103

AIDS AND HIV INFECTION IN THE AFRICAN-AMERICAN COMMUNITY

HEARING

BEFORE THE

HUMAN RESOURCES AND INTERGOVERNMENTAL RELATIONS SUBCOMMITTEE

OF THE

COMMITTEE ON GOVERNMENT OPERATIONS
HOUSE OF REPRESENTATIVES

ONE HUNDRED THIRD CONGRESS

SECOND SESSION

SEPTEMBER 16, 1994

Printed for the use of the Committee on Government Operations

U.S. GOVERNMENT PRINTING OFFICE
85–833 CC WASHINGTON : 1995

For sale by the U.S. Government Printing Office
Superintendent of Documents, Congressional Sales Office, Washington, DC 20402
ISBN 0-16-046750-0

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AIDS AND HIV INFECTION IN THE AFRICAN-AMERICAN COMMUNITY

FRIDAY, SEPTEMBER 16, 1994

House of Representatives,
Human Resources and
Intergovernmental Relations Subcommittee
of the Committee on Government Operations,
Washington, DC.

The subcommittee met, pursuant to notice, at 2 p.m., in room 2247, Rayburn House Office Building, Hon. Edolphus Towns (chairman of the subcommittee) presiding.

Present: Representative Edolphus Towns and Donald M. Payne.

Also present: Ronald A. Stroman, staff director; Martine M. DiCroce, clerk; and Martha B. Morgan, minority professional staff member, Committee on Government Operations.

OPENING STATEMENT OF CHAIRMAN TOWNS

Mr. Towns. The Subcommittee on Human Resources and Intergovernmental Relations hearing will come to order.

This subcommittee has had a long history of examining our government's role in combating the AIDS virus in this country. While the government has become more responsive with this administration, as this disease impacts new populations, there will be need for new and innovative government interventions. Today's hearing will focus on how AIDS and HIV infection is impacting the African-American community.

Given the violence in many inner city communities, the average person would assume that the leading cause of death for African-Americans, men in particular, is homicide. However, they would be wrong. In fact, AIDS now kills more black men than gunshot wounds. The Centers for Disease Control, whom we will hear from a little later on today, found that minorities now account for more than half of all the cases in the United States. For African-Americans, the rate was more than 5 times as high as that for whites.

This disease was equally—has equally affected women and children in the black community; 84 percent of the AIDS cases involving children age 12 and under can be found in the black community. And AIDS has now become the second leading cause of death for black women. I witness these statistics firsthand. The Fort Greene community in my congressional district in Brooklyn has the highest incidence of new AIDS cases of any area in New York City.

Certainly we are all hopeful that a cure will be found for this disease. The news from the International AIDS Conference in Japan, however, suggests that a cure for this virus is expected in the near future—not expected, I am sorry, not expected; let me emphasize that, not expected—yet questions remain about the kind of research that is currently available.

For example, one constituent has indicated to me that no research is currently being done on the issue of dementia and HIV infection. And AZT no longer holds the promise it once did for improving the quality of life for people living with AIDS. While a cure for this disease is not on the horizon, we have yet to develop an effective means of halting the rapid infection rates in the African-American community.

One issue that must be addressed is whether adequate funding resources are reaching the black community, which I think is a serious question. We also need to explore whether new prevention methods are needed to halt the spread of this disease. There is a question as to whether the diagnostic and treatment models that have been used with other