and would prefer to be inside rather than outside.

The second example of how simple daily experiences are affected by race involves people standing around a counter Christmas shopping, since that is the season that we are in, holiday shopping. First of all, I think all of us have had the experience of being at a counter, there being several people and having a clerk not ask who is next, but simply take the person that they somehow feel is the next person. I have not met a black person who has not had that same experience and wondered deep in our gut whether we were

not the favorite person on account of race; wondered whether the clerk was turning to someone else because they were white and we were not. Indeed, being rather certain about that phenomenon.

It is an experience that if you are white you just simply don't have. You may think this clerk is insensitive or slow or any of a number of things, but it doesn't occur to you, because in fact it isn't the case, that you may be experiencing a profound racial slight.

Those are just a couple of examples of how everyday life is very much affected by which side of the racial divide we fall on. What I want to suggest is that it is important to recognize that even though we may be in the same movie theater and looking at the same screen, we sometimes may be looking at radically different pictures.

My last point is I have described race as really involving a relationship between groups of people an historical relationship. It is extremely difficult to alter relationships, particularly those formed over time. We all know that from our personal experiences.

I recently had the great pleasure of watching some 80-year-old relatives engaging in sibling rivalry that has

continued unabated from Day 1. We all know from our family and other experiences that relationships continue to play themselves out over and over again, and it is hard to change old patterns. It is particularly hard where abuse has been part of the relationship because abuse begets abuse, as we know from taking a closer look, for example, at parents who abuse their children who often themselves are children of abuse.

We know that abuse often produces dysfunctional adaptations. So as we struggle to alter the historical relationship of domination and subordination between whites and blacks in America, we just understand that it is a difficult task, and it is not a matter simply of another generation being born or of a piece of civil rights legislation being passed or, for that matter, of good will. The struggle is much, much more complicated than that.

For the most part, I haven't made the connections between these observations about race and AIDS. That is the 50-minute version of my remarks. It is also the job of the fine folks who are going to follow me, and I am as excited as you are about hearing from them.

Thank you.

[Round of applause.]

CHAIRMAN OSBORN: Thank you very much, Harlon. We very much appreciate your colleagueship and your thoughts. Mark, can I ask you to join us now, Dr. Mark Smith? While you are getting settled, let me mention that the cameras are Howard University taping the entire session for the Commission, as we have asked them to do. We appreciate their being there and just so everybody knows what that is about.

Welcome, and we look forward to hearing from you again. We are pleased that you could join us. The responders will also join Mark at the table so that everybody will be there.

UNDERSTANDING A LEGACY OF MISTRUST

DR. SMITH: Good morning. My name is Mark Smith, and I am an Assistant Professor of Medicine at the Johns Hopkins School of Medicine and Associate Director of the AIDS Service at Johnson Hopkins Hospital.

I thank you for the opportunity to once again address this Commission. On the last occasion, we were talking about a lot of data-driven issues. We were talking about outpatient volumes and Medicaid reimbursement rates, and I am especially grateful for the opportunity to address

this important issue on this occasion.

As Commissioner Dalton said, I think it is an opportunity to have a discussion which is, of necessity, a bit more impressionistic, and so I would like to address my comments to the topic that I have been asked to speak to; namely, Understanding a Legacy of Mistrust.

As you know, HIV disease disproportionately affects the African American community in the United States, roughly double our percentage of the population or percentage of people with AIDS. But an additional tragic dimension of the epidemic is that in striking the African American community it affects a population already alienated from the health care system and the government and a population that is, frankly, somewhat cynical about the motives of those who arrive in their communities to help them.

My thoughts on this subject come not only from my own experience--I think you know something about my background--but obviously also from the thoughts and contributions of others. I would like to recommend to you three works that I have found helpful myself and suspect that you may find helpful in providing a context for this discussion.

The first of those works is a book called Bad

Blood: The Tuskegee Syphilis Experiment by James Jones. The Tuskegee experiment, as you know, was a study of the natural history of untreated syphilis carried out in black men in Tuskegee, Alabama, which continued long after the introduction of penicillin. While there is some controversy about the details of the project, there seems little doubt that treatment was inappropriately withheld in the name of science.

You should know that this project is well known. Though sometimes exaggerated, its general features are well known in the black community, and it provides validation for common suspicions about the ethical evenhandedness in the medical research establishment and in the federal government, in particular, when it comes to black people.

A second reading I would urge you to look at is a book called A Common Destiny Blacks in American Society published by the National Research Council of the National Academy of Sciences.

This volume painstakingly documents the burden of inequality felt in virtually every sector of American society by African Americans; employment, education, criminal justice, housing, health care and others. It is important reading because it verifies our observation that AIDS is but

one of many scourges affecting African American communities and that, indeed, with the continuing smoldering spread of HIV in our communities, the disease is increasingly intertwined with other problems of poor education, drug dependence, dysfunctional families, inadequate health care, and the general malaise which is settling over inner cities.

The third work I commend to you is actually from one of your own. It is Commissioner Dalton's piece called AIDS in Black Face. This article deals as skillfully as any I have seen with a number of themes that influence the black community's response to AIDs; compassion, homophobia, shame and others.

It is often said that homosexuality in the black community is hidden; that it is more taboo. I'm not sure if it is more taboo. It certainly has been my experience that many of the formal leadership structures in the black community; churches, fraternities, professional organizations and others, have a difficult time dealing with this subject at least in public. But in a sense it is beyond the point whether it is more a problem in the black community than the white, it certainly is a problem.

But perhaps of more relevance is drug use. It is

obvious to anyone with experience with addicts that they are victims, but are also victimizers sometimes as well. It is understandable that a community which bears the brunt of the disastrous consequences of drugs is ambivalent about supporting people whom it sees as tied up in the fabric of drug use and commerce.

It is largely for this reason I think that many parts of the traditional leadership in the black community have not become more mobilized to deal with AIDS in part because people who use intravenous drugs are not the sort of citizens that traditional leadership of the community would like to hold up as needy recipients of community or governmental assistance, particularly when they see so many other perhaps more "deserving" people whose lives are constantly under assault.

With that as background, I would like to address the five main issues, which I believe form the backdrop for the mistrust by the African American community of the government's efforts in AIDS.

They are, first, the origin of HIV; second, the synergy of discrimination in the United States; third, the inadequacy of health care; fourth, suspicions about medical

research, and, fifth, AIDS and drug use.

On the origin of HIV. Where did HIV come from? I'm not sure we know for sure, but there is a mounting body of scientific evidence that ties the virus to central Africa. This question of the origin of HIV has, I think, two important implications in the black community.

The first is that I think many people resent the speculation about the origin of HIV being in Africa, resent with the fear that "they are trying to blame this whole thing on us" just like everything else. Everything bad in society they try to blame on us.

People I think see numerous examples of anti-gay bigotry in recent years often tied to the gay community's supposed responsibility for the AIDS epidemic and correctly fear that in future years this kind of bigotry will spill over towards others thought to be responsible. An example I think of this resentment is the reaction which you know of the Haitian and Haitian American communities to the designation of the mere being Haitian as a risk group. It is I think a reflection of the same sort of unease about being tagged with the responsibility for the virus.

A second issue on the origin of HIV is the conten-

tion that the virus was manmade. There is a small but vocal contingent in the black community in the United States that believes that HIV was the result of biological warfare development by the U.S. Army or the CIA or some other agency. Actually, the New York Times poll documents that this is not perhaps such a small segment. This contingent believes that the virus was either accidentally or deliberately introduced into African and African American communities.

While there may be relatively few people who actually literally believe this, I think there is a much larger number of people who wouldn't necessarily rule it out. If you do believe this, I think of necessity you are inclined to disbelieve government pronouncements about how to protect yourself from infection, whether or not the virus can be casually spread, the effectiveness of early medical intervention. This is, I think, a backdrop for many people who are inclined to believe that the government would not be incapable of such a thing. Remember, Bad Blood.

The second issue is the synergy of discrimination. As you know, African Americans have been discriminated against. HIV-infected Americans have been discriminated against. What then about people who have both burdens? What

about HIV-infected African American women who have three burdens of discrimination to bear?

There is substantial concern in black communities about the degree to which being HIV positive will cut off opportunities for employment, education, even health care in a way that might not apply to more affluent white gay men with other resources and other supports.

If you take, for example, the recent revelation that many clinics in New York City which serve poor women, will not do abortions on women known to be HIV positive. You have to agree that a woman contemplating an abortion would resist being HIV tested because of her lack of alternative resources to have this procedure done.

In an economy where young black males face unemployment rates three and four times the national average, it surely is not a competitive advantage to be known to be HIV positive.

And so in these and other ways there is a lot of concern about the synergy of discrimination based on race and HIV status and sex, and I believe that concern about this discrimination is an important factor in the resistance to HIV testing among many potential infected people and their

advocates.

The third issue is inadequate access to health care. A common destiny and other numerous works document the inequities in access to health care for African Americans. As you know well, HIV-infected Americans also have problems in accessing compassionate and competent health care. It should, therefore, come as no surprise that the recent calls for more aggressive HIV testing based on the assumption that people will be able to take advantage of early intervention will fall on skeptical ears.

Let me be clear. I am a supporter of HIV testing. I think people who are at risk for infection should be tested. I do not believe that we can wait for some sort of guarantees to urge people to be tested. But I and I think many others have little confidence that adequate resources for care of those who are found to be infected will exist once they are tested, and, therefore, the call for testing has a different implication in the African American community.

As Commissioner Dalton said, it is the same theater, but a different picture playing. This is particularly true for members of the African American community who are infected by virtue of drug use or sexual contact with drug

users who are unlikely to be medically insured, unlikely to have regular medical providers and typically use the health care system only for acute interventions when they are in extremis.

Their experience with the health care system is marked by one word, "alienation." They are often the victims of prejudice against substance abusers which permeates the health care system. So a dynamic is established in which they go to the health care system late. Health care providers tend to blame them for their own problems and to treat them with something less than the dignity with which we would all like to be treated when we are ill.

So who does take care of people who are HIV infected in Afro America? The work of Dennis Andrulis and others has documented that it is largely urban public and teaching hospitals; entities that are already underfunded and stretched to the breaking point.

The other two main sources of primary medical care in the African American community are private physicians often themselves minority physicians and community-based providers in neighborhood health centers and other such clinics.

About private physicians, as I told you in my last testimony before you, though I think private physicians in minority communities are increasingly interested in and learning about how to take care of HIV-infected people, they are, frankly, not likely to see many, not so much because they have AIDS, but because they don't have medical insurance. Even if they have Medicaid, they will be reimbursed at 20 cents on the dollar, and they are, frankly, money losers to anyone in private practice.

As for neighborhood health centers, in many cities they are taking an increasing share of the burden of caring for the HIV infected. But my own view on this is that the jury is still out on how much we can expect the average neighborhood health center to take care of people with late-stage HIV infection particularly as we move into an era of complicated combination antiviral therapy and a medical regimen for HIV, which in my view is becoming more rather than less complex over time.

The fourth issue is fear of experimentation or the kind of guinea pig syndrome. I am a member of the faculty at Johns Hopkins School of Medicine. I am very pleased and very proud to hold that position. But I do recognize, as I think

Commissioner Dalton recognizes, that prestigious research institutions and their scientific investigators are not always trusted by African American communities in which they are often physically situated.

When I arrived in Baltimore two years ago, I started actually hearing stories from a number of people who had grown up in the vicinity of Johns Hopkins Hospital. That their parents had told them not to be out on the street after dark because if they were those people from Johns Hopkins would snatch them off the street and experiment on them in the basement of the hospital at night.

I heard this from many people, including some people that I work with on the AIDS Service. Now I know that all over the world parents make up boogie-man stories to scare their kids into being home at night. But I heard this boogie-man story a lot, and I suspect that it has been told to other black kids in other neighborhoods of research institutions around the city.

A recent issue of U.S. News & World Report carried an article on the U.S.'s best hospitals as judged by physicians. A look at the list is instructive. It includes institutions like Johns Hopkins, the Cleveland Clinic, Barnes

Hospital, Columbia, Presbyterian, Duke, et cetera, all institutions situated right in the heart of decimated minority communities.

Many of these world renowned medical centers I suspect have a reputation among their neighbors that is different from that at the NIH, and it is not perhaps based on the self-perception or even the motivation of the institutions or the investigators. It is much more complex than that.

Johns Hopkins probably provides more care for AIDS than any private institution outside of New York and San Francisco. The hospital has made an extraordinary financial and organizational commitment to providing AIDS care, particularly for the indigent in our community. There is no question that our institution and others like it are able to facilitate and subsidize care for indigent patients because of the availability of research in a way that might not otherwise be available.

But I also understand that the surrounding communities perspective on medical research has a historical basis which sometimes outweighs the demonstrable integrity and commitment of the individual investigators or even the

institution when doing AIDS or, for that matter, other biomedical research.

In light of the historical basis of the suspicion of being guinea pigs, it is particularly ironic to hear the cries for more access to experimental medicines from the AIDS advocacy community. I am an advocate for expanded access for minority patients, for Hispanic patients, for women of all colors, for other people who haven't had access to drugs. But please understand that this is not just a question of going out in East Baltimore and saying, hey, you all come. We have now DDC available.

There is substantial resistance to this, and it will only be overcome, frankly, with a more long-range effort to reassure African Americans that they will not be the victims of more Tuskegees. This is, as Commissioner Dalton has said, a historically conditioned response.

Last, AIDS and drug use. Perhaps no issue has been more inflammatory than the various proposals for the provision of sterile needles and syringes so as to reduce the spread of HIV; the so-called needle exchange controversy. Let me first make my own position clear.

I think that a program of distribution of sterile

needles can, and this is underlined in the testimony, in coordination with adequate access to drug treatment and with other aspects of HIV education and prevent, play a useful, if modest, role in reduction of HIV transmission.

Unfortunately, needle exchange programs are rarely presented with the other pieces of this package intact. These programs are too often championed primarily by individuals and organizations who have little background in or commitment to African American communities. So members of African American communities, including some who have been on the frontlines treating and taking care of drug users for years, understandably ask the question, "Where the hell have you been all of this time? What is the nature of your deep concern for people who are using drugs in the African American community? Why would you want to facilitate the AIDS-free continuation of a lifestyle, which has many other devastating health and social effects for the individual and the community?"

Then the ensuing interaction begins to escalate and results in charges and countercharges with which you are all too familiar. In addition, the proponents of needle exchange programs sometimes argue that one of their principal ad-

vantages is their inexpensiveness compared to other approaches, and that assertion predictably fuels the controversy still further because members of African American communities then believe that AIDS advocates and politicians are trying to take the cheap way out as opposed to grappling with the more expensive and difficult issues of drug treatment and drug prevention.

The entire controversy over needle exchange is, in a way, a metaphor for the deeper veins of skepticism in the black community about the motivations of the AIDS establishment, if you will. There is, I think, a continuing uneasiness in many quarters about the focus on AIDS in the black community and many other health problems seem to be receiving less and less public attention and funding.

In conclusion, organizations and leaders in African American communities are certainly more active in the fight in AIDS in general than they were two or three years ago. The devastation to our communities is more and more inescapable. More and more of our people know someone afflicted with AIDS or dying from it. More and more people in our communities I think are ridding themselves of illusions about the exclusivity of the virus for gay men or for drug users.

But the response of African Americans to the AIDS epidemic is historically conditioned, and it is also conditioned by present day realities. There is an abiding alienation from and suspicion of the government, the media, powerful health care establishments and providers and the scientific establishment in general. There is a reality to contend with of many other health and social problems which, though interacting with the HIV epidemic, preceded it and will probably outlive it.

During the recent NIAID Conference on AIDS in Women, a thought was expressed which I think I have been hearing more and more; a criticism of previous attention to AIDS in women as being mainly motivated by seeing women as a vector for the transmission of the virus to their children or their male partners.

In a way this same question hovers unasked around many discussions of AIDS in the African American community. In the face of such remarkable inattention to and disregard for the health status of black Americans in general, I believe many people, perhaps in their heart of hearts, ask the question are they interested in the spread of AIDS because they are concerned about us or are they interested in

us because they are concerned about the spread of AIDS?

Thank you.

CHAIRMAN OSBORN: Thank you very much, Mark. I think we will proceed with the responders, Marie St. Cyr, Alpha Thomas and Alyce Gullattee. That is the appropriate order.

MS. ST. CYR: I think that my concerns, Mark, are mostly on what is the implication of the legacy of mistrust in the area of prevention and education in the community. I think that it is rather serious. I work in New York City, and at this point I am working mostly with women and AIDS and previously worked with Haitians in the Haitian community in Brooklyn and New York City area.

The problems of denial in those communities and the problems of fear is a major issue in terms of allowing information to flow through and for people to internalize the information and make decisions on their lives.

I think it becomes a crucial issue when we look at the other legacy that we haven't talked about; that is, the legacy of who cares for the Afro American community and who cares for the Haitian community? Who cares for people of color in the United States?

I think in many ways I have to say that the communities have learned from the rules of slavery to care for themselves. When we don't address their concerns, we are not deliberating them psychologically to teach proprietorship of this disease and deal with what is the impact in their community. I see it happening in the Haitian community where in providing just simply a workshop on education we find ourselves very entangled in discussion of the anger, the fear and the problems of employment, the problems of lack of access to insurance, the problems of people being laid off from work every time we have a surge of information on this issue.

As we look at what occurred in this community, even the problem of prospective thought about AIDS becomes a major issue for the Haitian community, for example. Just thinking about AIDS, dealing with taking AIDS on and facing it in our lives become an issue because you are dealing with communities who are marginalized and we are dealing with communities where survival is an issue.

In New York City many of the communities that I work the problems of shelter, housing, the problems of homelessness, the problems of accessing basic care in terms

of health care becomes really marginal before prevention, particularly when we are talking about a disease that takes so many years to become symptomatic.

So the implication for prevention is one of a major concern. I think that the problems of genocide and the concerns of genocide brought forth and exacerbated the history of mistrust. Because it exacerbated the issue of mistrust, I look at the history. Our history is that the government and the officials have not responded to the issue of genocide. They have not responded to that concern of the black community. They have not given any inkling of what their own thoughts are about this, and they have not made the community any easier in terms of sense of dealing with this issue.

We are still really clutched in this situation talking about genocide, talking about where we are and how we proceed in this society.

I think that it is incrementally it is extremely important that we begin to allow for participation of the black community in our processes because the isolation of the black communities, not only in terms of service delivery, it is also in the process of developing services and the process

of dealing with protocol development, for example, in research, the participation of the black community has been minimal.

Therefore, the idea of taking proprietorship into diseases and dealing with it as one disease that affects us is not a reality. As you grow from talking about this illness now and talking about long-term longevity, increasing quality of life, this is not a reality in our community.

I ask myself in many ways when are we going to address the issues of concern in such a way that you become trusted; that is, you, the larger community that has interface with us as the black community and has maintained the legacy of discrimination and prejudice and bigotry. When are we going to interface so that we can start saving the lives of people who are dying sometimes without knowing it because their issues are much more centralized in surviving the daily struggles of being in a black community?

For me as a Haitian American and for me as a woman, it becomes even a more crucial issue. I see every day women coming into the Women and AIDS Resource Network dealing with the number of children that they have before HIV, before they are concerned with AIDS. As we see their babies die and we

see them dying, we have a number of children that are being left without parents, and we see absolutely no service delivery and no concern around these children who are orphaned in New York City, for example, where we know that there will be no care for these children. Our foster care system is overloaded as it is.

So the concerns from me is not only in prevention and in participation, it is also in the lack of response. I think there needs to be, frankly, a more truthful display of concern. We need to be able to access levels of participation that allow the black community to understand that it is a part of the solution, not simply a part of the problem. Because as we discuss over and over again, the problem has been blacks are seen as a part of the problem, and they are not seen as a part of the solution.

I think that there is another issue in terms of the mistrust that I would like to point out. One is that for many people in the black community and communities like the Haitian community, the issue of drugs are seen as a planned distribution of drugs. That why drugs are so pervasive in our community or why education is not appropriately done in our communities so that our children can remain in school is

one issue of planned problem. It is an issue of not addressing the solution in our community and, therefore, allowing another part of our community to disintegrate.

So it is seen as a tangent to the whole genocide issue. I think it is one, given that we are dealing with AIDS and we are dealing with HIV and drug use, I think it is one that needs to be looked at.

The problem of HIV is not only linked to drug use and not only linked to treatment of health care, it really, as Honorable Dalton talked about earlier, it is linked to how we perceive people of color in this country, and it links to how we begin to see ourself in relationship with you as other persons of color.

I think those are my comments.

CHAIRMAN OSBORN: Thanks very much.

MS. THOMAS: Good morning. My name is Alpha Thomas. I am a health educator with the Dallas Urban League. I assist in providing AIDS education and information to the African American Community.

Being from the south, let me just give you all a little history. We all know that the south is first of all the Bible belt. The south also was a very strong advocate of

slavery. As a result of that, we are just having a helluva lot of serious problems.

I also want to stress that racism is very much alive and kicking in 1990. Being from Dallas, Texas, Dallas is a very conservative city. We are very much into images. We want to project to America that we don't have racial problems and what have you, but if you have been following the news, Dallas is on the verge of a racial explosion. We are having a situation right now with our African American leaders who are just in a real big uproar with the so-called "good ole boy" system in Dallas, Texas.

So I come here to tell the truth because I believe that the truth shall definitely set us free. So if I make anybody uncomfortable, so be it.

What I see as contributing factors regarding the legacy of distrust in relationship to AIDS in the African American community is the effects of slavery. There are so many African Americans that I work with who really feel that because of the--I don't even know how to say it--because of the results of slavery these are just some of the contributing factors of the problems that we are having.

This distrust is just in the blood of a lot of

people that I come in contact with. Then we move on to the Tuskegee experiment that has already been alluded to previously. So many African American people that I work with do not trust hospitals or any of the other community health care service providers because of that Tuskegee experiment. It is like, hey, if they did it then, they will do it again.

A lot of this distrust African Americans have valid reasons to distrust the system.

Another point I would like to ditto on that has already been mentioned is the origin of HIV. Over and over we hear in the media and through the grapevine that, hey, AIDS came from Africa. African people are black, so they want to blame it on us. This is just another problem, another something that they want to put off on us. So as a result of that, a lot of people that I work with do not perceive themselves at risk of HIV infection.

The distrust of the medical profession from the perspective of folks saying, no, I'm not going to the doctor because they are going to inject AIDS into me or they are going to tell me I got something that I don't have or they are going to give me something that I don't have and kill me. These are very strong feelings that my community has shared

with me.

Another thing that I would like to echo on is the drug epidemic. Oftentimes African Americans that I work with say to me that there aren't any African Americans in strategic positions to bring drugs into this community, so it is a plan of the white man. Keep us loaded--that is really not the term that they use, but I am going to keep it clean--but if you keep us loaded and out of our minds and feeling helpless and hopeless, that adds to the control.

That is something that we really need to think about because we know that there aren't any African Americans who patrol the borders, who patrol the airways and what have you. We just don't have the power to bring drugs in this country.

Police brutality. I could sit here and talk about that until hell freezes over. In Dallas, again, I just want to say that we are having so many racial problems and one of the contributing factors is the police brutality. I am afraid to call the police because I am afraid that they may kill me in the process of coming out to just investigate what is going on.

Last week, as a matter of fact, an African American

businessman was shot by a rookie policeman in that it had been called in that this man's shop was being burglarized and the man was there getting some flowers together for a funeral. The policeman approached him and said halt. Well, hey, if it is 2:00 or 3 o'clock in the morning, you are at your shop doing business, and somebody comes up to you and says halt, what the hell are you going to do? It is going to frighten you. So this man he threw the flowers up in the air, and the policeman said it seemed as if he was going for a gun.

It is this kind of mindthought that continues to add to the legacy of distrust. If you cannot call the police for protection, what can you do? That is just one incident. There are numerous others that I won't even go into because of time.

Reproductive exploitation. Working at five family planning clinics, and I am not here to put the clinics down that I work for, but I see a helluva lot of undercover stuff going on at these clinics. I have counseled with women who were coaxed into being sterilized. They did not want to be sterilized but because somebody felt that, hey, girl you got too many kids. You are only 21 and you have got five

reproductive abuse sterilization abuse

children. When is it going to stop? Well, who is that person to make that decision regarding that individual's life?

Also, in terms of reproductive exploitation, there have been a lot of women who were sterilized against their will or sterilized unknowingly. Can you imagine what it would be like to have your tubes tied and for you not to even know it? Mind trip, control, genocide.

A lot of African Americans that I also work with feel that poverty in itself contributes to the legacy of distrust and racism. The "po" gets poorer, not the poor, the "po" gets poorer. The rich grow richer.

President Reagan vetoes a civil rights bill. What kind of message does that send to people of color? Boom, boom. You ain't going nowhere but down.

Having dual educational systems. "Thangs" ain't equal. I didn't say things, I said "thangs." They are not equal. Education in America today is a joke with the high rate of drop outs. There was a time when black folk wouldn't even entertain the thought of dropping out of school, but boom, boom integration, upward mobility.

So all of these are contributing factors to the legacy of distrust and, frankly, to be honest with you, I am

frightened because I feel that our community is in trouble. But I know that the only way that our community will be saved is we must save ourselves. When people in my community mention to me the aspect of genocide regarding this virus, I say to them I don't know where AIDS came from, but the fact of the matter is that bad booger is here, so what are we, as a race of people, going to do about it? We cannot wait for the federal government to come in and save us because we know the real deal on that particular issue.

Thank you.

CHAIRMAN OSBORN: Thank you for your very powerful comments.

DR. GULLATTEE: Good morning. My name is Alyce Gullattee, and I am the Director of the Drug Abuse Institute at Howard University Hospital. I am here this morning, however, not to speak for Howard University Hospital, but to share with you some of my concerns about this particular issue.

I brought with me this morning some of what I call community Bibles revolving around the subject of mistrust. For those of you who have not seen it, and I would suggest that if you haven't, copies be made available. It is called

The Strecker Report. It is a compendium of articles and statements made by various persons who have in some way been directly involved in AIDS research or a compendium of those things that have happened in the past revolving around the area of experimentation in the poor community, black or white.

There is mention of the Alabama Tuskegee syphilis study, among the many studies that are mentioned in this particular book.

Another resource document, and I show you these before I make my statements because these are the kinds of things that the black community, and the poor community and the minority community are aware of, and they study these documents with a dedication as if that which is in it represents the absolute truth. I cannot say whether it does or does not. I am just familiar with the content.

It is a document written in 1970, a discussion paper called "Optimum Population Resource Utilization and Environment" by John Roland, and I will mention him in the body of my statement that I am going to read. It is a damnable article in terms of what it represents and the kinds of things that it recommends; modern-day Dachau.

Another book called Eugenic Sterilization by Jonas

Robitscher, written in the late '70s on various aspects of eugenic sterilization. I heard Ms. Alpha say something about sterilizing individuals. One of the articles written in here was by a young surgeon who at the time was at Walter Reed Hospital, and it was customary when they would do an appendicitis in a female to also do a tuboligation, and for that reason he left the service and then ultimately felt that he had to speak about that particular incident.

There is also of course mentioned in here about those particular cases in the south where any number of women were sterilized because it was believed that they carried "bad blood" and/or "bad genetic material." Those people were whites.

There are a host of newspaper articles that started being produced in 1979 around the issue of what was happening in the world vis-a-vis experimentation and a lack of humanity and sensitivity to the survival of the peoples upon whom these particular experiments in the obtuse sense because they might have been involved in the exportation of dangerous and noxious substances from this country to other countries and items that were not approved for use in the United States but were then allowed to be exported to other areas.

So you see the community reads avidly, and for those who cannot read because of whatever the educational inopportunity might have been they go to meetings and they listen to what is being said and form an opinion about how they will believe the whole issue about AIDS, how they will react to that which may or may not be available to them, what they believe about that which is available to them and how they will in the future become a part of something to rid the country of this terrible disease.

I am thankful that I have an opportunity to speak this morning because I work with drug victims--I have, it seems almost all of my professional life, at a point in time when it was a thankless job and when one considered if you were to donate time to people who had a volitional illness, then something must surely be wrong with you. Now that it has moved away from just the few narrow subcultures and has become a part of the American ennui, everybody all of a sudden now looks more carefully at some of the etiological factors.

Of course along with the drug abuse problem has come all of the sequelae associated therewith because, as we moved away from narcotic analgesics and moved into more

sophisticated drugs than those drugs that were developed by pharmaceutical companies but had addiction potential, we find that we are dealing with a monster that will lower not only the individual's intellectual ability to interact adequately with his environment; namely, people, places and things, but then exposes him or her to all of the other risks that go along with the lack of adequate conscious observation of what is happening, AIDS being only one thereof.

Ten years ago I said that we were moving towards a nation that was insensitive to children, to women and historically, of course, to blacks. Now we must add another group to that and that is the group of the elderly. Because the problem of AIDS is not one that just strikes the high-risk individual who might be the practicing addict, but AIDS is a problem that will impact upon all of those individuals who will come in contact on a regular basis with the unfortunate circumstances of this disease.

The elderly are killed because they will not give money to their grandchildren to pay for the drugs that they buy. They will not kill the addict. They will kill the supplier of the money because the addict is going to continue to have a problem, so they threaten the life of the elderly.

If a child is born of an AIDS mother who dies, then generally the grandmother or someone in that family will take that child, after a child has spent long hours and months under treatment in a hospital environment. So that we have moved towards now the culmination of this kind of ultimate insensitivity, and it requires that we look at it very carefully because it doesn't matter really how the illness got to us. The fact that it is with us means that we have to come to some consensus about how we are going to manage to bring it under control and ultimately get rid of it.

I have fears of that inside of myself having seen the spread of this disease in Africa and knowing what has happened to us and having early on, eight years ago, seen patients who carried the virus, but who had no antibodies at all and recognizing that we had a simulated "Typhoid Mary" environment. Indeed even now there are those who carry the virus without antibodies. Unless they are in an environment when the testing is done where the virus is tested for and not just the antibodies, we are going to continue to have the spread of the disorder because we will miss people who happen to be the carriers who may themselves not even know that they are because we base our judgment on the presence of an

antibody.

I find that one of the main reasons for the seeming national inertia revolving around the dreaded disease AIDS is a basic lack of trust between the government and the public; a mistrust based upon the belief that the disease is manmade--race and sexual grouping specific.

Mistrust Conspiracy

Ethnic groups find that their tabloids are filled with information about AIDS and whether or not you believe that. There is the tendency to accept that which you see as being at least reasonable. College campuses address the issue of AIDS in their tabloids. Lay and religious cultures are replete with the pronouncements of the politics of genetics; population zero, involuntary sterilization and genocide all associated with the AIDS epidemic.

References are made to the documents entitled Optimum Population Resource Utilization and Environment by John D. Roland. A discussion paper prepared for the first National Congress on Optimum Population and Environment held in Chicago, Illinois, June 7th to 11th, 1970.

The development of the document was underwritten by the Defense Department in a contract to Watson & Sons in Sanguine, Texas. Methods of control for optimum growth are

advanced with emphasis placed upon Hewlitt and Mathis' philosophies of famine, pestilence, war, vice and virtue. Vice is characterized as excessive interaction stress. There is even suggestion that the polemic of preserving humanity as healthy species only to have them die from starvation is not acceptable.

Additionally, it is suggested that a sterilizing chemical or agent that would be inexpensive and affect only humans would be useful. More disturbing, however, is the suggestion that a disease may be the answer, particularly a disease in which disease control is suspended while disease susceptibility increases.

The decision that the disease might spread and reduce world population to a size that can be fed and perhaps clothed, housed and educated and employed. Perhaps the best we can hope for is a world plague, and this is directly a direct quote out of that particular document.

The document, the Strecker Memorandum, implies that small pox and hepatitis vaccines used in Africa and the gay community respectively were contaminated by a mutant retro-virus which resulted in the inoculation of the Human Immune Virus into those populations with malice of forethought.

In an interview with Dr. Wilbur Jordan, an epidemiologist, in December 1984 reported by Renya Cowan, states that the HIV disease was created in some kind of laboratory here in the United States. Likewise, in the same document, Dr. Jacob Siegal in 1986 implied that gene manipulation of HTLV/LAV, the AIDS virus, may have resulted in the more virulent genetically engineered virus.

We all hear about the P-4 Laboratory at Fort Detrick, Maryland in Building 550 established in 1977 to develop biologic agents of warfare.

In articles in The Washington Post in 1960 it indicated that the Dupont Company was testing its people for genetic disorders in the workplace. They were doing sickle cell screening on the appropriate population. Mind you sickle cell does not just occur in black populations. There is a similar illness that is found in the Mediterranean people; Italians and Northern Africans.

The American Cyanamide, i.e. Dupont Company was fined $10,000 because Dow Chemical they were screening their workers for genetic damage, but if high rates of chromosome breakage occurred, they refused to tell their people. That error was called the error of genetic confrontation. In 1980

we were moving into that particular era.

February the 25th, 1980, The Washington Post talked about firms that were exporting products banned as risks in the United States, and they mentioned pacifiers, 120,000 of them, that were sent to Australia that did not meet United States regulations.

In 1980 Representative George Miller, Democrat of California, accused the United States of environmental imperialism; dumping onto nations banned chemicals from this country and into those countries knowing that we could not do similarly in this country.

In that same year, the president of Sierra Leone rejected $25 million from Colorado because they wanted to dump their toxic wastes in that country. In the same year, DBCP factors that caused sterility in Southern California workers was taken down into Mexico and the Mexicans then decided that they did not wish that to be in their country.

Third world countries have been treated as a garbage can of the advanced industrial world according to Mr. Rebhan at a New York conference.

In Zambia one used to be able to ship anything there and only the shipper and the receiver knew. Mr. J.

William Houn, the vice president of General Mills, Incorporated, bemoaned the fact that if they had to go through a lot of red tape in order to send over their products, the byproducts, that it would create too much difficulty for them.

Then it is understood that what the United States will not export West Germany and other countries will.

I am bringing all of these things to your attention only because the threat of lack of cooperation is very real. The people in poor and minority communities will not see that which is being done as something positive for the elimination of the disorder.

In Virginia, as was mentioned before, there was an investigation 15 years ago on the sterilization of large numbers of so-called mental misfits believing that they were bringing forth children who could not be work productive and meaningful in the community, and as a result an investigation was begun to determine how frequently this was done.

You may say what does all of this have to do with what we are here talking about today? It has everything to do with what we are talking about today because, you see, in the black community, and I say black and not Afro American because blackness is the quintessential factor of our

existence in this country. We may talk about slavery and what slavery has done, but I am a believer that Americans in this country who are black by origin are the best that Africa ever presented.

Having myself personally seen where we were placed in the holes that were too short for anyone taller than me because I have had to bend down in order to get down and walk on the compacted fecal material of slaves by the thousands who were held down in these holes. Once we were purchased, we were then marched all of the way up the coast and ultimately ended in Glory Island on Senegal. For those of us who did not die while we were held there or we were not killed because we acted up, we made the middle passage sardine style, head on head, and if you were taller than 5'6", then you had to crumble up the best way you could.

So I say that in this country, when we speak about our need to be understood and our need to be a part of that which is going on, it is because we have given considerably to build the country into what it is today.

So when people begin to act out in their racist ways in a Dallas or in an Illinois or in a Washington or in a Maryland, then I look at their behavior, perhaps as newcomers

to this country, who do not know the full history of our contributions, and we have perhaps more right here than many of the people who are here. We do not apologize for that, and we will not apologize, and we will not for long be a part of that which is going to be self-destruction. We have been intellectually destroyed, but we will not continue to be physically destroyed because at some point passive resistance is not going to be the answer, and we must stop before we reach that point.

There are some things that might help us because among our black people we have certain kinds of anxieties. We are fearful of white Afro Americans. I am trying to find my document because I don't want to talk off the cuff about that.

We fear white Afro Americans, those persons trained in white schools who, through their intellectual acculturation, are believed to have isolated themselves from the sensitive issues of survival for the black Americans. The one of you, but not part of you syndrome.

It is of no value for us to have someone who looks like us attempt to work with us, but who has already become so different in their mentality that they cannot communicate

with us. We cannot have programs of this magnitude impacting upon the survival of people without the people being involved.

When you go and you talk to community people about becoming a part of an AIDS project, they will say who is in charge? And then they will, as we say in our community, do a reading on that person.

[Laughter.]

DR. GULLATTEE: Those of you who understand, you understand about doing a reading. Once they have been read, we will then determine whether or not we are going to be a part of whatever it is they have. No matter how much money they have, no matter how prestigious the institution, present company excluded, it doesn't matter because it is understood that there are, in some instances, some hidden agendas and because one's consciousness might be clouded because of the environment in which one finds oneself, you might not be able to fully analyze that which is there.

Jews in this country understand about that because they have suffered. In fact, when I went into one of the slave holding stations, there was a young man there who said, my God, this is the original Dachau, and I understand that he understood exactly what was happening. But I don't need to

give you that part of the history. I just merely mean to indicate that the black community, No. 1, believes that the disease is manmade. No. 2, they believe that there is insincerity in what is being done to eliminate it. No. 3, they believe that part of what is going on when one is doing experimental trials in using drugs is to do just that, experiment and see what is going to happen. So that when a vaccine finally comes about, it will be given to the proper community because we will have paid the price in having it developed.

There are so many other things that I can give you about this because this is a special interest for me. I have lived with those who have died. I have been with them when they have died. I feel very deeply being unable to do anything to impact upon it, and I would hope that whatever you do in deciding on how we are going to attack it, that you include the community, and if you give a university a grant, that you be certain that whatever their advisory committee it is adequate representatives from the people group that would be impacted by it.

Thank you.

[Round of applause.]

CHAIRMAN OSBORN: Thank you very much. We very much appreciate all of the powerful testimony that we have heard. I would like, if we could, to take a few minutes so that the Commissioners who have questions could direct them to the panel. If there is more than one response, that would be good, but our time is reasonably limited, and I do want to have the Commissioners have a chance to figure out--David?

DR. ROGERS: It was enormously powerful, and we are grateful to all of you. I heard some things that I hadn't heard quite in the same dimensions before. We much appreciate it.

Query, any of you. In thinking about institutions within the black community that we could call upon and could work with, churches. Could Mark or Dr. Gullattee or any of you respond?

MS. ST. CYR: I think that institutions in the black community, churches is one institution where I think that there is some headway being made. Organizations like the Black Leadership Commission needs to pool a lot of church ministers together to start discussing on the issue of taking on and answering the need of persons who particularly see this as an issue of God/men situation and also being part of

the whole structure that takes care of the community to start delegating part of the resources to that plan of care.

But I think there is another institution in the black community that is extremely important and that is the family. I think that if we look at New York City, for example, where you don't oddly have hospital beds any more. You are going to have to look at services that will train family members to take care of their sick ones in the homes and also to allow us to reduce the cost of care.

We are going to have to be able to look at how we allocate funds to families. At this point, a woman who has children may be weak and may not exhibit any symptom that we can categorize under the cities definition as AIDS and not eligible for services, but she still have a family to take care of and yet she is not eligible for funding to help care for that family. So we are going to have to really reevaluate how we allocate assistance and how we define this assistance in terms of AIDS prevention.

I think AIDS is a black family issue. I look at grandmothers who now take care of the children of their daughters, and I look at the problems that they incur with the system in terms of receiving care. So I think the

church, the family and the community as a whole in terms of participation is extremely important.

DR. GULLATTEE: I was going to comment about the churches because I think that there are some enlightened churches long before there was any grouping of them together. I think the reason the church is an important axis is because so much of religion now is turning towards building self-esteem, and that will then keep the individual from gravitating towards self-destructive kinds of behavior.

I think that if the churches were in some way part of an aggregate group. In Washington one of the medical societies has a grant going into the schools to impact upon targeted areas, but primarily for adolescent population. But before one can involve oneself in a school with the adolescents, you have to become involved with the PTA, and then you must become involved in some way with the church community because there are some issues that come up that are in conflict with some of the ideological philosophy of religions. That then obliges all of the people to get together; those who have the positive information and factual, those who have the spiritual aspect of the individual in mind and the moral and ethical tenets thereof, and then those who need to be

impacted upon; namely, the youngsters who are in school. So that one can come to a consensus of how best the information can be passed on.

Children see people dying in their churches, and they know they die from AIDS. Ministers preach to that. But if we had a system that obliged all monies going into a community to have as a concomitant part thereof, this kind of linkage, it would have greater impact over time.

I think we need to do something, too, about housing. It makes no sense for us to have houses boarded up as we have, when we have such dire needs for these young people to be out of the high bed cost care when they can go into the community. You can get churches, if adequately financed, to send their own people out, some of them under supervision who have work skills who may be out of work, to renovate buildings and then have those buildings as houses where the young people who have these problems can go and stay in a way that is humane, rather than have to feel afraid.

Some will say, if I am standing across the street and walking down the street, somebody is apt to yell across the street, there is old Mary with her AIDS disease. If you

are 17 or 18 and somebody says that, that is the end of your life because you are not only isolated, but you become victimized by others who are frightened of the disease as a concept.

So I think that churches, yes, in concert with schools because of the natural interaction thereof, and medicine ought to give some of its time in giving adequate information. But by all means, community has to be involved in no matter what institutions are used.

DR. SMITH: I would like to comment that I think in terms of trying to find mechanisms and vehicles to do AIDS prevention educational work I think churches are very important, traditional black leadership organizations, Urban League is very important, PTAs, doctors, lawyers. I think it is a mistake though to rely only on those traditional mechanisms.

One of the things I was trying to say in my testimony was I think there are some structural reasons why those organizations have been late in this battle and some of those structural reasons are not going away.

So one of the things I think has happened in most major cities in this country in the last eight years is that

new organizations have grown up around AIDS and minority communities. New leaders have developed. I think it is important to nurture and support them. There sometimes will be conflict between them and some of the traditional leadership structure. So I believe strongly that the traditional leadership structure, including churches, needs to be involved. We need to find ways to get them more involved. But I think it would be a mistake to hold our efforts in the black community hostage to them or to rely only on them because I am not sure that this epidemic will ever be as high a priority for some of them as we might like it to be.

MR. GOLDMAN: In talking to friends, clients and other people from the African American community, I often hear some of the echoes of what you have said, in many ways. But one other thing that I also hear is that the kinds of--I will call them just for the sake of a better word and to generically refer to them--the conspiracy theories; the theories that AIDS and HIV infection was inoculated into small pox vaccine into Africa, the idea that there was some organized conspiratorial form of genocide in terms of dealing in terms of issues involving birth control and family planning.

One of the things that is also said to me, however, is an interesting one and that is that I am told that at least in their communities the leaders of the African American community, whether it be the political leaders or whether it be the medical leaders or whether it be the church leaders, either agree with and believe those conspiratorial theories or make very little effort, if any, to disabuse their own communities of the truth or existence of it.

I don't know. Even in listening to you, each of you talked about the existence of the theories. None of you ever said whether or not you agreed with them or didn't agree with them or you believe those conspiratorial theories or don't believe those conspiratorial theories and how that can be effectively dealt with. You talk about it as a barrier to the kinds of programs that we are dealing with and yet it has just been absolute nothing in terms of coming down on it on one side or another in dealing with it head on. I was wondering if any of you had any comments.

DR. GULLATTEE: Attorney Goldman, I think it is a point well taken because it depends on which side of the color fence you are sitting. I guess a good analogy is that no one ever believed that Hitler was going to do what he did

to the Jews either. Not even Americans in this country believed that anyone could do such a dastardly thing. And yet there were all of the symptoms and the signs for years, and even this country sat back and paid no attention to what it was seeing.

We are hard pressed to come up with answers for this. This is not a disease that just came about de novo. It came about some way, whether it is mutation or whatever. Acquired Immune Deficiency disease has been with us for any period of time. But I can remember, and I reflected on this, in 1980 hearing a grandmother tell me, whose son and daughter were both in the armed forces, that her five-year old grandson was a tiny, little child. He looked like a little old man, and he had Acquired Immune Deficiency disease.

At that point in time, there was not a good deal of emphasis being placed on anything called AIDS. That came later. But, of course, in retrospect, pathologists have said the disease was here in the '70s. Now we are not saying that. Black Americans are not coming up with these kinds of things.

We recognize that white America believes what is scientifically stated and what is stated by whites. As a

result, if whites say these things about what has happened, then blacks look at them more carefully. Whether we believe that it was done specifically and purposely in order to destroy us, is irrelevant. The fact that it has occurred and is now occurring ten years down the road is that which has the greatest emphasis in the community.

Believe it or not believe it? You read avidly. You read scientific journals. You weigh whatever is said by scientific people. You determine whether or not their facts are correct. If you have any scientific background, you can at least recognize where there might be faults and pitfalls. We know that we have socialist and totalitarian and communist groups in our countries, and this is not bashing them specifically. But there is always a kind of innuendo or undercurrent of unrest that is easily stirred and churned around in people who see themselves as being oppressed and continually so.

The government does nothing apparently to eliminate the kinds of things that threaten us on a daily basis. Any time we have to worry about our personal safety when we go through specific areas of a community simply because there might be somebody there who is a skinhead or whatever kind of

head, makes you understand how we might feel.

I recognize that whites may feel the same way when they come down into a middle of a thick Harlem or down into a middle of a Wats not knowing what might happen to them. So we take what we see and read what we can, and when queries are made, we will ask the individuals to read more and come to a conclusion. We don't say it is not true because we don't know what the truth is. All we know is that we have a disease and now we have to do something about it.

Ten years ago it was not our disease, as we know it, but clearly eight years ago we were infected with it and only now has it come to be the kind of problem that we see. It seems as if other groups, because of the altered lifestyle, are not having the same incidence and prevalence of the disease that is now ever increasing.

We have two generations destroyed by this disease now; two generations of black people. We were destroyed early on when we started out integrating, and we ceased knowing clearly about our background, and we were told untruths about ourselves. That set up a frame of mind that clearly led going into the use of drugs, et cetera. Now we are having another problem associated with this disease that

is spreading like wildfire among us.

We see whole generations of black people gone, just gone. And now with our college campuses having this, white and black college campuses, having problems first with drugs and now with AIDS and seeing adolescents having the problem among them, our country is at risk because if we don't have a healthy population, we cannot even defend democracy. So when we talk about it as being real or unreal, it is not taking a stand against the government. It is not saying we don't believe that. Because the government has given us no explanation for it, and that is a true dilemma.

CHAIRMAN OSBORN: Thank you. I am going to take two quick questions; one from Scott and one from Larry, and then I think in a few minutes we are going to have to break to meet some of the other stringencies of the schedule. So if they could be brief and the answers brief, I would appreciate it. This is so important I hate to even say that, but it is important that we also proceed.

MR. ALLEN: My quick question is, as we have talked about the legacy of mistrust and you mentioned reading the white community, what is the criteria that needs to be read? What is it that the white community needs to bring to the

table that is read to be safe? That is my quick question. Do you remember the statement that when somebody comes in they are read? My question is what do we need to read?

DR. GULLATTEE: I thought you were talking about reading this--

MR. ALLEN: That is why I thought there was some confusion. What is that the white community or white person needs to bring to the table that is safe? What is that criteria?

MS. ST. CYR: I think I would like to respond to you because I mentioned earlier the level of participation and the lack of response of the government. I think that when we are talking about legacies, you also come with the legacy. We talk about it in terms of what the black community sees, but the legacy is also what the legacy of the white community is, which you heard before, one of oppression and subordination, which is one of domination.

I think that the reading that occurs is that at first when you come into the community, you come to basically to supplant yourself either as a researcher or as a provider, but not really part of the community.

The first reading is that you come with that

reading, which is a reading that you are not trustworthy until you have proven that you are trustworthy.

In the issue of AIDS I think it is clear that the total silence on the issue of genocide, the total silence and the recurrent issues of placing the origin in Africa or saying that Haitians are more apt to have AIDS than other people, it just exacerbates for the community the kind of suspicion that exists.

I think the more that we try to implant programs into the community headed by white persons, the more then we offend the community and the more we exacerbate the problem. I think the level of participation of which I said earlier has to be a real participation from community provider, from community care giver and community leadership, and I think that is lacking.

MR. KESSLER: This is a question I think for Dr. Smith, but for any others. I appreciate your insight in helping me around the question of the needle exchange. Over the past year I have actually changed my position several times. But I am wondering if you could comment about your feelings or fears, either one, about what I think is a horrible situation. When we look at the 11 states where

needles are not available, where drug treatment and access to treatment is inadequate, within those 11 states those addicts or users, black, white or brown, are most heavily impacted and the AIDS statistics show that. Where do you stand or what do you say or advocate about the laws in those 11 states or should we adopt those laws in the other 39 states?

I think we are stuck, and this is probably the wrong question for the short period of time we have, but in 25 words or less do you have any thoughts about where we should go on that level, setting aside the needle exchange schemes?

DR. SMITH: In general, I think that sterile needles and syringes ought to be more freely available. Clearly, nonsterile ones are freely available, and I see no evidence to suggest that more direct laws about making them illegal or making their possession illegal is going to help anything except get more contaminated syringes in the community.

So I actually favor, as I said, I think that making them available in a variety of ways, both through exchanges or distribution and getting rid of laws that say their possession is itself a crime plays a useful, if modest, role.

I guess my contention, however, is that I think this whole issue has received much more heat than light and, frankly, I think has caused more bad will than its usefulness is worth in terms of its actual risk reduction. But I believe that making sterile syringes available ought to be part of a package of adequate drug treatment, more increased prevention and other services. That is my own position. I don't know that answers the question.

DR. GULLATTEE: I would like to add though that you should add education to that. That if you are going to give the addict the needles, that you also tell them about their cotton, and about their water bottles and about the other things that go along with the process of using those needles.

CHAIRMAN OSBORN: Yes?

MS. THOMAS: I just have one comment that I would like to make, and I am going to make this very brief. This is in response to the genocide piece. Folk ask me that question all of the time. The way that I like to respond to that is in the words of public enemy. They say fight the powers that be. I see AIDS as a form of power, and we know that there has been all sorts of things perpetrated on the African American community, and I want to specifically say

that I am not saying that that is the case.

What I do definitely want to say is that the virus is here, and no matter how it got here, the real deal is it is here. It is real. It is in our community. Let's just ban together as a community and fight the powers that be.

CHAIRMAN OSBORN: On behalf of the Commissioners, I think I speak for all of us in wanting to thank you all especially for being very articulate and giving us a great deal to learn and to think about. I appreciate you talking with us.

We will take a break for about 15 minutes and then reconvene.

[A brief recess was taken from 10:45 a.m. to 11:10 a.m.]

CHAIRMAN OSBORN: Thank you for putting up with our somewhat erratic scheduling. We are particularly happy to welcome Secretary Louis Sullivan to this portion of the meeting. I know his schedule is awfully tight, and he will need to leave us at 12:15 kind of regardless of where we are. I hope that you will feel free to excuse yourself when you need to for schedule purposes. But we are delighted that you are with us and welcome.

DR. SULLIVAN: Thank you.

CHAIRMAN OSBORN: We will proceed now to the second set for the morning. Dr. Wilbert Jordan, Sandra McDonald, Sonia Singleton and Elsie Cofield are with us. I think you may have a way in which you want to proceed, so let me turn the matters over to you to proceed as you will.

ORGANIZING AFRICAN AMERICAN COMMUNITIES

DR. JORDAN: Thank you, and good morning. After my presentation, Ms. Cofield will respond followed by Ms. McDonald and then Sonia Singleton.

It is, again, a pleasure to speak to you. A lot has happened since January, and I hope you have received the patient profile that was placed in front of you. I looked to see that some of the numbers are out of order, so I will have to tell you what pages to look at.

The first session I think it was quite appropriate to help you understand the background in terms of how we have to deal with AIDS, understanding the mistrust and the mistrust does indeed exist. However, at the same time, it is important to realize that we can overcome some of that and things can be done.

Some of the things that we want to discuss this

morning in our presentation is to look at some of the issues and what we think the Commission can do to help us really deal with AIDS and the community better.

I hope you realize that in our community, and I am speaking of the black community, though early intervention has been around, and we have seen the success in the white middle class community, it is not working as much in the black community. The reason being that is due to more of the psychosocial problems that these patients bring with them and those problems are not being dealt with.

Often, when we see patients, they come in knowing for the past two years they have been sick or fearing that something is going on or hoping it is something else for a variety of reasons, but fearing that if they tell someone in the family, they are going to be ostracized. They fear that because the things they have heard gives them reason to believe they will be ostracized.

I had one mother testify before the L.A. Convention and she stated I told my son that if you get this disease, don't bring it here, and she said, and he heard me. What I meant she said was I love you. I am concerned. Please be careful. But he heard what I said. So when he became ill,

he didn't bring it home. In fact, she did not know until he was so sick that he couldn't get out of bed. That was a lot of wasted time that had we gotten him earlier, had he felt comfortable earlier, we could have treated.

In this day, when there is hope, if we test people and we find out where they are and we can start them on different regimens, we can many people healthy and functional. We can't play God and for some we will still use, but many we will not. It is tragic to still see a lot of people come in with a T-cell count of 15 or 10 with an infection, which is nearly impossible to treat, and you have to deal with a variety of problems then as well.

The profile that I gave you the one I wanted you to look at first if you turn 12 sheets back, you will see Page 1. These are basically the black patients that I have treated in South Central. Not all, but I have started doing a profile on my patients. As the first sheet shows, there are 412 patients involved. 375 are male. 37 are female. Though we are seeing an increase in the number of females, one thing to still remember is the majority of patients are males.

Where it says No. 1. I am dealing with a subsegment

of black homosexual men, and these are men who are effeminate, who self-identify as effeminate. In the community, we call them sissies, and I am not referring to this in a derogatory manner. I am simply describing a subsegment of patients who identify themselves as being feminine, et cetera.

When that group of patients are asked the question, when you were a child were you routinely molested by a straight relative, I had 117 patients say yes. 6 at first had sort of blacked it out, but in talking, all of them related to having had multiple experiences of being molested either routinely by one person or by several persons.

When this patient now comes to see me, as a physician, 15/20 years later, he brings several things because most times he is still at home with mother. Few of them will have told their mothers, and a few will come with mother not knowing something. That will be very few. Many would have told and she would have, because she felt totally inadequate to deal with this, refused to believe it or blacked it out.

Many will not have told, but the mothers would have suspected something and not had a way of dealing, and some will have seen and, again, will black out. If you turn two pages forward, you will see the ones described as mothers

with black-outs.

I had one instance where one young lady kept getting gonorrhea infections in the mouth, and the family came and wanted to know why. It was obvious from what she told me why, and with the whole family in the room I simply said to the mother, the two brothers, and the father and the two sisters, the reason your daughter keeps getting gonorrhea in the mouth is because your sons and your husband keep having oral sex with her. At which point, in talking, the mother just had one of her "seizures." Of course, we were diverted for a moment to dealing with mother's seizure.

And in talking about that, came to realize she has had a CT scan that was negative, an MRI scan that was negative, an EEG that was negative. She has had everything that was negative, taking medicine. And talking it became apparent that her black outs occurred during times when molestation was occurring in the home.

So I went back to the charts, looked at some other parents and tried to find other mothers with a black out history. I found five more who had the same kind of history of "black outs" with negative EEGs, negative CT scans, everything. All neurological exams are negative, but black

outs. So I ran over to the UR, and I started pulling some charts. I wanted to see how many. I have found 15 so far.

What this is is basically women who are experiencing something that they cannot deal with, and the way they handle it is by blacking out, basically.

When I get the patient now 15/20 years later, I also get a mother who I need to have support him. If she has known, but never dealt with it, she has a tremendous amount of guilt. And now she pays it back by smothering him. Rather than being a support, she becomes his worst enemy because she won't let him move his hand.

If she hasn't known and she is faced with dealing with one of these issues, if there is no one to realize her inability to deal, then you have created another problem. My point here is for those who are delivering care in the inner city, particularly that group of patients, it isn't just the patient that we are dealing with. It is the family.

We have to understand that and to appreciate that, if I am going to have the support of the family, I have to anticipate and realize their needs or all of the garbage or the bad stuff that they bring into this relationship, and if there has been 15 years or 20 years of other problems, if you

told his mother 20 years ago and she didn't believe it, and he has now had 20 years of a play mother and a hole history going on because of that, I have got to deal with that. The mother comes in mad because he has had a play mother for the last 20 years, and she is hurt about that, not understanding why. She has denied the whole issue of his molestation. I have got to sit down and deal with those issues with her so she can be able to be supportive for him. Otherwise it is worse. I need psychosocial help, obviously.

So one of the areas that is needed is obviously to have more people, more social workers, psychiatrists too if I can find some, who can also help in terms of dealing and counseling with this group of patients.

The third and fourth sheets from the back I list another category, and I think the fourth sheet from the back are patients who are bisexual men who are married, and I have 64, and the sheet behind that is a profile of women who unknowingly were married to bisexual men. There is a difference in a woman who knowingly marries someone who is bisexual versus the woman who doesn't know.

One thing I have found in terms of my profile of bisexual men, they are much more romantic than their hetero-

sexual counterparts. So what the woman has had for the past four or five years in terms of her relationship, the things that stand out is, one, he tends to pull her from her family. The family doesn't like him. But he compensates by being very, very romantic. So in her workplace and where she is around people, she will hear from her friends, "You are lucky. I wish my husband sent me flowers every month or he remembers your anniversary, your birthday et cetera? Mine doesn't remember anything."

But what she has had is a reinforcement of how lucky she is that she has a husband who really loves her, who woos her. It becomes very difficult then when she is faced with the fact that he knew that he was positive for four years and didn't tell me.

When she comes in, her initial problem isn't HIV. Her initial problem is a tremendous amount of pain from trying to get these two issues together. "He loved me. At the same time he knew he had something that could be killing me and didn't tell me." If she basically, to very much generalize, is from the lower class, she will use crack and keep herself high. If she is middle class, she will keep herself drunk. But her initial problem is she drugs herself

out to deal with the pain of the initial fact that she has been exposed by someone who knowingly knew that she thought loved her.

There is the recurrent this activity of now using so much drugs or drinking lowers her immune system far beyond what it would have been if I could deal with her right there. It is important to appreciate that to be able to deal with her up-front and to understand what her initial needs will be before going on trying to simply give her the ABCs of HIV at this point in time.

If I focus on that, she will not do well. I will lose her. She will come back when she has gotten worse. It is important for the practitioner to understand these things.

Those profiles, and there are others that you are free to look at, have helped us to appreciate how we have to deal with the issue of AIDS in terms of the black community. There are several things. I think the first issue is to realize that we cannot use the same model that we have used in the white gay community. I think it is a model that has worked in the gay community, but I think too often now we see ourselves being pushed upon or pressed upon to do the same thing in the black community.

The same as what would work in the black community may not work in the Hispanic community. I think we need to have a structure and a situation that allows us to be able to develop the kinds of program that will work in our community. If it works in some other community, that is fine. They can be free to take it and use it. If it doesn't, so be it. But we should not be allowed to develop something that works and then push it into some other community.

It should be recognized that this is what is needed in our community. One of the big problem that it has become is stigmatization, and the overemphasis on is he bisexual, gay? Particularly for women. Frankly, who cares? If the person has AIDS, I am going to treat them the same. The reason I need to know if the person is a drug user is to deal with that drug problem otherwise it doesn't matter.

I don't need to know if they are bisexual, hetero-sexual, a drug user to treat them other than how this is going to impart on their behavior. But because this has become such an important issue in terms of the community now, it is very difficult for a lot of people to really want to deal with the issue, and this is something that one has to look at; the fact that we have so emphasized categorizing

people that many people either say I am not in that category or become offended because they think they are going to be put in the category and, again, they are not going to get themselves tested.

I was asked seven months ago to go to Memphis, again, to consult on a patient. I had been there before to see the same patient. I think I talked to some of you about that patient when you were in Los Angeles. My first time there I thought it strange, I felt it good, my ego was, "Great. I am going to Memphis to see a patient." But in looking back, it seems stupid to fly me from Los Angeles to Memphis, Tennessee to see a patient when there are doctors in Memphis.

His mother came up with him. They are from Alabama, as I said. Then she had a mark over her right eye. I asked her in talking how she had gotten it. She very proudly related the fact that she had gotten this during the civil rights movement. A police had hit her with a billy-club and she had sustained this mark over her eye.

It was a strange feeling because, basically, this lady had given her life, had marched, et cetera so many of us could get into medical school. It was ironic now that though

she had paid her dues to help us get into medical school, now when she needed help to receive care, the very people whom she had marched and gotten bitten by dogs, got hit by a billy-club, in the city, were not there to offer her care. I think it is ridiculous that we have a situation in many cities, the majority of health care providers be they private or whatever who are giving care to black patients with AIDS are nonblack physicians, and I think we have to deal with that, and it is a problem.

I would like to address that, and I would like to ask the Secretary to ask the National Medical Association to call a special meeting on that, devote one of its days of its national meeting, not just on AIDS 101, but more to help you as Secretary of Health to bring to them the issue that this is an issue in the black community, and we need to have more black physicians being involved, and this is what we need to do in terms of treating patients.

One thing that I have done in L.A. that has helped to get other physicians involved, rather than simply trying to get people to go to them, which the physicians did not want, I have sort of co-managed patients with them. I would admit the patient to the hospital with them under their name.

I would co-manage them, basically, but in time they learned that these were people, the same as other patients.

Now I have a small cadre of physicians who also will see patients. The sicker ones they still send to me. If they have a problem, they call me, but they are not afraid now to treat patients. We need to develop some system nationally, particularly in smaller towns where physicians can sort of have that kind of system where they can either know somebody they can call on, but feel comfortable. Because as time moves on, you will see more patients.

One of the things I fear is that we are going to see more diseases missed in smaller towns because, again, it has not hit a lot of physicians, but this is what is happening. Often the disease presenting itself obviously to me because I think of it now when I see someone, but someone in Pine Bluff, Arkansas may think it is something else, and that physician has become more alert or feel more comfortable in being able to call someone. One way I think of helping him do that would be to have a system and to ask the NMA to look and see if they could develop a system that would allow their more expertise doctors to work with other doctors in seeing patients and treating patients so they can become more

comfortable in doing that.

Some people have called for a separate AIDS Commission. I disagree with that, but I do think an AIDS Task Force from the black community is needed to give it the responsibility of getting the community involved. The church is important, but other community organizations also are important. Just as the church goes, so goes the black community.

Our leaders in the community generally have not responded. Leaders are like parents and parents have the responsibility of raising a child, not doing what the child wants. You are not being a good parent if you let your kid go out at 11 o'clock at night to get candy or watch t.v. until 2 o'clock in the morning even though he may think or she may think you are the greatest parent in the world. That is not your job as a parent. Your job as a parent is to guide.

The same for leaders. The job for leaders is to guide and sometimes to make unpopular statements, but to make sure that the masses hear what they need to hear, not just what they want to hear.

I would hope we could have a task force that would

deal with taking the responsibility of really bringing the issue of AIDS more into the community so that people can discuss more.

What is absent in the black community is talking about it. There has not been a way that people have talked about it. The masses have not talked about it. I don't mean a t.v. show. I am talking about a situation or a structure that allows people to talk so that when that kid who is worried that he may have AIDS, if he then feels that he can say something to someone, he would have heard something positive.

As it is now, all they hear are sort of cut and dry statements like what the mother had said. So if she feels that she tends not to share anything because there hasn't been enough discussion to make her feel comfortable that her friends, her family will support her. So she hopes that it is not there and that it will go away, and she keeps hoping and she gets sicker, and sicker and sicker, and by the time she finally comes in, it is too late.

We need this kind of visibility. The black newspapers, black radio stations are there for the black community. That is why they exist. The most potent sexual

music is black music. Yet we can listen to black radio stations, and some that are all day, you hear very little news. You never hear AIDS mentioned. You never hear you have got to be careful. That needs to be done. I would hope they would respond from a request from the Secretary of Health to at some point to take some time to put this in integrated.

It is one thing to have an AIDS program at 2 o'clock in the morning. It is something else to have the disc jockeys, whom the kids listening to the stations have a relationship with, when the disc jockeys say something, there is a stronger element of hearing and response than when there is a program that they don't want to hear in the first place set up at 2 o'clock in the morning.

To have the newspapers deal with AIDS, not just in a sensational issue. In some instances, the only time I have seen AIDS in some of the black papers is when the issue about is it happening. This is an issue that should be ongoing, and to ask them to develop articles that do something. We have the manpower that we could provide them what they need, but we need to have that in the community.

In terms of what is in the community, too many

people who rely on those structures around their community don't see those things happening, therefore, they have no reason to believe that AIDS is important.

The importance of what is in one's community is very important. If Rip Van Winkle were to wake up and walk down the streets of West Hollywood, whatever, he would notice there is a difference than when he went to sleep. But looking in all of the store windows, he would see something about AIDS. If he stopped and asked someone in the community, they would tell him something about AIDS. If he listened to the gay-oriented radio programs, he would hear something about AIDS. If he picked up the gay periodicals, he would read front page, middle page, back page something about AIDS.

But if he listened and talked and even realized that it is even a higher incidence in the black community and got a cab and went to whatever the part of Baltimore is or to Wats or Harlem, he could walk down many streets in Compton and in Watts and he would not see a sign anywhere that mentioned AIDS, unless it was Rolaids.

If he were to listen to the radio stations, he would hear again very sexual music, but nothing about AIDS. If he were to pick up the black newspapers, except for maybe

one or two editions, he would see very little about AIDS. He would not, in looking at those things in those communities, those institutions, that supposedly give you a guide as to what is going on in the community. He would not be able to tell that this is an issue in the community.

Just as he would not, many people in the community don't have that sense, and we have to deal with ways to get those institutions to address the issue. This is when the masses will start looking and start seeing that this is our problem.

As Dr. Smith mentioned earlier, homosexuality--

DR. ROGERS: Dr. Jordan, because we have the Secretary here and we are anxious to hear from your colleagues, too, this is powerful, could you wind up fairly fast and then let your three colleagues speak so we can have some interaction with you too.

DR. JORDAN: Sure. The other issue I want to mention is the issue of research. There is a lot of research that is being done, but often it is not germane to what is needed in our community.

Again, it would be wise to have people from the community, who have hands-on care, who are involved also

participate in developing policies, but also participate in developing the kinds of research that is needed to be done. That includes having some recovering drug addicts if there is going to be an issue around drug use.

But the issue should be looking at involving the people from the community. What was stated earlier was very important in terms of distrust and how we overcome that is to have people involved in the community. We don't have distrust in Los Angeles because from all of the elected officials in the city we have a community group that meets and I think they all are involved. Because they are respected, I think I am respected, there is no distrust there. The people who are providing care and who are working are perceived as being a part of the community and when that happens, you don't have the distrust, and that is important.

I will stop here and let Ms. Cofield start.

CHAIRMAN OSBORN: Thank you.

MS. COFIELD: My name is Elsie Cofield, and I am from New Haven, Connecticut. Maybe I can give some light to what we have been talking about with churches. I am from the Immanuel Baptist Church which celebrated its 165th anniversary this year, and my husband, the pastor of that church for the

last 24 years, is sitting to the left on the front seat.

We are very proud of our church. It is a church where Adam Clayton Powell, Jr. was born when his father pastored our church. We have tried to carry on that heritage that we take care of our own.

We developed this strategy I guess because no one else was taking care of our own. If you would come into our church at any time, you would find information on the bulletin board in the front about AIDS. We have one bulletin board that states our church has AIDS, and we had a big picture of our church with love, courage, faith and hope in the corners of that bulletin board.

Right now there is on the bulletin board in the church a sign that says the only hope for AIDS is you, of course, meaning us. There is another sign that says the only thing that stands between our church and AIDS is welcome. And we have been trying to break that down in our church.

We are very happy that in 1983, I guess, not happy that this man came down with AIDS in our church, but the musician of our church developed AIDS, and we didn't know what AIDS was all about, no more than anyone else knew in 1983. But we did know that this man was human flesh and that

he was a person like all people are. So it was our job as a church family to take care of this individual who lived and died I think in 1985.

After taking care of this one person, we had three or four more people in our church who came down with AIDS, and we started getting people like Dr. Novak from Yale and many more people to come into our congregation to address the congregation about what AIDS really was.

At that time, I was a public school teacher, and I taught for 31 years. I retired in 1987. I guess I had been retired about six months when someone came to me from Yale Divinity School, a young white lady, and she said, you know, your people are dying with AIDS and no one seems to be doing anything about it.

That was distressing to me, first of all, I guess because someone white had to tell me that my people were dying and no one was doing anything. Like I guess when I heard Commissioner Rogers over there say what are you all doing? See, people have been asking us what are we doing, and to me this is what she was saying. What are you doing? Because your people are dying. Well, they are not only my people, they are everyone's people.

Anyway, I thought about it seriously. What was I really doing? Because we were having symposiums and workshops in our church. We were taking care of our own, as my husband said there, but what were we really doing? Had we made a dent on anything happening in New Haven with people that were dying with AIDS?

She asked me if I would help her develop some organization that would address AIDS in the black community. It took me three weeks to pray about it and say yes, and I did. My answer was yes two and a half years ago. Now for the last two and a half years I have been the coordinator of the AIDS Interfaith Network in New Haven.

This complex is stationed in the Immanuel Baptist Church. We have two rooms and a conference room. It has been the hardest job I have ever done in all of the days of my life, even harder than living on that tenant farm where you gave the man half of what you made every year. That was hard, especially when you were the second oldest of 13 children. But now to come out here in a world where you are trying to help people with AIDS and to look and think that almost every door was closed in your face because you are trying to help your people.

It was really difficult. It is still very difficult if I go to the Health Department and I find that the major emphasis there now is on the needle exchange. I find that the black community has not really been educated about what is happening even in a place like New Haven where we, I guess, have been declared the AIDS capital of the world, and we find that the community has not been addressed.

Education in New Haven is addressed when I go into the churches and education in Hartford, Connecticut and New Haven, Connecticut and in Bridgeport, Connecticut and Waterbury, those are places where I have organized in the last eight months other churches that will help me address the churches in the community.

We have gone into these churches. We have organized, with the help of the State Department of Health, a $35,000 grant to organize churches to bring in churches because we do know that the church, as the black church goes, so goes the people. That has always been the rule in the black church.

The black church is a leader in the community. I had a hard time at first trying to convince the ministers in the black church that this was what was needed. I have been

able now to get a lot of missionary organizations in the churches to organize, and what I have asked each one to do is have every church adopt a family, and I am very happy that today it is happening in New Haven that the churches are adopting families with AIDS. Not only are they adopting the families, but they are seeing to the needs of these families; the social needs, the medical needs, the psychological needs.

One church said to me don't worry about it. We have social workers. We have medical doctors. We have this. We just wish that every church in the United States, especially black churches, would listen to and hear the message that we have been trying to promote for the last two and a half years.

It has been very difficult, as I watched at least 40 people die and held hands with at least that many people in the last two and a half years. I spent a lot of my time the first two years crying, and then I decided that I would cry later.

So what I am doing now is working. Sometimes my husband says when are you going to take care of your life? When are you going to take charge of your life? I say to him it is not my life because there are people in New Haven who

are dying today on the streets with AIDS. There are people in the homeless shelters who are put out of the hospital with a note in their hands saying take this to the shelter.

It is bad enough to die with AIDS, but it is worse if you are dying in a shelter. I know because Immanuel Baptist Church has a shelter. We sleep 60 people every night. Our daughter is the person who runs that shelter, and you can go in there any given day and find six people who are unable to go out into the streets because they are sick with AIDS.

Housing is a serious problem. We have nowhere to put our people. Not only housing, but drug addicts, and I deal every day with the hard-core drug addicts, and I am not afraid because I don't exhibit fear. I know that if I am going around making them think that I am afraid of them, then they are not going to respect me. I had that problem when I first came into the job and someone saying to me why don't you send them down to AIDS project in New Haven and my people saying to me I am not going anywhere but to you.

That is where it is. I have worked two and a half years with one person with me plus myself being a half-time worker, and I work from sunup to sundown every night without

funding, without a place for our addicts, without food, without clothing, without shelter, and most of the time when a person comes to you with AIDS they are sent to me mostly from the hospitals or we find them in the streets or a friend will tell someone about us, and when you get that client, you have to go the whole way all of the way with this client. You are going to have to start trying to get welfare, first of all. Then you are going to get social security. Then you are getting SSI. Then you are going to get a doctor or a dentist who will pay attention to your client. And the work is not easy.

I think that this is what we have done and what we are doing in the black community. I have a book here, and it is called AIDS Black Church Coalition Curriculum and AIDS Interfaith Network.

What I have been asked to do was to develop a curriculum for a model church for the black community. This is difficult, and I am not really sure that we are getting where we are trying to go. But the only thing I know is that in Connecticut everyone knows Elsie Cofield, and they know me because when you call me, I will come. They know me because at midnight hour or any other time, if a person has AIDS, I

don't mind sitting with them or holding that person's hand. This is just an organization with one and one-half people, where you are asking for volunteers from the churches and from the community.

We have just had so many people say no to us. No, it is not done that way. You don't have that kind of organization. But we do have the organization. We care for our own, and we are needing support. We will be there to care for our own. We do hope that the other churches, especially churches, will get this message.

Dr. Jordan talked to me, and we were talking about some ways that we are trying to reach our communities. In this curriculum some things, and I will be closing, says call together your religious leaders, your citywide denominations, interfaith groups locally on a statewide level and let them know what is happening. We did it in New Haven. Help provide and promote readily available AIDS, HIV-related prevention education to children. We are trying now to organize a peer group where children will be trained to help other children. We can't wait until they get to be adults. We have to start in kindergarten probably--at least third grade to educate our children.

We as black leaders must bring to focus culturally appropriate AIDS, HIV-infection related prevention education. It is different in the black community. This is what we are trying to get people to understand. We must promote readily available AIDS, HIV-related preventative education to all of our age groups in the context of sexuality-related education which teaches the fundamental goodness of sexuality. That is the church's job to teach that sex is good, but to teach people how to use sex.

We must be sure that adequate services in the field of drug use, addictive behavior and AIDS are provided. Our people need drug programs. Our people need our help with their homes. Our people need guidance. Our people need training.

We have many young mothers now, 16 percent of the people in New Haven who are coming down with AIDS are heterosexual mothers with babies. Right now I have one mother with six children saying to me that I want to make sure that my baby dies before I die. I say to her why are you saying that? Because if my baby dies before me, I will make sure my baby is taken care of until that baby dies.

That is bad when we get to in a black community

where we have to say that. My mother had 13 children, and she always said I want to live to see my children get grown, and now we have mothers who want their babies to die so that they can make sure that baby is being taken care of.

In closing, I would like to say that I am a member of a group called the Interdenominational International Association of Ministers' Wives and Ministers' Widows. This year our president, Dr. Shirley Hart, from Norfolk, Virginia called us together to organize an AIDS task force. So we have done it in the black community. We are doing it in the black community. What Dr. Hart has done is to put out fight out AIDS with facts. Ignorance kills. This is from the Interdenominational International Association of Ministers' Wives and Ministers' Widows.

The last statement here is to be Christian is to minister to the hurting, including those infected and affected by AIDS. The last statement comes from this book. This is a little book that I wrote and got a copyright for my first year working with people with AIDS. In this book it tells about 13 people who died with me holding their hands or giving them their last meal or whatever it was. They shall not walk alone.

The following are people whom I walked with this year who taught me that PWAs are people who need to feel valued and be valuable to others. They need to live their lives in a healing community where there is peace and tranquility, and most of all they need to be free of fear and inhibitions that would keep them from living life at its fullest in fellowship with God and man.

This card was made by a person who died, a person with AIDS. A beautiful card. She was a designer. She could do everything. In this book that I talked about, there is a poem that she wrote. A very beautiful person. A person of flesh and bones. A person who needed love like all of us need.

And my appeal to you is to give us funding so that we as ministers' wives or religious leaders can then get into communities. It is hard for a religious organization to get any funding to work with people with AIDS, but that is where the answer is. My appeal is that you would allow us to do some of the things or more things than what we are already doing because we are going to take care of our own.

Thank you.

[Round of applause.]

MS. McDONALD: Good morning. I am Sandra Singleton McDonald. I am founder and president of an organization called Outreach, Inc. It is in Atlanta, Georgia. I am southern by birthright. My good friend Dr. Rowland and as we go around the country, people tend to think we are a little different, and we are. They can always tell by our accents that we are southern.

So my remarks this morning are going to be centered around being raised in a black southern family in the southern part of this country and having some particular values that I was able to bring into this organization and talking about how it is working.

I have chosen to bring you a report this morning from the frontline. I want you to know what it is like out there, what is going on, what is working, what is not working. I am going to talk about some positive stuff and some barriers.

I also want you to understand that personally I am a person enraged. I am driven by rage. I am enraged about discrimination. I am enraged about too much young death. I am enraged about the use and abuse of illegal and legal substances in our community, and I represent a black community

that is enraged and sick and tired of being sick and tired.

Everything we hear about ourselves is negative. Our black male sons are at risk for their very existence and now here comes AIDS. The topic that we were to deal with this morning is how to organize our communities.

I might look in one vein and say what now? We already are now dealing with drug abuse. We are dealing with crime. We are dealing with drop outs. We are dealing with last hired/first fired, and now you want me to deal with another problem? Where is the good news in my life? Give me something positive about which I can get up and listen to. Don't tell me anything bad.

My respects to Mrs. Cofield and Reverend Cofield and all of the great things they are doing in their church. But too many times in our community, others look at us and say the church is it. That is the one entity in our lives that ought to center all of our attentions and all of our educational efforts and et cetera.

I agree with that on Sunday, but there are six other days in the week. If you look at Wednesday prayer services, there are 50 folk there. So perhaps on Wednesday nights I shouldn't be doing my intervention at a church

prayer meeting, whether I was to be in the night clubs where the majority of the people are taking their mid-week break with a little alcohol, making it feel a little better so I can get through Thursday and Friday.

I am going to focus my remarks on other than the church, organizing people where they are. I first want to say the black community is not homogeneous, although many people think it is. We are going to give you a grant to do education in the black community. I love that one.

[Round of applause.]

MS. McDONALD: We have many subpopulations in the black community. We have subpopulations in the black family. We do not embrace homosexuality. We do not embrace drug usage. We don't talk about either. And then you want us to sit down on Sunday dinner and talk about AIDS? Let's be real. Let's talk about why we don't embrace these things and why we don't talk about them.

Many of us grew up very much the same in households in the '50s, and that is we all grew up in a box. You all didn't realize we were in a box. Let me remind you what some of the rules were on the box. You were malleable. You had your place and your place was out of the sight of anybody

grown. You did not talk back. You were not outside after dark. No young man would have the nerve to call your house after dark, nor would one appear on your doorstep and answer, as your mother or father answered the door, he would not say, "Yo." He would be dead.

[Laughter.]

MS. McDONALD: Nor would he pull in front of your door and blow and expect you to run out of the door. You would be dead. The worst thing that could happen in this box is pregnancy. The worst thing that could happen in this box was pregnancy. Pregnancy in that generation meant that you had shamed your family. You had shamed your church. You had shamed your race. You were dead.

The worst thing that now happens to our children is much more than having babies, although we need to talk about teenage pregnancy at another time. What happens to our children is death. Our children die. They just don't have babies anymore, they die.

Let's talk about organizing people where they are. Let's talk about some of the places where black folks go; sporting events, schools, after schools, around schools, street corners. There is always a hanging place in a

community. Whether it is urban or rural, there is always a place where people congregate. It is a "hang" place. It is a fun place. I love "hang" places. You can just go and shoot the breeze. It is good. It is a good place to communicate. Beauty parlors and barber shops, the best educators in the world. Whether it is right or wrong, that is where we get the information because we do a lot of idle talking when we are in these shops.

Recreation centers. Where are the kids that aren't going to school during the day if they are black males? They are shooting basketball. They are at the recreation centers. They are inside and outside of those centers. Another great place.

Pool halls. Some more athletic skills. Video stores. My God, I wish I had money in some of these video shops. These kids live on those machines. They are there in droves. Sometimes they are there in the daytime. I wonder why somebody doesn't know they are not in school. The storekeeper doesn't mind. He is glad they are there. That is more quarters for the machine, but where are their mothers and daddies? Why don't they know they are doing the machines rather than being in schools?

Pizza parlors. Another good "hang" place for the younger group. Night clubs, shopping malls.

Let's talk about some other interesting places. Have you ever noticed how many people come to the emergency room of a hospital with somebody that is sick? There might be four or five family members who accompany this one person who is ill. You go in and you are sick, and there is nowhere to sit because everybody is there with their family. You say, well, I hope I don't have to wait for all of these people. But once their family member comes out and they all get up, you say, well, what an excellent place to do AIDS education--emergency hospital room.

Unemployment lines. Have you ever had to stand in one? You are there all day. You are there forever. An excellent place to go in and do some interventions.

Let's talk about the message and the messenger and let's be very clear that that is very important in the black community. Let me say it is just not enough to be black. It is not just enough to be black. It is not just enough to know about HIV and all of its medical terms. You have to not only walk the walk, but you have to talk the talk. If you have never been pregnant, you cannot talk to me about having

a baby. Because when you say I understand, I know that you are lying because how could you understand? You have never gone through labor pains, and while you might have been there to hold somebody's hand and all of that, you didn't actually have this child. So you can't really tell me what I am getting ready to experience because you haven't experienced that pain.

Addiction is bigger in our community sometimes I think than life. Addiction is rampant. We are just now understanding that addiction is a disease. Many people who have active addictions do not understand that they have a disease. No one has ever told them about recovery. All they understand is this is something, for some strange reason, I have to continue to do. Quickly, the reason I can tell you that, on our staff of 26 people, 23 folks on our staff are either recovering substance users--all kinds of substances--and are people with AIDS.

I have lived it because I have a son struggling with addiction, and I absolutely want you to know that it is horrendous. Around addiction there is so much pain. Not only the person using in pain, the family members who are trying to deny it are in pain. The struggles of saying,

Lord, how can I tell anybody my son has just sold our VCR? That is the real world of addiction. It is not in just low economic households. It is many households all over.

If we are going to do anything about HIV infection, we have to do something about addiction. We talk about sterile needles, and we talk about other kinds of ways to get addicted people to change their behavior. We think we are experts on it. We, in 1989, our street team of 12 recovering members did 98,000 101 interventions. 98,000 people they talked to. They are well respected and received in crack houses that police won't go into.

Let me tell you what it is like to have an ongoing addiction and then tell me about a clean needle. I have prostituted all night to get this money. That means I have been in and out of sexual situations from 12 midnight until 4. Don't get concerned I'm not talking about me. That is not what I did last night. I'm just giving you a scenario. I don't want you all to get concerned now. I didn't do that last night, but I might.

[Laughter.]

MS. McDONALD: At any rate, at 6 a.m., I can't wait for 6 a.m. to come so that I can hit the dope house. I have

been waiting on that. I physically need a fix. My body is dictating. Everything about me is driven to get this fix. I do not have my works. I broke them. I left them in a trick's car. For some reason, I don't have them. The dope man has a needle there that he will let me use for a dollar. It is not mine to keep. He will let me use it.

Now I have a choice. I understand about AIDS. They were here last week, and they gave me this literature and, yeah, every now and then I use these condoms, but right now I have got to have this fix. Now I have a decision to make. Am I going to not use this needle because I feel that someone else has used it or it is not clean? Am I going to say, you know, I really do want this dope, but you have to give me a new sterile needle because of AIDS or is my desire for the drug so driven that I will use anything to get the dope in my body?

Unfortunately, it is the latter. I have got to get the dope in my body. Now the good thing that has been provided is that our programs around the country supply bleach. If it is there, I will use it. I don't want to get HIV infection either, but I am driven by addiction. So if you then give me the bleach, I will use it and thank God for

it. I will clean my works because that is a routine I go through anyway before I shoot my dope. I take the syringe and pull up the water and squirt it out. To myself, I am not only cleaning the syringe, I am making sure it doesn't stick because once I get this dope in this syringe, I want to make sure I get it all in my system.

So, yes, if you have bleach there, it will work. So what can you do as a commissioner to make sure that happens? Make sure that you keep empowering us to put bleach there. If we don't do it, no one else will.

Cute story. The first time we did bleach, we took it to a shooting gallery. We took several little half pints, and we were so excited. The young woman who runs the house said, thank you, it is really good. We went back in four days and all of the bleach was gone except maybe a half bottle. We said, God, we are really doing something right. We said, God, you mean you used all of this bleach and they really used the bleach? And she said, yes, you all going to bring me some more? So something about that had a little game in it.

So we said, wait now. Are you sure you used this bleach? She said, well, I am going to tell you the truth. I

washed my clothes with it. Do you see what I am saying? I washed my clothes with it.

Well, then we had to change our strategy. We now do personalized size bleach bottles that someone can carry on their person so that we no longer leave gallons so somebody might wash their clothes with it, and it works.

What can I say to the Commission that would influence you to understand that CBOs work? Empowering us to educate and take care of our community is what we need. Don't tie us down with regulations that are not realistic though.

For instance, just because you have a report that you need to write that says you need me to go into shooting galleries on corners and ask people a lot of history about their sexual use and all of that, don't tie my hands by asking me to do that. First of all, if you ask us to do it, we would have to tell you no because when I then go on the street and do that, you make me ruin my credibility with my clientele. Because asking questions with a pad and pencil is taboo on the streets. You can get killed by doing that on the street because you have set up a reason for the community not to trust you.

Why do you want to know my name? Yeah, I did dope last night. Why? So do this to us. Tell us what you need and allow us to do it the way we do it. We ask questions and never write a stitch. We then give it to a reporter who is sitting in a car who writes down all of the numbers. The person on the street never sees the person writing so they don't know that we are keeping numbers. We don't go up to folks and write. That is a very dangerous thing to do.

Secondly, allow us to do what we do well and that is talk black, be black, interface with our community on our own level, hire our own staff. Let us hire very flamboyant gay males to go into gay nightclubs because that is what works. We can go in there all night, and we are not going to get the real deal. They are going to give it to somebody they trust. They don't trust me. They don't know who I am going to give it to.

Allow us to hire people who might have active addictions because sometimes they can get us into dope houses that nobody else can get us into, and so we need that person to work with us for awhile until we can get that person drug free. And empower us to have local community drug treatment places. I am not saying that they all have to be 28 in-day

patient beds, but we need the ability to have community walk-in drug clinics so that when somebody wants to get clean, they can come to a safe environment. If we can do nothing else that day but talk to them about getting clean, they have that opportunity. It does not exist now.

Let me leave you by saying that what we have done over the last four or five years with the money that has been allocated for minority education has worked. We started out in 1986 we used to have to start a session by saying blacks get AIDS too. That is how we had to start out. People were not aware at that point that we, too, were at risk. AIDS 101 now if you start a session could be done by anybody in the audience. They very well understand how this virus is transmitted. Don't think they don't. They understand very well that they cannot get it casually.

Help us do now the harder step. We have now done the education real well. Let's go to Step 2, which is helping people modify their behavior, and the way we get that done is continue to fund these community-based organizations which have worked. We want to be empowered to do it our way in our own communities.

Thank you.

[Round of applause.]

MS. SINGLETON: Good morning. My name is Sonia Singleton. I am from Miami, Florida, case manager for the Pediatric Demonstration Project, South Florida AIDS Network, Jackson Memorial Hospital.

I would like to first share that I am very pleased to be here because I have been given an early Christmas present by seeing Sandra McDonald, Marie St. Cyr and Phill Wilson who early on validated me as an HIV positive woman, so thank you. Of course, it is always a pleasure to see Harlon Dalton.

First, I will give you the good news. Since May, when I was here, I have finally qualified for a research protocol, so it appears that you did listen and hear my plea. I am very pleased Dr. Sullivan is here because I need you to read my lipstick. By virtue of my history--no, not history, but "herstory" and experiences as a professionally and personally impacted woman, I am obliged to be truthful.

I sometimes feel I was born with a plague when I was born an African American. I was treated as such you see for a very, very long time. Nevertheless, what HIV infection has done for me is to help to utilize all of those past

experiences and to help change and grow from them.

I refuse to be mistreated by any means ever again. It is my opinion that people like myself, African American, HIV positive, recovering IVDU and crack addict can take the message to people like ourselves. As Sandra McDonald stated, it is not the message, but the messenger.

I believe that recovering people should be encouraged and supported, not punished for having had a drug problem. I am highly offended when someone asks me how I got infected. Does it matter? Will it make this virus less deadly? Or if I didn't get it from my dentist, am I going to live?

Pardon me for not being Allison Gertz. In essence, I am saying the African American community has been greatly affected by the categorization of this infection. In Belle Glade where I worked for about three years it is a typical example of how our focus on IV drug use instead of focusing on behavior of addicts period has allowed a whole community to die from this disease.

Belle Glade is inundated with crack cocaine and nobody even talks about crack cocaine and sexual involvements of its participants. When the Surgeon General Koop sent AIDS

information to every house in America, he should have sent someone to read the information to these people because, you see, most of them are illiterate.

The AIDS crisis, I believe, has only just begun in terms of dealing with the heterosexual African American people. It appears that the resistance of mainstream America and HIV infection in terms of heterosexual transmission has not even been addressed appropriately.

The African Americans will continue to believe what is dictated to them. My recommendation is that you move aside and allow us to empower our people in ways we know we can do it.

Finally, to Mr. Goldberg, I believe, until proven otherwise, HIV infection is a manmade disease, but it will not curtail my efforts in educating and advocating for my people. I say to you that many of the programs that I have been working with and for are working, but we especially need to have people of color educating and giving information. We need your help.

Thank you.

[Round of applause.]

CHAIRMAN OSBORN: Thank you very much for a very

moving set of statements. We very much appreciate your being here. I know, Mr. Secretary, that you have to leave soon. Do you have any comments that you would like to make?

DR. SULLIVAN: Yes, let me begin by saying before people to whom we have heard since I have been here that your stories are very compelling and very powerful, and I want to thank each of you for your willingness to come and share them with us.

Let me also state this that, as Secretary, and certainly I speak for my department, we want to do everything that we can to work with you to address more effectively the problem of AIDS and HIV certainly in the black community as well as in other communities as well.

There are a number of comments that were made that I would certainly welcome perhaps more information. Let me just list them and perhaps ask if you might get them either to me or to Dr. Allen, who is here, because I am going to have to make them and then unfortunately leave.

But the first to Dr. Jordan, your request that we set aside time to meet with the NMA members concerning physicians refusal I gather to treat patients with AIDS. Let me say that I would certainly be very willing and pleased to

meet with physicians, who are facing this problem, at any time. The one suggestion I would have is perhaps rather than waiting for the NMA meeting, I would say at any time, say, in Washington or elsewhere, if there are ways that we can help with that. The question I have is this is a problem I think with all physicians. There are a number of white physicians who continue today to refuse to treat patients. I wonder if your statements imply that this is even worse among black physicians than among white physicians or whether it is really a side of the same coin.

The second comment concerning a minority task force on AIDs. Again, I would like more information. My own reaction to that would be I would hope that if there is to be anything like that, it really ought to be part of this larger Commission because, quite frankly, I think we have sufficient difficulties, I think not only federal, but state and local governments and the private sector, I think dealing with the problem as it is now, and there is a lot of expertise and history on this Commission.

I would feel that if there are ways you feel this Commission cannot meet this, I would want to see if there are ways that we can help this Commission to change or modify so

that it can. But I think that with any task force, just the administrative issues, getting such a group up-to-speed, the funding of such a group, the organization, as well as the inevitable confusion with different groups, I think would pose a problem. So I would really want to argue for that activity being a part of this group rather than a separate group unless there are some compelling reasons that you didn't have a chance to get into.

So far as PSAs on AIDS, we have, in my department, developed a number of ones both addressed towards the black community and for the Hispanic community as well. Your comments suggested these are not getting out. They are not being used, but we have a whole battery of things that I have made myself that our public affairs office has done, and we want to look at this and see why they are not being used and see if we can help that as well.

A quick comment to Mrs. Cofield. I am very encouraged by the report that you have given on the churches' activities. I think that is very important because I would echo Mrs. McDonald's comments that I know that in order for us to be successful in this effort we need to have a lot of help from other organizations. I know that the federal

government is often looked upon really without complete trust, and I know that the authority for changes in behavior or educational programs can be much better carried out by people who are known and trusted by people in the local community. So we certainly would encourage you to continue your activities.

I don't know what history any of you have had in terms of getting funding for your organization. You comment on the need for funding, but certainly we would like to know more about that to see if there are ways that we could be helpful.

A quick comment to Mrs. McDonald. I know Mrs. McDonald, being an Atlantan, and having worked with her in Atlanta with her AIDS organization before coming here. I simply want to commend you for your presentation here and again reinforce our desire to work with you.

To Ms. Singleton, I think certainly I would agree with you that having the perspective that you have and others have and the access that you would have to people that many of us don't have, for a number of reasons, we want to encourage that.

So, in summary, I would like to say we want to find

out where there are barriers or lack of support or insensitivities because we want to do everything we can to remove that. So we certainly do want to work with each of you to try and get successful approaches underway to addressing the problem.

Thank you very much.

CHAIRMAN OSBORN: Thank you very much, Mr. Secretary. As the Secretary said, since his schedule is tight, Dr. Allen is with us and can convey some of the responses and certainly continued correspondence as well.

Ron Jerrell, I know you had a question earlier.

MR. JERRELL: Yes, my question is to Ms. McDonald. I commend you on what you have said. I agree with you 110 percent. The community-based organizations is where it happens. I am especially interested in your comments on the places for conducting AIDS education. As a person living with AIDS myself, I have had the opportunity, I guess, it is not exactly the right word, to stand in long unemployment lines as well as the Medicaid office, the food stamp office, social security. What has been your success in providing education to the people that are in those situations that are sitting there with usually nothing to do that could benefit

from the education?

MS. McDONALD: You would be surprised. Well, you probably wouldn't. You have probably seen it, too. People are very receptive to information. First of all, they are shocked that you cared enough about getting the information to come to them where they are. You would not expect Outreach workers to come to an unemployment office.

There are two sides to that coin. We weren't invited there by the unemployment officials, so really it is kind of like trespassing. So we had to kind of pretend we were also there for--you have to be a little different in this one. It helps. While we were doing our one-on-ones, we did get asked on several occasions to leave, but had a person who was asked to leave said I'm in line waiting for my claim. What I am saying to you is, the reception from the group that was waiting was great. They needed the information. They wanted to hear the information. They were glad we were there.

The reception from the officials was a little different. We all had jobs, and we have to protect our jobs and all, but we have now tried to work around that by sending our information package to the officials that be and say we want to continue to do this. But we have done it on a back-

door porch maybe 20 times, and each time the reception has been great.

MR. JERRELL: Thank you.

CHAIRMAN OSBORN: No other questions or comments from the commissioners?

[No response.]

CHAIRMAN OSBORN: I think you have given us a lot of new and important insights and reinforced some of the ones that I think we have been learning repeatedly about the value of the kind of interventions that you are talking with us about. We express our appreciation to all of you for your very rich testimony.

David, did you have any comments you wanted to make before we adjourn?

DR. ROGERS: We are very much in your debt. We heard you.

[Whereupon, at 12:20 p.m., the proceedings were adjourned to reconvene at 2 p.m. the same day.]

Thank you.

MR. WILSON: Our process it is going to be now that Catlin has laid an overview. The three of us are actually going to have a discussion. Keith and I will introduce ourselves, and then we will begin our discussion.

My name is Phill Wilson. I am the newly-appointed AIDS coordinator for the city of Los Angeles. I am the founder and co-chair of the Black Gay and Lesbian Leadership Forum and the past educational director for the National Task Force on AIDS Prevention.

MR. CYLAR: My name is Keith Cylar. I am the coordinator of client services for the Minority Task Force on AIDS. We are the largest and first minority cooperation in central Harlem providing AIDS services for people of color. I am also a founding member of a new organization, which is going to be to provide housing for HIV-infected people, particularly people who don't fit the normal systems; those who are chronically addicted to substances and those who have chronic history of mental illness.

I am also an active member in ACT-UP New York.

MR. WILSON: Catlin, now that you have laid the overview about coalition building, I have to come to the

table with some questions. First of all, I need to ask the question what is a coalition and why do we want to do that and look at the issues of interracial coalitions, multiracial coalition and interdiscipline coalitions. As a black gay man, one of the things that I bring to the table and one of the things that I have said to people, as a black gay man living with HIV disease, I am a nigger, I am a faggot, and I am a leper. So I bring that to the table.

One of the things that I have discovered when we talk about coalitions, we are talking about ways for people to say they are connected as opposed to being connected to me. In interracial environments, I find that I come to the table with nongay people with an expectation that when I come to that table, I stop being gay.

When I find myself in multiracial environments, particularly those environments that are initiated by white people, I find that I come to that table and often I am required to leave my ethnicity behind.

I am reminded of an experience I had a little while ago at an event called the War Conference, where it was an event for the gay and lesbian community to deal with issues in our community. The first person got up to speak and spoke

about the diversity in our community, and this is a room of 300 people, and I looked around the room and there were three people of color in the room.

After I brought that to people's attention, a number of people approached me and said, "You know, we are supposed to talk about gay and lesbian issues, and I wish that you would stop bringing up the divisiveness of talking about race." My response to them and my response when I come to coalition meetings is how do I do that? Am I supposed to be black on Sunday, Monday and Tuesday and queer on Wednesday, Thursday and Friday? It doesn't work that way for me. I don't know anyone that it works that way for.

The final area of question for me in regard to coalition is the issue of interdiscipline coalitions. Where I find more increasingly it becomes a battle of AIDS/or, and in the community that I work with that is not an applicable strategy. That is not an applicable approach.

The reality is that AIDS is in a health context; it is in a deficient social service context. So I need to talk in those terms.

Finally, I find that I come to tables and it is about me learning the rules. I am reminded of the film "Cry

Freedom," where Steven Beko is instructed about how to work together. His response is you want me to come to your table and use your silverware and eat your food. I suggest that we build a new table, that we throw away the old table, we create a new table that is our own creation.

So if we are going to talk about coalitions, we need to talk about all of those issues and what the relationship between those issues and where we want to go.

MS. FULLWOOD: I think, just to respond very briefly, and then Keith we will turn it over to you. I think that what we need to do in terms of the formation of these coalitions is that, first, they must be forged by people of color. We must have the resources and the power by which to forge our own coalitions, and to set our own agendas, and to build our own tables, if necessary.

I think that, as Park Parker said, we will know when we have true freedom when we can take both our black self and our gay self to the same party. I think that that is true of coalitions as well; that we must be able to take all of ourselves to the party, and we must be able to take all of ourselves to the table in order for the dialogue to have meaning.

In terms of multiracial organizing, I think that in a state like Washington, where we make up 12 percent of the population, it is critical that we organize across lines of race. As part of that organizing across lines of race, is that we across those lines confront homophobia and the different manifestations of homophobia within our community, that we deal with cultural difference, that we talk about the things that separate us as people of color and how to overcome those barriers so that we can ensure that when the time comes, those communities can unite together in order to effect the kind of change that has to happen.

I think that the reality of it is that what we are working against is the lack of prior claim; that we weren't there when the rules were set, and we are asked to adhere to other people's rules and that in order for us to forge our new rules, I think that we have to ensure that prior claim is held by all.

MR. CYLAR: In response to what my colleagues here have been saying, I want to start off with what we have to do inside our community. The first thing that we have to deal with is that black gay men are real, that black gay men are present, that we have to deal with the homophobia.

When people tell me time and time again that the black church is the only way that the black community can get organized, I have problems with that. The black church has not dealt well with black gay men. They have not dealt well with AIDS. They have not dealt well with the stigma around drug use.

We need to confront them. We need to do that in-house, and that needs to be put out on the table first before we can come together and form a multiracial coalition. We aren't together on that.

When you deal with multiracial coalitions, you have to deal with the issue of power. People have to be willing to give up some of the power, some of the control, some of the media glamor. We have allowed ourselves to be manipulated by the media. Constantly people tell me, as a member of ACT-UP, that ACT-UP does not speak and that there are no people of color in ACT-UP. That is not true. That is consistently not true.

We are people of color. We are part of ACT-UP. We do believe in a lot of the things that happens. When you go out and you say that, people say, well, you are an exception. I am not. There are lots of us there. A lot of times what

ACT-UP has said and not been heard is that people of color need to be here. People of color need to be involved in the ACTG. They need to be planning this. They said that, and now there are people involved, but no one takes credit for that. So there has to be some power there. There has to be some sharing of responsibility.

In addition, you have the need for CBOs. CBOs are nontraditional. A lot of the AIDS work is done by CBOs that haven't had a long history because they were formed in response to this epidemic. When you compete with hospitals and hospital-based clinics, you have to fight against the traditional medical establishment.

From a CBO perspective, a lot of times you are the guy who sees a client. You are the guy who sees the homeless person. You are the guy who sees the women who won't go in for prenatal care to a hospital. So you have to have some legitimacy when you begin to dialogue with the hospital so that you can have some of that power sharing, so that you can say my perspective is valid. This is what our clients are telling me, and I see the client. We need to respond in this kind of way.

Hospitals don't want to give up that power. They

want to be able to collect all of the money to do all of the work and base it in a hospital. You can't do that because community-based organizations need some of that money in order for them to develop.

With regard to the question of infrastructure, part of what has happened again is a result of the growth. CBOs have been forced to respond to this AIDS epidemic. They sprung up overnight, and a lot of times we don't have the infrastructure. We don't have the systems in place to handle what we are handling, and we are doing it, and we need some time to catch up.

We need some time. We need some money to hire the staff so that we can better utilize the resources that we have because we have access. We are the people in the community. We have the gatekeepers. We are the people who have the most access to these people and not the traditional institutions. So when you begin to take a look at the role of the CBO in the coalition building, they have to be legitimized. They have to be included.

Part of the problem with all of this is the way the federal dollars are spent, the way the funding streams exist. That needs to be looked at. There needs to be a way to fund

dollars to community-based organizations that bystep the traditional institutions.

Let me stop there.

MR. WILSON: I have a question again on this issue of resources. Now one of the concerns that I have about the mandate for coalitions, particularly in people of color organizations, and maybe this goes back to this issue of distrust. It seems to me that there are two motivators or at least a motivator and then a response to that motivator, and that is really the motivation around abdication; that it provides an opportunity for the federal government or other entities that have a responsibility to provide service, and to deliver care and to be responsible health bodies to abdicate power.

What we are left with are people fighting over a pie that is already too small. It is really kind of a cynical environment to be in. One of the things that happens, I come to the table again and one of the concerns that I have is that I have repeated experiences where we are sitting at the same table, but someone else goes to the funder. The issues that we talk about at the table are not discussed, and the reason why they are not discussed is

because they are afraid that if they discuss the whole pie, they discuss all of the needs, that the needs that they have are not going to be met or the constituency that they serve is not going to be met.

Consequently, we work in an environment where we approach the table with the accurate assumption that there is not going to be enough pie to go around. So it boils down to how do I make sure my constituents, my clients get the services that they need.

MR. CYLAR: I think part of the way to do that is that we have to create and generate a larger response on the part of our constituency. Our constituency has to become more active. They have to become proactive and say we deserve a larger piece of the pie. We at the grassroots level we vote. We take part in our government. We are people, and we need to be able to mobilize them, and that isn't happening.

MR. WILSON: But how do I do that? For example, I was with an agency before I took this position where we had a staff of two people. The two of us were required not only to deliver programming, but to go to coalition meetings, to go to the conferences, and then to be the black people who spoke on AIDS across the city. We don't have the resources to be

true partners in a coalition environment.

If I participate in an ACT-UP demonstration and get arrested, I spend four hours in jail, and that is four hours that I could be delivering services to someone who needs services this moment. How do I resolve that?

MR. CYLAR: Again, it is a hard decision, but I think part of why you do the ACT-UP demonstration is because for us we have to at least get some attention on what the issues are. Unless you get the media coverage, unless you get the issue out on the table, it remains a nonissue. As long as it is a nonissue, you are never going to get a bigger slice of the pie. You are never going to get those people involved.

I like to drop the issue right back into the clergy. The clergy have a responsibility to begin to mobilize a community. They, in that regard, are a structure. They are an institution, and their homophobia, their sexism, their addictaphobia prevent them from doing that. So it comes down to an individual response. Somehow or another you have to have an individual take the responsibility to be the lead person, to go to those people who are less responsible.

What I see happening in New York, for example,

there was a town meeting, the first town meeting in central Harlem about AIDS. It was called for by the borough president's office. The town meeting happened. People came in. They dealt with AIDS. When they dealt with AIDS in the black community, they dealt with women, they dealt with children, and then they made all of these homophobic remarks about black gay men and disempowered them. That wasn't really dealing with AIDS in a community. That wasn't dealing with the real issues. So somehow or another, we have got to get people to deal with these very difficult issues and deal with drug treatment also at the same time.

MS. FULLWOOD: I think my question in all of this is how do you define community? Are we talking about the middle class or are we talking about the people who we ostensibly are trying to reach; intravenous drug users, crack cocaine users, women involved in the sex industry, gay and bisexual men of color and lesbians of color?

Organizing us among ourselves oftentimes is an important component that we overlook and that we can have power. I think that we can effectively move a county council by walking in with 20 intravenous drug users. We can effectively make change by coming together as gay and lesbian

people of color and marching on city hall. I think that we must remember when we talk about mobilizing the community, that it is not just about mobilizing the church, that it is not just about mobilizing the black intelligencia, that is not just about mobilizing the middle class, that it is really about mobilizing all of us.

I think that I find a lot less resistance among people who feel themselves most specifically and dramatically affected by the disease to be mobilized than I find from those people who consider themselves either above it or so removed from it that it has no relation to their lives.

MR. WILSON: I think that the metaphor of community doesn't work and that the metaphor of family certainly doesn't work, particularly in an environment of dysfunctional families all of the time. The reality is that we are communities, and we need to understand that and that there are times as communities we need to meet common enemies or common challenges and work together.

But one of the things that happens with the metaphor of community and the metaphor of family is that we get dishonesty. We get the conspiracy of silence that often happens in dysfunctional families. Consequently, when we

come to the table with the real issues, the real deal, then we are viewed as being divisive by doing that. So I think that part of the process of building coalition really has to move away from this metaphor of family or community singularly and work on some other metaphor.

MR. CYLAR: I think, in light of that, we also have to take a look at AIDS fits into a context. As you said earlier, we need to take a look at the comprehensive care model of delivering health services. AIDS fits in that whole continuum of health care. We need health care. We need prenatal care. We need drug treatment. We need prevention. We need education. We need nutritional counseling.

When you take a look at that kind of model and compare it to what we don't have in our community, it is a lot easier for our communities to then become mobilized because as long as we say AIDS, they say it is not my issue. I am not gay. I am not an IV drug user. It is not my issue. I have to deal with housing. I have to deal with poverty. I have to deal with unemployment.

All of those things relate also to AIDS, and we need to begin to build a comprehensive care model that allows everybody in the community to say, yes, I can live with that.

I do not health care. I do need prevention. I do need housing. I do need a job, and why don't we have these thins here?

MS. FULLWOOD: My question then to you, Keith, is are we talking about setting up dual systems? My position has always been that there are organizations in the public and private sector that get paid by government dollars to provide services. They have to be held accountable to provide those services to everyone. At what point do we say this is not working, give us the money and we will do it? What are the ramifications of that in terms of the ethics of it, the accountability and the morality of it, realizing that we will never have the level of resources necessary to effectively meet the need? Or Phil.

MR. WILSON: I take it that you have to do both of those things. I think that an agency that defines itself as a broad-base AIDS service agency or health care agency or whatever they cannot abdicate that responsibility. At the same time, there are populations that they cannot reach and only we can reach. So both things have to happen. We need to hold majority cultural agencies accountable, and we need to do that at that coalition table.

At the same time, part of that accountability is advocating for people who are appropriate to deliver services, and that means gay agencies or white agencies need to advocate for people of color agencies, and a majority of cultural people of color agencies need to advocate for gay men to talk to other gay men because we do it better.

Sandra said earlier you cannot talk about having a baby if you have never had a baby. Nothing makes me crazier than talking to heterosexual men who tell me that they understand what it means to be a gay man. They don't. Unless you have slept with a man, you don't know what that is about. Unless you have had the experience of being called a sissy or a faggot or any of those experiences that you internalize, and you live with, and you carry that with you, you don't know. So consequently I bring inherently with me a skill that people who have not had that experience don't bring.

MR. CYLAR: Let me also say that a lot of what we need to do is I don't have a medical facility at my site. I don't want to have a medical facility at my site. I will never get a medical facility.

But what I do need to have is access to a medical

facility. I need to have access to some place to refer my clients that they are going to get the kind of care that they need and to have a dialogue back and forth between us. I need to make sure that when I refer this client, that not only is he going to get seen, but that he is going to get talked to in a in which he can understand and relate to, and I also need to have some feedback about what happened. Maybe the client is not the best person to be relaying that information, so I need to be involved in the treatment planning for this particular client because the medical process has a major impact on such things as his living arrangements, such as how he gets home care, who his support systems are.

If I don't know that you are considering putting a Hickman catheter in, which means that he is going to have to make these daily trips back and forth and you don't know that he is an active substance abuser, your medical plan isn't going to work, nor is my social service intervention. So we need to have an open dialogue and a more responsive kind of dialogue that doesn't exist now.

MR. WILSON: The last thing I want to say on the issue of coalition and on the issue of dual service is we

live in a society in this country where we use this metaphor of a melting pot, and I think that that metaphor is dysfunctional. That in a melting pot you end up with soup. I think that, based on my cultural experience, since the next workshop is on cultural relevance, but I think that a stew is the more appropriate metaphor, that we do different things and, as in a stew, you have your meat, and your potatoes, and your vegetables, and they keep their identity, but they all work together to make the stew a viable meal. I think those are the issues we need to deal with in the context of a coalition.

MS. FULLWOOD: So we are the cooks of the movement. We would like to invite comments or questions from the Commission at this time.

MS. AHRENS: I think I have heard you well in terms of your coalition building within and/or between the various ethnic communities in a local situation. I guess what I would like to hear from you is how you would perceive the relationship of those communities to the "public sector" or the sector that really is, in a sense, in control out there in terms of how the money is passed on; how the scarce resources that we have are utilized.

We have made a real effort, not enough, but a real effort I think in terms of the counties across this country to get the message out to counties--and in most states it is counties that are responsible for the public health. I think that is probably not true in New York City, but I think it is true in the State of Washington and the State of California--for working together or finding ways to build the coalitions with the public sector so that the communities that need to be involved are involved at the planning stage, that they participate in the allocation of those resources and get their fair share. But at the same time, the accountability for the use of those resources is also very much a part of that equation. I wish you would talk a little bit about that.

MS. FULLWOOD: We have found, in the State of Washington, that a public/private partnership is the only way to go and work closely with state government, county government and local government as well as with our regional AIDS nets. We have that structure as well.

What we have endeavored to achieve are local minority community-based organizations that help develop and identify leaders from within each of the communities in Washington State and probably have been most effective at

this time in identifying that leadership in Spokane, Yakima, Tacoma and Seattle and are working now in doing organizing in Snohomish County as well as in southwestern Washington. So that when it comes time to go to the table, when it comes time for county government to elicit response from the community or to sit down and make those decisions, that there are people of color available in those communities who are learned in the area of AIDS, who are learned in the needs of their communities and can come to the table with a wealth of resources that can be shared.

If I tell you that this always happens, I would be lying. But this is what we are trying to achieve. I think that we have been fairly successful from the community level in terms of identifying those leadership and need to continue our efforts to encourage the regional AIDS nets and the local health departments and county governments to make sure that they call upon that expertise.

MR. WILSON: I think that one of the things the federal government has to do is that the evaluators of the county health departments have to be from the community bottom line. The reality is that we are the people who are seeing the clients. We are the people who are doing the

education. We can tell you whether or not the county health department is doing its job or not.

I consistently have experiences with a director of health in the County of Los Angeles who will tell you very directly that his job is to keep the county board of supervisors happy and will tell you that there is a difference between the needs and the interests of people living with HIV disease and the interest of the county. That is a problem.

So if we are talking about a partnership, the people who are the evaluators are the wrong people.

MS. FULLWOOD: Keith, did you want to respond?

MR. CYLAR: It is hard for me to respond because New York is a little bit different. I guess one of the things that we need to do is to have more community involvement. Right now the way New York is broken down there are only maybe four or five people who are considered to be leaders and experts. Some of those people aren't, in fact, the best people to have involved.

So I think one of the things that we need to do in New York is to take a look at who are the leaders and how did they get to be there? Are they self-appointed or are they actually from the community? Do they really reflect the

needs of what is going on?

New York is I think different also because of the way things are stratified in terms of the city, the state and the federal government and also the different boroughs. Each borough has a different kind of flavor. Each community has a different flavor within New York, and that is very difficult to try and meet those needs on a wide-based basis. So it has to be very individualized to that particular community and that particular community's needs and who speaks for that community. It is not just one person. Not one black person can speak for all of New York City nor can one Latino. So you have to have a multitude of different people.

MS. FULLWOOD: To the other half of your question that talks about accountability, I would like to see us develop systems that help us maintain a high level of quality of services, education and prevention efforts within our communities, so that we as peers can look at what we are doing, at what needs to happen and provide the kind of technical assistance and leadership develop that is going to be necessary in order for our programs to be as excellent as we want them to be.

That requires, of course, resources, and it also

requires self-determination and control of our programs. I think that that kind of a peer-review standard could be very effective in ensuring that that happens.

DR. ROWLAND: I have always felt that problems like this, just like the problem of infant mortality, can be best addressed on a local level with local people dealing with it. But I have heard this morning, and I have heard from you, someone made the statement, if you haven't had a baby, you don't understand about having a baby. If you are not an African American black male that is gay, then you don't understand about the problems that that individual has.

Listening to this morning about the legacy of mistrust that exists in the black community, if you are not a black, you don't understand what goes on and what takes place there. What is the best way for people who don't belong to those particular areas to help in dealing with it?

I find myself somewhat confused about what can I do as an individual to help with the problems that you are facing. Do you really trust me to help? I wonder if I work and try to do something to help is what I am doing in vain or does it make any difference? Are there insurmountable obstacles that you can't overcome?

I haven't heard that really explored very much here, and I would like to know what your feelings are about that.

MR. WILSON: First of all, I would like to bring some clarifications to at least my statements. Sandra has to clarify her own statement. I believe that if you are not a black gay man you don't understand what it means to be a black gay man, but that does not mean that you don't have a part to play and that we are getting some place, hopefully, and we all have roles to play, but you can't play my role, and I can't play your role, and that is what I mean by using that phrase.

To the question of what role can nonblack and nongay and lesbian play in issues that impact black gay and lesbian people, there are experiences that are mutually relevant that you may not know what it means to be a black gay man, but you know what it is to be a man, and then that commonality those are things that we can share.

You may bring technical expertise, but I can apply a cultural relevancy/a social relevancy to work. You may bring resources that may be helpful for me to do the work that I need to do.

You may have access to people that I don't have access to. You can be an advocate in that respect. So I think that there are roles that we all can play and we need to be clear about that, that we don't have to all play the same role.

MS. FULLWOOD: I think that, once again, your comments really point up that need for coalition. Because, as Phill says, we need the support and the advocacy of white people, basically. I mean we as black people have lived next to and with white people all of our lives. White people can say that I grew up and I never met a black person. A black person can't say I grew up in a world in a country where I never knew a white person. We know white people very well.

In that relationship, we have found that it is important that we be able to identify these commonalities and thereby forge these collegial coalition relationships in which we all, as Phill said, have our part to play and that each part is recognized and sometimes rewarded, oftentimes not. Coalition work is not a very rewarding activity except if you have the vision to look toward the long-term goal.

I think for each of us, in terms of determining whether or not making the effort has any meaning, that

question is between us and our conscience, and one that can't probably be answered by another person.

MR. CYLAR: I also want to say that I think one of the real important things that I got out of what you said was that you recognize the fact that you can't speak for us, that you recognize the fact that we need to be included and you need to be asking us what will work. You need to hear us. We need to be a part of the planning. We need to be a part of the evaluation. We need to be a part of the process that says this is the amount of money we have, how do we spend it?

If we are there, then we can help you. Because as long as you dictate to us how the money goes, who gets the money, how it is going to be spent, how the program is going to work, it is not going to work.

So having us there and recognizing your own limitations is real important.

MR. WILSON: On that issue of hearing, really hearing, for example, for years, and Reggie Williams is here, for years I have been a part of tables where people will say what do black gay men need to hear? How do you deliver those messages?

Just this past year, I developed a program that was

funded by the County of Los Angeles and developed a curriculum that offended white heterosexual women. I was developing a program for black homosexual men. Because my program offended white heterosexual women, it was deemed culturally inappropriate. Why ask me to come to tables to tell you what is culturally appropriate, and then we go back and develop those programs that work in our community, they have to stand up to some test of people who are not a part of that community.

So don't invite us if you are not going to listen to us because we have work to do.

MS. DIAZ: This is a question for any of you because I am sure all three of you have experience in this and feelings. The models that are present in New York City for receiving input from the diverse ethnic and racial communities are somewhat along racial lines. We have a Black Commission on AIDS, now a newly-formed Hispanic Commission on AIDS, and I sure various other groups that are really inputting into a governmental or public system of these are our needs, these are the dollars that we need and the resource allocation distributed this way.

The model in Seattle is definitely one of multi-

ethnic/multiracial coalition and collaboration where you go into these public-funded systems with a common agenda.

In Los Angeles, kind of a mixed bag I think of both and probably now the system of Ryan White moving us toward a truly collaborative coalition multiethnic, we hope.

But I just wonder, from the sense that you have in your various communities, whether one model in the times we are in now of really scarce dollars, the epidemic increasing in its significance to our communities of color, what would you say from your experience is really the major challenge at this point in going along either multiethnic/multiracial representation for making our needs known and how do you think that this is going to pan out in the various areas you are representing?

MR. CYLAR: In New York, one of the problems or one of the areas that I think we need to do some work on is within the African American community there is a tendency for us to want to speak in solidarity; that we want to speak as one voice, and that is the kind of urban league model, and that isn't working because the black community is more than just a model of.

Those of us who aren't the mainstream black

providers, the mainstream black institutions are still struggling with the fact that whenever we begin to criticize other people who happen to be also people of color, that we are disempowered by being told that we are tools of the white man. The issue of racism then begins to be used against us. So there is some internal housecleaning that needs to happen when you begin to take a look at coalitions.

When you take a look at how that plays itself out in New York between the Latino and the African American community, there is beginning to be a real split. So we need to begin to take a look at that. We need to do some closed-door housecleaning, I think, among ourselves. We need to be able to criticize each other and then from there have a real discussion about how to share power within our community and then we can then join together and go to the table and better respond.

MS. FULLWOOD: I think in Washington State, because of our small numbers as well as because of what we have found to be an effective and powerful model, we will continue to organize multiracially. One of the new layers that we are going to have to deal with in terms of a new level of conflict is services versus prevention. Keith and I almost

had a fist fight last night, but Phill managed to get in the middle.

But this whole issue around do we focus our energy, and our time and our resources into services for the people of color who are ill now and ensure that that happens and create whatever liaisons or whatever systems of care have to be created in order to ensure that or do we put our money and continue our focus on prevention? At this point, the services are critical and prevention is prophecy.

So we are really--we are going to fight about it again--we are really in a position of having to make some very difficult decisions. That will vary from race to race. So the only way that we can come up with a comprehensive analysis of how to proceed with our resources and our energy is through having that commonality of being able to come together.

MS. DIAZ: The question is does that work because of the few numbers in each of the groups in Seattle?

MS. FULLWOOD: I think it works because of the few numbers. I think it also works because we do not have separated communities as much and because there is no barrio. There is a community of central Seattle that is primarily

black, but Rainier Valley is black, Asian, poor white. It is a very culturally and ethnically mixed community. So I don't want my outreach workers out on the street acting the fool around Asian people. I want them to be able to act appropriately no matter what person of color or what white person or what person they come into contact with to be able to do an effective job and to make that connection.

MR. WILSON: What I would say, and a business school motto that I learned when I was in business school was the motto of long-range planning and balancing that with cash-flow management, and I think that is what this is an issue of. That the long-range planning of it really is multicultural planning that we need to understand that we need to do that. The cash-flow management of it is ethnocentric work.

For example, in Los Angeles where we have barrios and we have ghettos, we need to understand that there needs to be strong ethnocentric voices that speak. At the same time, we need to come together and create multicultural coalitions to talk about the common experiences that we have together. So I think that is the way we balance that so that when I go to the table and talk about black and lesbian issues, I can,

in fact, advocate for the Latino gay and lesbian community and the Asian gay and lesbian community, but I cannot speak for that community.

One of the things that we are doing in Los Angeles is having a commitment that we call each other when there are these coalition meetings, and that is how we address the resources. All of our organizations have one or two or three people, so we empower one person to go and to report back to the group. So that is how we deal with the cash-flow management portion of it while we do the long-range planning.

MS. FULLWOOD: We also have a Washington State Latino AIDS Coalition. We also have an Asian AIDS Council realizing that within our coalition efforts, African American is the dominant culture. So that even within our multiracial organizing it is very important for there to be separate power and separate space for people to do that organizing that that feeds into the greater coalition.

DR. ROGERS: Just to comment, I found your dialogue there wonderful. I think we should put you all on the road. That is a very effective show, and we learned a lot of important things there. We thank you very much.

[Round of applause.]

CHAIRMAN OSBORN: Many thanks. I think we will take a 15-minute break and then return for the next panel. Thank you.

[A brief recess was taken from 2:55 p.m. to 3:30 p.m.]

CHAIRMAN OSBORN: Having participated in getting us off schedule, I must apologize, but I wanted to have a very good chance to hear the final panel for today and welcome you. I hope you will organize your time the way you probably discussed it.

I do want to mention that at the conclusion of this panel, there will be an interval of public comment. People were to have signed-up somewhere if they would like to. I guess if somebody wants to sign-up still there is a sign-up sheet just outside where that can be done for brief public comment.

Let me then turn to our panel who has been very patient, and thank you for talking with us. Rashidah Hassan, Jacob Gayle and Reggie Williams, welcome and thank you for being here.

DETERMINING WHAT IS CULTURALLY APPROPRIATE

MS. HASSAN: Thank you. As was indicated, my name

is Rashidah Hassan, and I am the founder and executive director of an organization called BEBASHI, which is Blacks Educating Blacks About Sexual Health Issues.

The agency was organized in 1985 to provide nonexistent targeted information to people of color in originally the City of Philadelphia. Within six months of its founding, it moved out into Pennsylvania, and a year and a half after that, we were in Pennsylvania, Maryland, Delaware, Virginia.

Across the country we provide the identified model, as it were, of minority education. We serve as consultants across the country for the development of targeted education projects for people of color.

What all that meant I don't have the vaguest idea in the context of determining what is culturally appropriate because I never know whether culturally appropriate means for you or for me, and that probably is the biggest difficulty in trying to identify, neatly box and package what is culturally appropriate. It can't be done.

But I will try to give you some idea and, as we have our discussion, we will all give you some ideas I think about what we see as issues of cultural appropriateness.

One of the things that I think just the phrase alone implies is that there is an acknowledgement of our history in this country and the diversity of the African American community. I am always amazed to find that African American includes everyone who is darker hued in the country who is non-Spanish speaking. I have seen literature that has indicated that it is appropriate for Haitians and those that are born in the West Indies, as well as those who are born in the United States, Canadian Africans, all of that is sort of lumped in together, and it is culturally appropriate if it is designed on a third-grade level.

I discovered in the City of Philadelphia that that is what is culturally appropriate; the assumption that all people of color are functionally illiterate and, therefore, we need a lot of pictures.

The review panel that was developed for literature did not initially include people of color, but did include third grade teachers, and so that is how they determined whether or not our review was acceptable or not.

One of the things for me that even cultural sensitivity and culturally appropriate sort of evoke almost immediately is an annoyance and on some days outright

hostility.

I suppose that probably in the last three months one of the things that has stuck out for me is having gone for the first time to Europe. I had an opportunity to attend the Nongovernmental Organizational Conference in Paris. To say that, first of all, it makes it real clear that I hardly ever go anywhere outside of the United States, I am very impressed with myself to have been in nearly 40 states in the United States, something that will live in my family truly as a famous person because very few of my relatives have left the State of Pennsylvania.

So the idea of even going to Paris was a shock to everyone, and they are all incredibly proud, and they are running around with pictures of the Eiffel Tower.

But part of what I want to say about that was it was the first time, also, I was called an American, and that was a cultural shock because I have never realized I was American, only born in Pennsylvania of African descent. I must tell you that I was incredibly offended most of the time because peoples' impression of American was so negative; that we are essentially rich and that we just flaunt our abilities, and I was sure they weren't talking about me. I have no gold

card whatsoever.

[Laughter.]

MS. HASSAN: One of the difficulties I think in trying to determine what is culturally appropriate, even to explain to someone else, is for you to, first of all, recognize we are talking about our history, and you have heard a great deal about the impact our history has had on how we interpret health issues and how we try to develop models of education, et cetera, in our various communities.

One of the things that I try to bring to peoples' attention all of the time is that people of color live two separate lives. One life is the one we have out front where we are incredibly articulate, that we command the English language as though we were wrestling a beast to the ground, that we are extraordinarily conscious of our verbal subjugations, that we learn to pause as opposed to saying "ah." We never speak quickly so that you won't think that we are too stupid to be able to breathe in between our words and essentially we carry ourselves in the best way possible so that you will realize that we are a group of very intelligent individuals.

And then the sun goes down, and we take our various

transportations, in my case it is the subway of Philadelphia, back to the neighborhood where I really live. On the way there, I note for myself tremendous changes that happen. In Center City Philadelphia, the stops that are important are trees. They are all located downtown. There is Walnut, and there is Locust, there is Market, Chestnut, et cetera, and the border that separates the African American community from the Center City begins essentially with Girard Avenue.

When you get to the other side of Girard Avenue, I find myself slouching in the seat. That is culturally appropriate because you want to be as inconspicuous on the subway as possible. It makes you less susceptible to muggers. I know that from having been on the subway watching other people get mugged who insist on sitting up straight and flaunting all of their jewelry. You don't do that when you cross Girard Avenue. That is culturally appropriate. It is also very sensitive.

[Laughter.]

MS. HASSAN: We cannot put that in a brochure or put it on a video. That also is an issue that for me has created consistent difficulties. We have developed in Philadelphia no less than four films. I am on no less than

three of them. I am the culturally appropriate, culturally sensitive spokesperson for the black community of everything that looks relatively brown in the City of Philadelphia.

I did not know that until I found out that they translated my words into Spanish so that, even though they couldn't find a spokesperson for the Hispanic community in 1986, my words now have the mouthing of Spanish, which of all languages, which I cannot even speak. Yet there is a film that mouths the words in Spanish.

One of the biggest debates we have had, for example, with our AIDS Activities Coordinating Office in the City of Philadelphia is also the issue of cultural appropriateness. My colleagues--used incredibly loosely--in the department feel that we should not bring negatives to the appearance, to the knowledge of whites on our AIDS board. So what they would like us to do is show the lovely tree-lined streets of the black community of Mount Airy and Chestnut Hill, which would be fine if we had significant incidence of AIDS which we would want to bring peoples' attention to, we should show the tree-lined streets.

But they felt that we needed to show culturally appropriate diversity; that all people with AIDS are not

poor. They are not all IV drug users. They are not sex workers. That there are actually one or two people in the City of Philadelphia who hold jobs over $50,000 a year--the two of them--also might be susceptible to AIDS. But that would be considered by their recommendations culturally appropriate.

I do not have culturally appropriate material I don't think. I can't tell. People that use it understand what it says. Those that don't understand it, don't use it. So it works out very clearly for us.

We do talk a great deal in our presentations about history because the issues of our own creativity, putting our concepts on paper, turning them in, as we are often asked to do to the various health departments to give a concept of what is culturally appropriate, often turn up as new projects for the City Health Department, and we are rarely, if ever, given credit for it. So I am not sure that they understand, since very often the most important element, the spiritualness that is associated with our cultural sensitivity, is also missing out of those programs because you cannot put that down on paper.

We are frequently "pimped" for those very ideas and

that always creates a difficulty because you cannot get the job done. Consequently, in Philadelphia we have a most interesting situation in that we have the City Health Department and its AIDS Activities Office presenting the black community with a message in competition with the message that we are funded by them to present--a very confusing thing, since they can't say words that are not written in the dictionary and expect to get clear understanding of the meanings that are trying to be presented when you are looking at behavior change.

They also wouldn't want to give up the funding associated with the administrative overhead of managing the office if they didn't do culturally-specific education as they describe it.

What that basically means is that they do what is devoid of the spiritual, historical perspective and culture in their education, and we speak the language of the people. Consequently, we also do more AIDS education than they do because people don't understand their message.

I think that one of the most important issues probably around recognizing what is appropriate depends on what culture you are talking about, and it is different for

every group within the subgroups of our community. We have a large contingent of people in Philadelphia who migrated, and they are second and third generation migrants, as it were, movers from the south. Those who came up in the late '40s/ early '50s to the new land, as it were. Many of them from the most southern regions of our country. Lots of North Carolinians in Philadelphia, a lot of Virginians in Philadelphia. If you perhaps go further north, you will have an even more diverse group, depending on what the jobs were like between 1920 and 1950.

That also reflects then the kinds of basic cultural values that were present at that particular time. My family has a long history of participants in Masonic Orders, and so the value systems that we were presented with were very much based on you live right, do right and everything will ultimately work out properly, even when it didn't. It didn't matter. Those were the attitudes.

We also have a generation that came through during the '60s and '70s and said, "We knew it wasn't going to work out that way, so it doesn't matter if we are good or not." There is another culture, another language that is associated with that, a different type of anger. One that we try to

contain, but that actually also is reflected into our behavior.

There is also a new group coming up that people are very intense about because they wish to deny our second or third mechanism of communication because they don't want to talk about rap. I love rap. I am learning how to rap. But it is a communication tool that is very much appropriate for the culture, when you are talking about adolescents, for example, or if you are looking at what some of the best vehicles for transmitting information is.

So I think that talking about cultural appropriateness is a very confusing term. It requires the impression of validation by others that what you see as part of your culture is satisfactory and that that is the measure by which is made to say that this program should or should not be funded.

I am not sure how you are ever going to be able to determine what is culturally appropriate. I can, and I think that the presentation of programs in generic language you simply have to nod and understand that and let us do what needs to be done in that perspective wherever we are.

DR. GAYLE: Buenos dias, bon jour, hello, what is

happening. I use a few of the languages that are very important to the people that I am going to describe in just a moment.

To first of all introduce myself to you is sort of like introducing myself to my sisters and my brother. Nevertheless, as you know, I am Jacob Gayle, and I serve the Centers for Disease Control as special assistant for minority HIV policy coordination.

Of course, when we talk about minority in our country, we are talking about people who represent worldwide 80 percent o four global population. Hence, my reticence in using that title at times.

Nevertheless, in talking today about the issue of African American communities and HIV and AIDS, I shared with you a presentation that I am not going to take the time to read because, of course, you have it before you.

I wanted to just say before Reggie Williams speaks something very quickly that sort of defines who we are as African Americans. Please indulge me for a moment.

Who are we as African American? We have been niggers, colored, negroes, Afro Americans, black, African Americans and people of color all within my years of life.

We are every phenotype that you see here in this room today. Genetically we range from 100 percent to 1/16th of African stock.

We are daughters and sons of American slavery, yet we are also immigrants from Africa, the Caribbean, yes, even Europe, Asia, Australia, the Pacific region, Mexico, Central and South America. We speak English, very good English. In fact, it is almost to the point where if you hear someone described as being articulate, you almost know that is synonymous for being black.

Yet, despite our good English, we also know how to speak the community English, [witness spoke French and Spanish phrases], and many other languages and dialects that reflect our own national and ancestral past and historical backgrounds. Yes, in fact, we are a very diverse people.

I want to tell a real quick story, and this has to do with the Commission. When we were traveling together in rural Georgia, a black physician came up to Harlon Dalton and said that he was very glad to see that there was a Baptist minister on the Commission.

[Laughter.]

DR. GAYLE: Now I am not convinced that Scott Allen

is not black, so I don't know. But once again even our diversity sometimes is not recognized by our own community. Yes, we are black Baptists, and Methodists, and Pentecostals. We are also Catholic and Protestant, Jewish, Islamic, agnostic, atheist, areligious. I could go on. We are married. We are single. We range from zero to 6 on the Kinsey scale. We are employed and unemployed. Pharmacists as well as drug users. Recalcitrant patient as well as physician.

Bottom line, however, is that when we talk in the society that we live in today, black is yet black, nevertheless.

I hope that as we open up our dialogue, and Reggie I know has words also to share, that we keep in mind the importance of cultural diversity, not only in the message that we share in terms of HIV prevention, care and services, but also the importance in terms of cultural diversity and recognition when we talk about requests for proposals, for guidelines, for federal, state and local policies.

I say that if our national agenda is uniformity at any cost, then we should continue doing the great work that we have conducted thus far.

If instead our agenda really is prevention and eradication of HIV and AIDS, then we have to recognize and celebrate the diversity of our African American communities as well as our nation's diversity and total.

MR. WILLIAMS: As you may already know by now, my name is Reggie Williams, and I am the executive director of the National Task Force on AIDS Prevention, which is a project of the National Association of Black and White Men Together and our Men of all Color Together chapters across this country. We have 25 chapters.

When I was asked to come and speak to the Commission, I was really quite honored. When I was asked to present on the topic of what is culturally appropriate, I began to wonder a little bit why someone like myself would be asked to talk about cultural appropriateness to you guys, when, in fact, what I do is men. I do men and that is what my agenda is. So I knew that I had to come and tell you that.

Now how that plays into AIDS and HIV in the African American community I think is quite significant. As a black gay man living with HIV, coming out of the black community, I think when you begin to talk about what is culturally appropriate, it is a role for someone like myself to have and

to present to you.

As you heard this morning, there are specific issues and problems within the African American community that we may not be as cohesive as we should be given what is going on in our community around this epidemic. A part of that problem for me is not having been embraced for whom I am and what I am as a black gay man by my community.

Someone spoke about how the churches in the black community are beginning to get involved, and this is true, but it has been a long struggle. I was very, very pleased to hear the woman from the church and her husband about the great things that they are able to do for their constituency. But having worked in this epidemic since 1984 and having been diagnosed since 1986 and living in San Francisco, coming from a city that is the model city, and finding in my work that the model did not include people of color and now being a part of a process that is changing that model because the model is not working.

Those are the kinds of things that I have to deal with on a day-to-day basis in the work that I do, whether it be inside of the African American community or outside of the African American community.

For black gay men, we are like walking a fence. We have the "mainstream" community, which really consists of white gay community because they, in fact, were the ones who initiated programs in the beginning. They were the ones who came to the beck and call of the epidemic because what you saw in the messages that were being put out were white gay men and what you saw in people who were soliciting action were white gay men.

So now we are trying to change that, but for many of us, as people of color, specifically, African American, we are not accepted by the mainstream community because of the racism that they want to impart upon us in not giving or sharing that power.

We have the problem in our communities of the homophobia; the fear of people who are gay and/or lesbian, because there is not that acknowledgment of me, as an individual, in my community, not that I have not been there for many, many years. Black gay and lesbian people have been a part of the black community for centuries in this country.

So we are fighting this double-edged sword as people on the battlefield dealing with AIDS and HIV. Those are some of the issues that I wanted to be able to put forth

to the Commission before we begin our dialogue I think.

MS. HASSAN: I think one of the things for me coming in was really looking at how you get a willingness for the sharing that would allow you to develop materials, for example, that makes sense for black gay men, for example. One of the things that has always been very difficult is people's willingness to share.

For example, even though I know in the white gay community white gays are ostracized from their community, what was really hard for me to understand was what is homophobia in the black community because I know for a fact it is different than what is said in that global statement. So I needed to know what that meant, since many of our choirs certainly are full of gay men and church music wouldn't play on Sunday without them.

MR. WILLIAMS: Absolutely.

MS. HASSAN: So it is not the same issue of homophobia, and I always wanted to know what that meant. You can't really get a sense of that because we don't have that kind of exchange.

MR. WILLIAMS: The experience that I have to use, the most recent experience that I have to use happened a few

miles down the road in Washington, D.C. last month where we have a chapter there, a Black and White Men Together chapter there, and we did trainings there. We have trained facilitators, black gay men to be AIDS educators and facilitators. We have a workshop specifically for black gay men that was, in fact, designed by Phill Wilson when he was a part of our staff, and we were working with a black community-based organization to do AIDS education and risk reduction workshops to the black community.

The community-based organization in D.C. put an advertisement of our poster series, which was approved by the CDC. As a CDC-funded program, I have to get all of my materials approved through that process.

The community-based organization, like I said, ran an ad in a local black community newspaper in D.C. when someone in the AIDS office in the District of Columbia felt that that ad was inappropriate for the black community. Now we weren't trying to reach the black community through our workshop. Our workshop was for black gay men. But this black straight woman felt that our program was inappropriate for the black community.

So I hear your question about homophobia in the

black--you know, where does that lie? My question was why was she in charge of what was going to happen for black gay men? How can she say what is not appropriate for black gay men?

DR. GAYLE: I think it also brings up an issue that I wanted to bring up in terms of some misunderstandings within the community itself; that I think we sort of exemplify what has happened to us. You talk about a woman who is straight in the black community who doesn't understand the issues of gay men within the black community. There is no such thing, as we had said earlier, in terms of a black community.

We are just as pleuralistic in our backgrounds and our interests and involvements as any other community.

MR. WILLIAMS: And we are not a monolithic community by no means.

DR. GAYLE: By no means at all. One of the issues that I deal with quite a bit on the position that I am holding now is that of African American populations that are not of the mainland; such as our populations that are either born or raised in the Caribbean or from Africa itself or elsewhere that are all lumped together within "the black

community."

I think that when we talk about race, ethnicity, nationality, also when we talk about the specific issues in terms of sexual orientation, you have got to see the multiplicity of even this community that people would like to see as being one monolithic community.

MS. HASSAN: I have had some interesting experiences most recently with these review panels, where you are there--I must admit that once again I am the black community representative. I was able to get another nurse, however, to participate, who is a school nurse, but we are reviewing materials for our school board.

One of the things that was incredibly interesting was people kept reading over these masses of statistics that talked about the effectiveness of, for example, sexual health education, and here are all of the pamphlets and brochures, et cetera, followed immediately by all of the statistics that referred to the fact that none of the programs worked, but we were going to review them to make sure that we could continue using the same materials. No discussion at all on whether or not we should perhaps change how it was being presented.

I think the best example that I still see con-

tinuously repeated are the ones that talk about the actual act of fertilization. Every child in the City of Philadelphia does this. They say an egg and a sperm come together. It is part of the whole persona. So nothing that happens below your waist is related to anything that--now that seems to me to be inappropriate when we are talking about an adolescent pregnancy rate that is off the charts. There is something about that that is not quite appropriate.

But to get to change, it was impossible. No one wanted to hear that we ought to be focusing on behavior changes and that that might mean things like self-esteem workshops, whatever that means, because I am not sure. That is another one of those catch-all global phrases. Let's build everyone's self-esteem and how you go about doing that exactly that could be translated into university-base language, which is what I spend a lot of time trying to do.

One of the things that we have been using as a mechanism is that when we develop a project, we sit in the community and we talk about how we do focus groups. Of course, we don't call them focus groups when we are doing them. It is just neighborhood speaks or somebody stopping by for coffee, but you have to say focus groups because that is

the translation.

We do a lot of that. I go to several university-based human service organization institutes. They send someone to sit in my staff meetings. The staff, we talk among ourselves as we talk, with the "this here" and the "thems" and "yos" and all of those kinds of things, and the person's responsibility from the university is to translate that into their English.

That is how we are able to determine what is culturally appropriate because it is translated by someone else. We don't try to pretend that we wanted to create it that way in the first place. That way we can be sure that we intended to happen actually is written into the development of the program.

We found that to be very successful, and it proved that if you get someone to translate for you who understands the other language, it does help a little bit in terms of getting the information down.

MR. WILSON: That other language that you talk about is also what we feel is important for reaching black self-identified and nonidentified black gay men, black gay and bisexual men, because you do have to be able to be

specific. To look at trying to change behavior in people, you have to be able to be specific. What we talk about in a workshop designed for black gay men may not be appropriate for black mothers, and women and other people in the black community.

So when you look at programs that are culturally appropriate, you have to make sure that you are able and you have the ability to address all of those issues.

I want to refer briefly to the findings from the National Research Study of black gay men that we did last year, and we found some phenomenal things, and this was just a baseline study because no one had ever done any research on that community; black gay and bisexual men. We found our respondents in all kinds of places. We found respondents right here in the City of Baltimore, in Washington, D.C.

We did 17 cities across the country, and some of the findings, and I presented to the Commission, are startling. Most of the men that we interviewed knew what AIDS and HIV was, and they knew what safe or unsafe sex was. But less than half of them always used a condom when they had anal sex.

Now something is wrong here with this picture. When they have that high of knowledge, but it doesn't

translate to behavior change. There are other copies of it in case anyone in the audience wants to have a copy of our findings. But those are the kinds of things that we say need to happen when you are designing programs.

MS. HASSAN: So you agree then that just saying use a condom--

MR. WILSON: That does not work.

MS. HASSAN: It doesn't relate. And why doesn't it? Because culturally condoms haven't been a part of our life and experience.

MR. WILSON: Of our experience, exactly. If you don't take the condom, and also with the condom show the proper lubricant that you need to use, people will take a condom and use an oil-based lubricant, and they will not be--

MS. HASSAN: The universal lubricant; vaseline.

MR. WILSON: Vaseline, right. And they will not be protecting themselves from AIDS or HIV or any other sexually transmitted disease that is out there.

DR. GAYLE: One of the other things that is difficult to deal with in terms of cultural diversity and putting it together with some of the guidelines we sometimes get from the federal or state or local level is the role of

religion or spirituality in our communities. Sometimes people I think misunderstand as to how the government can work together with the community-based organizations that represent the spiritual entity of our communities. That is a very, very important part of our community and the diversity.

It doesn't necessarily always mean the funding of church-related programs; such as within Christian church per se, but might relate to other kinds of spiritual perspectives that have been very important to start community growth and development.

The recognition that not only does that play a part, but then also the issue of ethnicity and race along with the aspect of spirituality. We talk about all of them as if they are all mutually exclusive, but what do you do in terms of the issue of the Hispanic African American who also is involved with certain aspects of spiritual growth and development that are very central to her or his community.

What do we do and how do we deal with that? Let's throw in the fact that she or he may be gay.

MR. WILSON: And then where does that take her? Well, at lunch, Rashidah, we were talking about the traditional medicines.

MS. HASSAN: What was the term that was used? Alternative holistic medical intervention. What that means is down-home remedies. It is a wonderful translation of the idea that you should eat right, sleep right, that there are herb teas that you should take, there may be laxatives or certain additives to your diet, and you must have some kind of spiritual intervention which may include reading of some specific religious texts or it may mean meditating. But to hear it sort of narrowly defined or nontraditional medical intervention--

MR. WILSON: Change.

MR. HASSAN: Yes, change. All of that sort of implies a cultural relatedness and say that is what black people do. They do nontraditional health interventions. So it also brings with it a certain negative judgment as well because if it is nontraditional then it is not sanctioned. If it is not sanctioned, then it can't possibly be correct. If it is not correct, it is obviously detrimental for you and you should give it up, which very often is in conflict with what we know is culturally appropriate, but there must always be room for the combinations of therapies, of prevention messages that come through that identify and, again, validate

who we are and what we have been about here.

I think that still probably the biggest issue for me is that most of the types of education that we try to do and the development of services have to look at what is real in the community; a reality of the community.

One of the things that we have had difficulty with, for example, is all along in all of our health issues is being called noncompliant. I find the term fascinating. I am a nurse. I have worked for 17 years in a hospital. I have done patient teaching and have fallen exactly into that trap. What it says, again, is that it is negative.

We are noncompliant, and very often I think my most frequent experience was with diabetics where they said here is an 1,800 calory ADA diet full of wonderful food products; broccoli and asparagus and things that are not even sold in the markets in the neighborhood. The person then goes back home, takes this diet, looks at it, puts it up on the refrigerator, and eats everything that is not on the list because it is not available in the market.

I have watched a very interesting transition. I bought a home in a neighborhood which was changing. I didn't know that, but now I am aware. It is a changing neighborhood.

The change for me has been what is available in the supermarket. Originally it was a very highly integrated neighborhood of professional and paraprofessionals. I thought it was a neighborhood with a good price--again, culturally appropriate I suppose falls into that.

But what was very clear there, there was a far more diversity of vegetables and meat products that were available. Today if you were to come to visit that same market there is one case available of beef, one case available of chicken, one case you might find mixtures of fish and turkey, but there are three cases of pork. Yet the very first thing on an 1,800 ADA diet you have to give up is pork, especially if you mix it with--you know, they have to be low sodium and low in cholesterol, and yet that is what is available.

So this noncompliant patient actually is trying to live up to a diet that is unrealistic in the context of who they are. It very much is reflected also in the demands for certain sexual behaviors for the black community. That while it does not recognize who we are when we were identified and labeled as dysfunctional family units.

Even physicians of color who care for us, speak of us in terms of being dysfunctional units, having noncompliant

family relationships, et cetera. When, in fact, if you took the labels off of it, it merely reflects the historical perspective of how we have been forced to relate to one another. I think that just adds again the kind of negatives for ourselves, so we don't want to talk about this is actually how we exchange information.

That if I am doing education in a housing project, I need to, in fact, educate the men who are there because if I am a woman living by myself in a project with two or three children, I need the $30 that he brings in whenever it comes, and he needs to know that I have got him and two others like him each bringing me $30 to help me get through this week. It is not saying that it is negative. It is simply a reality of the community, and we need to recognize that when we are talking about education.

DR. GAYLE: Yes, that is important. I want to play the devil's advocate in this. I am known to do that every now and then. I heard both of you and I also heard myself talk about the fact that we have learned how to be able to live in many cultures; that we can speak this language and that language, we know how to sit on the train when it is in one part of the city versus another. If we are gay, we

nevertheless know how to be able to interact with the nongay community. If that is true, then why do we need any targeted kind of culture-specific communication?

Can't we just communicate to people as Americans? If subcultures understand how to speak the predominant language, act a predominant way, can't we get the message across in one uniform way?

MR. WILSON: I believe that what I call the broad-brush message of AIDS and HIV prevention are not effective and have not been effective because they are just that; broad-brush. I think that programs need to be targeted in specific so that people can see themselves in the message.

We are fighting a battle now of trying to get the black community--we are going around saying black people get AIDS, too. Black people get AIDS, too. Why are we having to have to say that? Because black people did not see themselves with AIDS or in the AIDS messages on the brochures, on the posters, in the newspaper. Every story that was ever done in the early days of this epidemic had white gay men.

So if the people don't see themselves, then they don't believe that they are at risk. So we need messages, we need programs that are targeted specific to populations and

groups that will modify behavior. Because now we know that black people get AIDS, too. Now we know the Latino people get AIDS, too, and Asians and all of the rest, and women and children and all of that. The messages have to be targeted for those specific groups is my belief, and that is the way that we approach our work.

MS. HASSAN: Yes, I do think the message has to be done in a way that it allows the individual to identify themselves; that they can personalize the message. Most of what we see in the media right now doesn't do that. It is sort of the neutral individual, and that has allowed many people to back away from it. I think that while we are at this point talking about our communities being most at risk for ignorance, we also have to admit that there is a portion of white suburban American who will be equally ignored because they don't see themselves either.

It is more difficult for us because, aside from just having I think to overcome the issues of whether or not they believe AIDS exists, but we also have to be clear to our community that we are bringing a message that is safe; that we are actually translating what they are saying and trying to use it and present it to them in as clear a way as we can.

I have not done any presentations that didn't present the same kind of issues we talked about this morning. Is this a real epidemic? Is this something that is being perpetuated against us and what should be done about it?

MR. WILLIAMS: The issues of mistrust.

MS. HASSAN: That issue of mistrust.

MR. WILLIAMS: Definitely. That is a reality.

MS. HASSAN: That keeps coming back. Part of what we have been trying to say to them is it doesn't matter where it came from. Not only that, it doesn't matter what they say we should do about it. That what we need to do about it is what we know we need to do about it and set and establish our programs in that way.

BEBASHI has been, I suppose, somewhat fortunate in that we have, with great consistency, flew in the face of what was set out as the traditional methods of education. They wanted us to sit with little groups of 50 and do this basic broad stroke this is what AIDS is presentation. Do you have any questions? No. Well, thank you very much for your participation and kind of send them on.

Where, in fact, what we know has to be done is people essentially have to be fired up. They have to feel

committed to the personalization of the issues. So you give them a little bit of statistics, but you also have to paint a picture for them of who we are actually talking about. Say we are talking about mothers, and fathers, and sisters and brothers, et cetera, that they know who it is that we mean.

I find it very distressing, for example, to hear about intravenous drug users--drug addicts. Well, my brother did drugs. I never thought of him as a drug addict. He is a junky, and that is all that meant. He is still my brother. He still came to dinner on Sunday afternoons, and we tried to keep him from nodding off in his soup so grandma wouldn't notice.

But it did not in any way negate who he was in our family. So I find terms also are very important. You have to be careful of them that you don't end up labeling people as much as sort of systematically is done to us.

It is the same way with issues of prostitutes. What is a prostitute? To me it is someone who is using what resources they have available for personal economic development. If we look at it in that way, that seems a little bit different. But if you have no other alternative, no other means of resources, that is what you get.

Now that isn't to say that those behaviors ought not be in someway modified for the greater protection of the community. But if I approach every woman who is on the street with the idea you are a prostitute, and you need to do something about yourself, and it is always followed up with you pull yourself up by the boots you don't have and do something. Get a worthwhile and meaningful line of employment. Except there isn't anyone to take care of her children. Except there isn't any real access to health care. She doesn't have job training. We have eliminated all of those kinds of activities.

When we talk about setting up culturally appropriate now drug treatment, that is even scarier to me. What in the world does that mean? Culturally appropriate? Except that clearly what we have that exists does not reduce recidivism, so it isn't appropriate for whatever it is we need, and most of it is because the model is set as a male model. Go in, live up to yourself. Face your problems, and then turn back to the very community that set you off in the first place with all of its negative poverty issues.

So I have a lot of trouble with how we translate what we are saying to the community. So I admit essentially

ignoring a lot of that sort of jargon that comes out and looking at what it means in terms of setting up programs in the community.

MR. WILSON: Also, the mindset is that you shouldn't have to reinvent the wheel. Well, if the wheel is not working for us, then, yes, we do have to reinvent the wheel.

MS. HASSAN: Yes. Absolutely.

MR. WILSON: We may be able to take some of what was already out there, already going programs and look at that and change those programs to be more culturally sensitive to our needs and our issues or we may have to throw it out the window and start from scratch in our communities and have all of our people a part of the process of developing a plan for our community.

MS. HASSAN: I think if we take it from the perspective, again, of just realizing how we communicate ourselves when we are not in front of a big group; how do we talk to each other? How do we pass those messages on? That, in fact, is what has become for many of us the method of exchanging information and talking about informing and making people aware. I think ultimately it will have to be translated into services.

I think for me just at this point now looking at issues of buddy programs, what is a buddy program in the black community? It is the missionary society. It always has been. It is the sick and shut-in committee of the churches. It now may adopt a new name as we see the need to change it and modify it for different subgroup populations, whatever that--but, again, we already have names for that that are very distinct and very different from what was originally intended by such a word as buddy systems, and I think it is more reflective of who we are and how we have taken care of each other.

MR. WILSON: A part of what you talked about, though, Rashidah, and it is an old cliche that has been overused now, "empowerment," but it is a process of empowering our community to do the work. Part of the reason why I have been so involved in the black gay and lesbian leadership forum and conference every year is because that in itself is a system of empowering black gay and lesbian people to stand up in our own community and be validated by ourselves and our community.

That we are part of the African American community as well, and we don't have to run off to the white gay

community to find validation. That we can stay in our communities because, for the most part, black gay and lesbian people don't segregate themselves away from the black community. We live within the context of the black community. We have been there. We have been the nurturers. We have been for centuries, and so it is about empowerment for me as a black man to tell other black gay men that you can do this. Also, that even if you get HIV, I have to be a witness, that you can survive this disease. You can help other people from getting infected by this disease.

MS. HASSAN: Even the issue of rejection has gotten to be a real annoyance with me. I have many on those broad panel presentations I have had black gay men who are living with HIV infection talk about how they feared rejection of the community. My question always is so who did you talk to? What I find more than anything actually is that they took what white gay men have said, and that is what they mean by rejection.

As I have explained in some of the other conference panels that I have done, if you mean that you don't want mother to go through reading you the entire time she is bathing you and feeding you, yes, I guess you will get--

because you have to get the lecture. You didn't have no business going out to that place. But in the entire time that that is happening, there is still--

MR. WILLIAMS: She is taking care of.

MS. HASSAN: She is still taking care of you. It is very much, again, the way we grow up. I find myself saying exactly the same things to my sons that I swore I would never say, but, again, it isn't that I don't care. It is just that if they don't stop that, I really am going to knock them to a floating opportunity, but it doesn't mean that I don't care about them.

I think so for ourselves we, too, have to be honest about what we mean by issues of rejection, of denial, of homophobia and define it within a context of our own community and not so much that satisfies these broad and sweeping definitions by others.

MR. WILLIAMS: Interesting you should ask. In our survey, we found that 70 percent of the men that we surveyed felt that black people who have AIDS are often forgotten when it comes to caring and helping. Another 80 percent of the men we surveyed believed that religious people should be more sympathetic toward people with AIDS. This is what we found

through our respondents around the country.

DR. GAYLE: What happens sometimes in terms of determining what is called truly appropriate is that sometimes we let the wrong people determine what is culturally appropriate for us, and it is real hard because I think when we look in traditional systems, whether it be governmental or nongovernmental systems, the decision-makers are not the people of color, are not the African American people who we are trying to represent in our activities and our initiatives.

So what happens is that we take the time and opportunity to explain what is culturally appropriate in our society and in our system. But yet if we are not on the other side of the table also in setting the agenda, then it means that it goes for naught.

MR. WILSON: I think that it goes back to what Keith had said earlier around demanding certain rights for us, and it also goes back to what the other panel talked about as well in terms of coalition building, particularly around people of color, because there are strengths. There is strength in numbers, and the more of us that come to the table, the more power and validity we have.

DR. GAYLE: Exactly. The last thing I wanted to

say about that is that I think it is always very interesting how we do get called upon. I think of a former president that called on James Brown to find out what the feeling of the black community was at the time. It wasn't that long ago. Yet, it is funny how I think we can help in terms of setting the agenda for our communities and yet it sometimes neglected the fact that we also can help set the agenda for the community in total.

Likewise, on the other side, I think we deal with the issue of HIV and AIDS in the African American community as if it is the African American community's problem. If, in fact, again, I go back to the beauty of diversity in our country, then we have got to realize that the problem of the African American community is the problem of the American community. While I think we can help by helping ourselves, we can also help the entire community by being able to provide that kind of guidance in terms of the direction in which we go in the epidemic.

MS. HASSAN: Do you all have questions for us?

CHAIRMAN OSBORN: That is a wonderful kind of comment to get us into the conversation. Are there questions?

MR. GOLDMAN: That was a wonderful presentation for

which I thank you.

I have I guess it is a question. I haven't really framed it and forgive me if I am not clear, but I guess I have two questions or maybe it is the same question.

I am concerned about the question that you raise about educational materials being culturally appropriate, when I wonder whether or not, if the National HIV Research Study is correct, whether or not it is education that we are talking about in the first place.

According to this, 97 percent of the men surveyed know how the virus is transmitted. 89 percent know what the virus is. There seems to be a high level of general knowledge, and yet clearly there are issues in terms of whether or not there is the kind of behavior change that one might hope for, given that level of knowledge.

The question I have is whether or not education is the issue at all, and that is there any reason to believe that for a population that is already educated whether or not more culturally appropriate education is going to, in fact, effectuate any behavior change. I was wondering, and I can remember, I know I have read a number of materials in terms of some general theories of health education, and behavior

change and some of the issues involved in terms of being clear on whether or not you are talking about food habits or smoking or any other issues, that clearly more than knowledge and education is necessary in order to effectuate behavior change.

I was wondering if either of you might address the first question that I asked. If you might also address the second question at least in terms of traditional health education, are there any special considerations in the black or African American community that need to be addressed and that we ought to be aware of?

MS. HASSAN: I think, first of all, we really haven't, despite all that we have been talking about, we really haven't done a great deal of education towards behavior change. We have spent the last five years trying to raise the awareness in the community that this problem even exists. Part of being able to raise that awareness was to impart on them methods of transmission, some statistical data, et cetera.

I have not seen presented by anyone in any sector any real behavior modification kinds of education. I think it is inaccurate to think that we have done that in America

at all. We really have not. We have presented AIDS awareness information, and we have raised it to some very sophisticated levels that for me is No. 1.

No. 2, it wasn't even brought to the attention of the community until 1985 that we had something to even raise awareness about. It was not until then in the original year of the minority where we had the single-focused federal agency in our public health service talking about that, and that is the Center for Disease Control. No other public health service member has said anything about HIV infection at any significant level, which to me in 1990 is appalling as we move into even talking about financing care.

So I think, given that we have had to spend the last five years wrestling with community leadership, who did not want to deal with the issue or know anything about the issue at all, and then moving into actually hands-on education projects that simply were bringing to people's attention, that actually the black community has moved along a lot faster than most communities that are dealing with the epidemic.

I think we are at a point now of determining what that behavior change needs to be for ourselves. It isn't just not having sex for adolescents. It isn't just using

condoms for men. It is also not just nothing for women, other than essentially submitting themselves to this ridiculous idea of getting somebody else to use condoms on an organ that doesn't belong to us.

So I think there is still a great deal to be done in terms of figuring out exactly what that behavior change needs to be. We have spent a lot of time I think in the last four years focusing on things that are wonderful generalized ideas. Generally, we should get intravenous drug users not to share needles. We should get people off drugs. Those are very broad and sweeping ideas, but none of them are being presented with any real substance.

The fact that our drug treatment programs have a very high recidivism rate especially among minority populations; 28-day wonder programs do not remove a lifetime of addictive behavior. That you certainly need something much broader than that. The idea of coming out of a fairly decent drug treatment program, returning to the same neighborhood with the same conditions, no improvement in education, no improvement in the availability of jobs, no instruction on how to even go about doing a lifestyle change cannot possibly be an effective way to do it.

I think the other thing that we need to look at is where we have seen other kinds of awareness-raising activities. It has taken 25 years really for any significant change in seatbelt use, 30 years that I know about of anybody talking about reducing smoking, and we are still trying to get people to modify their behavior.

So even where we have recognized generally that there is danger, it has taken quite some time to figure out what the appropriate "stop behavior" kind of change really needs to happen. That is where our program is, is trying to really work on the issues that now people are generally aware of what do we do and how do we go about changing behavior.

MR. WILLIAMS: Absolutely. I think that that 97 percent of general knowledge does not translate into behavior change, particularly when you look at the point at which we got involved in this epidemic, and that was, in fact, after 1985 and here it is 1990. The survey was done and completed in 1989.

So there is not sufficient time to measure or gauge behavior change. Behavior change is something that happens over time. Particularly, given the statistics of black gay men who are continuing to be infected or come down with full-

blown AIDS, we know that that has not translated into behavior change. Particularly when you look at the years between 1981/1982 in San Francisco, particularly, and 1988 when the cohort studies in San Francisco said that new infection rates of white gay men were at baseline level. It took that many years to even bring about that kind of behavior change in that community that had most of the resources, knowledge, education, information, money, all of that.

So for us as African Americans and particularly African American gay and bisexual men, it will be a while, unfortunately, before we begin to see reduced rates of HIV infection in our community.

MS. HASSAN: And so much of the way we learn things is by word of mouth. It is extraordinarily labor-intensive because there has to come with it a certain amount of credibility from the people who are speaking it. So it is almost like doing it one at a time.

DR. GAYLE: I just wanted to add in terms of the question about behavior change theories, and I think that if we look at some of the theories from health psychology and health education, they become very relevant in terms of the

things that we have talked about today.

One of the models that is brought up most often would be the health belief model. Without going through all of the components of the model, there are a few issues that are very important, in terms of why AIDS 101 is still very necessary even when you look at the statistics as you see.

For instance, the need for the information to be perceived as salient, something that is very appropriate to whatever community I identify with. The relative value, should I be concerned about HIV or should I be concerned about finding a job, housing and general care for myself and my family? Also, the ability to feel that there is something I can do to alter my outcome in life. If I feel that in some way or another this HIV epidemic is something imposed upon me, be it through some kind of scientific study or whatever or just the fact that I feel that I have a very low locus of control or a low internal locus of control, I might feel like there is no way out.

Some of the activities, such as the one that Reggie was talking about, tries to appeal to all of those things. Make it relevant. Show that it is very important relative to other issues in life and that there is a way to control it.

The other thing too is you asked about some of the theories, and many of them are based upon the idea that cognition will then effect affect, and then, of course, have some kind of psychomotor changes. In fact, I think many of the theories that people are looking at now in health behavior and health psychology, show that perhaps the psychomotor change will in some way or another propagate changes in affect and cognition; such as we see in childhood. Mom teaches us or dad teaches us, in my case, how to brush your teeth. Is it because we learned first that in brushing our teeth, we will avoid certain kinds of dental problems or was it that mom or dad showed us how to brush our teeth and then as we went along in life we realized the cognition that ensued?

DR. ROGERS: Mr. Jerrell, did you have a question?

MR. JERRELL: I am just going to try to get a comment real quickly from you. In the information statistics that we received this morning from the South Central Los Angeles project, in looking over that and what you all have said in making education culturally appropriate, not only do I see the problem of making it culturally appropriate, but also lifestyle appropriate, when you have got almost a third

of these homosexual and bisexual men who are totally secretive.

Can you comment on possible past successes with that in developing information when you have got a large group of people out there that are not acknowledging the fact that they are homosexual and need that type of information, but don't want to be receiving that type of information.

MR. WILLIAMS: What we found through our survey is that there is a large segment of black men who are closeted gay or closeted bisexual who, in fact, have sex with both men and women and do not share that information with either party.

What we feel, as an open out gay organization, that it is important to educate, identify the gay population because they in turn are who the men are having sex with. If you can make those self-identified gay men strong and powerful in the knowledge that they will carry, that they will, in fact, only engage in safer-sex behavior, then they can impart that to the men that they have sex with, who are closeted bisexual or nongay identified at all men. That is the approach that we have.

Often, just like our respondents that we got from survey, we were told that they would be impossible to reach,

that they were the "hard-to-reach" populations. They were only hard to reach because mainstream agencies, white agencies would not go to where black people gathered, and we went to where black people gathered to get the questions answered that we wanted to know.

So that is the way that we choose to look at that, and there may be, in fact, other ways to do that within the context of the African American community, through churches, through civic groups, to reach those men who do have sex with other men, but don't identify as gay.

DR. GAYLE: I think of the study that Julius Johnson did quite a while ago in San Francisco, I believe, that dealt with the issue of black-identified gay men versus gay-identified black men, and then I think later on, in talking with him, he added another group of sort of the "I'm not either one of them, but I just sort of do what I do" group.

I think when you really look at all of the categories, you are talking about some different types of risks that could be involved. Usually you think of the person who is gay identified as more likely to be involved in relationships that may be long-term versus one who does not identify

himself as such and that the strategies in terms of trying to reach those populations are going to be different, but are very possible. It is not like those are communities that are impossible to reach.

MR. JERRELL: That you are educating your educators; is that true?

MR. WILLIAMS: In a sense, yes. Oh, yes. Constantly. That is a constant process.

MS. HASSAN: I think they learn sort of neutralized information, what Alyce had referred to as sort of being white African Americans, and it gets very diluted, and so their entire ability to even pass on information is very difficult, very diluted.

DR. ROGERS: Other questions?

MR. ALLEN: Mr. Williams, during your opening comments, you gave the example of the educational material for Black and White Men Together that subsequently was found not to be acceptable by a heterosexual person. But the fact that that material was approved and I think had been distributed, it was approved by the CDC review panel as being appropriate, suggests to me that the system is actually working. The fact that that material had been in circulation

and used does suggest to me that the process is able to work, even though imperfectly at times.

I think you, as a panel, as well as earlier panels have talked about the fact that the basic educational information is getting out there through a variety of sources. That this first step has been successful. Subsequent steps, obviously, are more complex, and they include building skills, teaching skills, giving people motivation and then building the community support.

In other words, I have got four teenagers, and my kids don't listen at all to what I say. They look to their friends for what is it that is okay to do and where are the norms. So that we have got to build the community skills in there.

Do we have impediments, other than the ones that you have already mentioned, but impediments put in place by our system, by our bureaucracy that make it impossible for us to achieve the next steps that we need to? If so, what are those impediments and what might we do to overcome them?

MR. WILLIAMS: The example that you cited that I cited it is true that it does show that the system can work and, in fact, we did go through the process that we were

supposed to follow. The impediment would be people in places like the officer of public affairs in the D.C. AIDS office, whoever Ray Palmoor works for, whoever she is, who can stop a process like that just on a whim. That is the impediment to the process.

Yes, the system can work and does work often, but for me it was unspeakable how someone could choose to do that or be allowed to make that kind of decision at that level. Those are the kind of impediments that I see to the work that we do.

We are, in fact, trying to change the community norm, change the community standard. For black gay men, that is a process of building a community that is not necessarily there because we are not segregated away from the African American, the black community, but individually and collectively we need to build a community just like the white gay and lesbian community did.

We have to build a community for black gay and lesbian people to, in fact, use peers, like you say, to teach, to show, to lead, to guide, to do all of those things that helps sustain behavior change. Show the behavior change and help to sustain the behavior change over time.

MS. HASSAN: I think also for our end, particularly the constituency that BEBASHI is dealing with, I think one of the impediments at this point is this idea of mainstreaming. What that means essentially is ignoring and diluting our efforts, ignoring the contribution that community-based organizations, as they sprung up to deal with specific parts of this issue have contributed.

Mainstreaming in my community now in the City of Philadelphia would mean that we would go back to what is called traditional educative methods. That means, if you are so sick that you finally get to a doctor and the nurse who is assigned to that office or the health educator that is assigned to that office for the 15 minutes that you are there for your total examination, is also going to give you complete health education information.

Well, it didn't happen when I had diabetes, hypertension, sexually-transmitted diseases and a whole host of other illnesses. Then why am I now in five minutes of someone's very busy day going to get everything I need to know and understand about protecting myself from HIV disease?

So, for me, that is becoming very rapidly an impediment to the kinds of information that people need to

have to get involved in behavior change.

I think the other issue as well may be the fact that just as some of us, at least, have been able to convince the community of the seriousness of this issue, our funds and support are being cut back. So that, for example, when we were able to do 15 public service announcements on 27 radio stations and send identified, well-educated people from the agency out to do all of those programs, I now only have four people that are supposed to take care of the 600,000 blacks that live in Philadelphia, plus all of those that surround us because we are the city.

So that is a real difficulty. When we start to talk about media messages, media messages are no longer visible. Even something as sort of generalized as American response to AIDS, which was supposed to bring the coloreds on this season, didn't happen.

Again, right at the point where we have made some critical indent into the process, we are now changing the process entirely. We are not going to do this anymore. We need to focus it, mainstream it into this narrow pathway, which was not effective before.

MR. WILLIAMS: And the reason often is the funding.

MS. HASSAN: Oh, very much it is the funding. We can't do it.

MR. WILLIAMS: We don't have the funding or it has to be shifted or now we are sharing the pot with more people.

MS. HASSAN: And diluting the efforts of organizations who have, in fact, been around and doing these kinds of things for a while, we are now funding everything that is vaguely minority-AIDS specific. So, in Philadelphia, much like at the CDC, we went from $32- to $350- to $600- in some agencies. Now everybody gets $2,000, which you cannot possibly run effective education programs with.

Agencies that have shown that they have been effective and who could be part of the I think the coordinating and coalition building effort, as was identified by Catlin, we are struggling ourselves for our very existence. There are so many smaller agencies that depend on us to sort of say what the issues are and what direction we should be going with it. So there again is a barrier.

DR. GAYLE: There is another barrier that I want to mention, and it is sort of hard to say it in the proper way in light of time where we find ourselves cutting back from supporting, let's say, minority students going to

college on scholarships set aside for them specifically, and yet recognizing the need to continue to support the education of minority physicians and other health care providers in the same end almost; the same breath. But yet we know that is very important.

We know that in most of our minority, especially in our black communities, black physicians and health care providers have traditionally and continued to traditionally serve black communities. That has been very important in any other kind of health issue, and I think that is very important in terms of HIV epidemic.

I think also when it comes to, again, the people who are in the position of making policy and establishing the guidelines for cultural specificity and sensitivity, it is going to be very important that the communities that we are trying to reach are involved in that process.

CHAIRMAN OSBORN: Again, thank you very much for a very rewarding afternoon for us. We really appreciate getting the chance to hear your interchange.

MR. WILLIAMS: Thank you.

[Round of applause.]

CHAIRMAN OSBORN: We have five people who have

asked for a brief period of comment to the Commission. I hope that you can keep your comments within about a 3-minute outer limit. We will start with Mr. Ken Hill. Come up to the table, if you will, Mr. Hill.

MR. HILL: I am not the mayor, but I would like to welcome the Commission to Baltimore. I will start off on a pleasant note.

I have to say that, even though I welcome the Commission, I am sadly to say that it is not very reflective of the people that are most affected by HIV.

I think it is most imperative that the Commission immediately--we have heard what we do. All day you have heard what we do--and by the way, I am the executive director of BEMORE Maryland, which stands for Better Educating Minorities on the Realities of the Epidemics.

Having not said more about that, because we have been talking about what we all do, I can go on and on about what my organization does, but I will say that I would like to see the Commission set up a task force made up of racial and sexual minorities, women and children with AIDS, HIV-positive persons, and people of color and work in conjunction with that task force because you are ultimately responsible

for setting policy.

The Reagan Administration is over. Koop is over. You are the new appointees. You are representing the Bush Administration and the Congress, and you are ultimately responsible for the citizens of this country. So I feel that, to save face and to be responsible to the American public, that this is what the Commission should be doing. It should be setting policy.

So many things that you have done have been fairly well commendable, but there is more that needs to be done. We have an epidemic. We have a pandemic. It is time for some new approaches. It is time for people like us to work in conjunction with you to better educate and with prevention and education.

If anybody has any questions of me, that is fine.

CHAIRMAN OSBORN: I think perhaps people will want to talk with you afterwards, if they do, but thank you very much for your comments.

Sandra Lowe?

MS. LOWE: I am Sandy Lowe. I am a staff attorney with Lambda Legal Defense and Education Fund. I am a board member of GMHAC and a member of VOCAL, which is lesbian and

gay voices of color against AIDS and for life.

Originally, I had not wanted to speak here. I had come to listen. I was sort of dazed. I wasn't sure why I was here or what was going on. As I sat through the day and heard several of our national treasures speak to you in the hopes that we could move this thing one more step and reach into our communities, I found myself getting incredibly frustrated.

I am frustrated by the fact that Secretary Sullivan found he could not stay all day. I am frustrated by the fact that we have talked about, in one way or another, trying to organize our communities under almost impossible circumstances; a history of systematic disorganization of the black community for the 400 years that we have been here and a history of laws, practices, health care established practices, education that disempowers us in every possible way.

I know that I am very emotional about this because, you see, one-quarter of our males, of our young men, go to jail. Another quarter of them die. Black males in our community do not reach the age to gather social security. Black women in our communities go into hospitals to have children. The children are found with antibodies; the

babies. The mothers are not counseled. They are not given treatment. There are no studies on women and AIDS, no studies, no clinical trials.

This is an absolute breakdown of the systems in this society. If I felt that we were valued, I could believe in this Commission. I could believe that we could transcend this. I feel we are not valued. I feel our children are despised. I am a lesbian with two children. I have given everything to this country and so have most of the people here. We work often for nothing to make a difference and to make this society a better place for all of us.

You have all of the studies. You know everything I know. There is 400 years of information that you have. What you cannot get around is the greed, the need for profit, the need to control, to have various people control the resources in this society. This is what stops us. This is the disinvestment. There is no time for us. We are surplus.

I hate to sound this way, and when I said this at lunch someone said to me, "Well, you don't think they really care." I guess because I am human and because you are human and because I know that I have value, and I know the people in my community have value, somehow I want to break through.

It is about declaring a national emergency in this country. It is about bringing 200, 400 or however many troops, and we see how fast we got them to Iraq. We stopped everything for whatever interest we felt is worth fighting for over there.

Somehow this Commission has to deliver this urgency over to the powers that be. We cannot go on as we usually do. If we need to declare imminent domain over drugs, if we need to fund hospitals to do the job that they need to do, we cannot afford to have this genocide happen.

I don't want to leave on this kind of note, but I am 48 years old, and I have been through the civil rights and antiwar movements, and the union movements, and the feminist movement, and I am now on the forefront of the gay and lesbian movement, and from what I have seen is there is a whole lot of studying, and a whole lot of hopelessness, and a whole lot of disintegration, and the gaps are getting wider, as the Kern Report told you 20 years ago.

Somehow we have to stop everything and make a difference. That is all I have to say.

CHAIRMAN OSBORN: Thanks very much, Ms. Lowe. It was a very moving statement.

[Round of applause.]

CHAIRMAN OSBORN: Joseph Smith?

MR. SMITH: My name is Joseph Smith, an RN, and I am a coordinator with the Stop AIDS campaign here in Baltimore. We have talked about the pie and everybody wanting a piece of it. I would like to talk a little bit about some shifts in funding that are greatly concerning me.

I am presently involved in a communitywide AIDS education training program, but up to this point, I have been involved with CBOs and development of buddy programs in taking care of people.

At the beginning of the epidemic in the CBOs, we were constantly confronted with the problem that there was only money available for education and prevention, nothing for direct care. Now we are seeing a shift in that. CBOs are losing that. Special minority outreach programs, special populations are losing those special funds.

I pose the question why do we have to have this competition for funding? Someone talked about earlier the comprehensive model of care. I am a nurse. I believe in prevention. I believe in taking care of people who are ill. Doesn't the comprehensive care model address education, appropriate pre- and post-counseling and testing, and linking

people into case management and care coordination programs?

It is my opinion that it is unethical and immoral to pull someone into a test site, test them, give them their results, but provide no follow-up. I think this happens to many people of color in low income and uninsured Americans everyday. We offer people nothing after we test them.

We need to develop models of care where both of these; education, prevention and care and treatment can be integrated. We need funding for such model development.

However, though, we see funding with HRSA for case management and many of these programs being cut everyday. I find that frightening. Isn't it counterproductive to promote this competition for funding?

Thank you.

CHAIRMAN OSBORN: Thank you very much, Mr. Smith. Richard Johnson?

MR. JOHNSON: Hello. My name is Richard Johnson. I am a hemophiliac, and I am an outreach worker with New Jersey and Delaware Valley's outreach programs.

I just wanted to express something that I have observed by holding rap groups in Philadelphia to minority hemophiliacs, and that is a lot of them do not trust the

treatment centers. They are normally staffed by white people with lots of degrees, and I'm quite sure their hearts are in a lot of good places, but they do not or are not able to identify with the minority hemophiliacs. So when they tell a minority hemophiliac to come in for AIDS education, HIV prevention or for alternative sexual with their wives or loved ones or whomever, they don't show up. A lot of times it is just that they don't identify with the people who are there.

The other thing I have observed is that a lot of minority hemophiliacs with HIV or with AIDS are crisis people. When it becomes the biggest problem that they face everyday, then they go to take care of it. If it is not the biggest problem, then it goes onto the back burner.

Hemophilia, if it is not a crisis, they don't go get treated. They don't go to treatment centers. They try to avoid any information or examinations because they feel this is where they only get bad information or they only go here when there is nothing else to do.

I have observed that a lot of minorities just do not want to participate in any type of treatment that is governed, that is staffed, that is run and operated by only

white staff.

A few other things is that hemophiliacs with HIV problems, as far as their hemophilia is concerned, they don't want to deal with that, so now they have to deal with another problem, which is HIV and AIDS, and hemophilia has always been such an introverted problem that these people take care of themselves. In the black community, you don't walk around with a physical disability for everyone to see because then you become a victim to everyone.

So to identify this problem and to relate it to other people is something that has not been done and it is not being done now.

Until treatment centers and people become more sensitive to the problems of minority HIV hemophilia AIDS victims, that there is not going to be a participation by the people who need the most help, the most social services, the most overall, from top to bottom, treatment.

It has even been expressed to me several times that, sure, I would like to go to the treatment center, but my uncle went to the treatment center, and he was being treated for hemophilia, and now he has AIDS. So how do you get these people to go to a treatment center where their only

experience or one of the experiences they have with these treatment centers is that the other person who did it, now look at them, not knowing they have probably been exposed already.

Their sexual behaviors are not going to change. Not that they are not going to change, but they haven't changed. Most people who have been exposed who are HIV positive are very reluctant to even express anything to do with a problem with their sexual habits. So to tell them to use a rubber or come in here and talk to this white lady for two hours about your sexual habits is not going to work.

There seems to be a real reluctance for treatment staff to put people of color in positions to deal with people of color. It seems like this seems to be a very big problem in dealing with the issue related to hemophilia and what I have observed up to now.

Thank you.

CHAIRMAN OSBORN: Thank you, very much. Troy McMillion?

MR. McMILLION: I am Troy McMillion from Baltimore City. I guess the group that I may represent may be considered the human race. I look at approaching the Commission

as one of the impossible dreams of my life. It is rather difficult to understand why the gay community is best served and the research and the efforts that have been initially imposed to the situation of HIV.

It is understandable that because it was identified as a gay disease gay people stood the most to gain by getting the most knowledge and gaining positions, decision-making positions, that they could best effect change in the arena.

We all stand in the same boat of being infected people and people who are at potential for being infected. The implications of the IV drug users being the second wave of people being hit by the virus coupled with cutbacks is somewhat interesting.

When I stop and look at the people who are running the support groups, they are not HIV positive people. They are not PWAs. They are professional people from a different perspective with a whole set of other issues and interests. I begin to wonder how effective can we be in expressing our needs within supposedly a support group of us, for us, by us.

I have decided to dedicate my life and deal with truth and honesty in these issues. One of the situations that is very perplexing is how effective is the National

Commission on AIDS? Do you hear us? What do you do with our suggestions?

I would speculate that if one week of your expense monies were used to help us, that we could help ourself best. I think that you are now placed in a position that the community-based organizations are in, when groups from our communities approach them and say, "Let us help. Let us be a part of the system." Effectively what we are saying is, "Share some of your money with us."

Truly, I believe that I am my brother's keeper, and I am responsible for all of the members in this boat of the human race. I think that until we begin to use some simplistic approaches, such as distribution of condoms within penal institutions, until we have a situation where there is a surplus of bleach in penal institutions, until we begin to deal with issues relevant to and not exclusive to lesbian, black gay men, the IV drug-using community, until there is a meeting in which we are allowed to produce literature and have the means of getting that literature to the people who need it, until there are suggestions from the National Commission that mandatory testing is not mandated until there is more thought given of how the system will deal with the

influx of people who will find out that they are HIV positive, not the people who want to know, but the people who don't want to know, until we begin to address such situations of what will we do with the young people who will test positive, what type of institution or settings will we have for them, until we address the situation of providing adequate health care for us, mental health as well as some other approaches, such as holistic approaches, to the environment and the arena of dealing with HIV people, until the day that you acknowledge that we are a part of this system, it becomes impossible to hide behind your configuration or maintain a limited point of view based on your sole experiences.

CHAIRMAN OSBORN: Thank you. We were trying very hard to hear you.

Harlon, do you want to make any final comments? Since you started the day, do you want to close this day's conversations in any way?

MR. DALTON: It seems rather a privilege to get to close the day. It has been, as you said, we have heard a number of our national treasures. I am quite moved by what I heard during the public comments section. I sort of knew today would be as it was, but to be here and to experience

has been, for me, enlightening and a thrill. If the people sitting to the left and right of me took in half as much, and I sort of felt them doing it, then it has been an extraordinary experience and one that I hope, if you talk to us next week, next month or next year, it won't be lost.

Thank you.

CHAIRMAN OSBORN: Thank you. Thank all of you very much. We have had a rich day, and we appreciate your input.

[Whereupon, at 5 p.m., the proceedings were adjourned to reconvene at 8:30 a.m. the following day.]

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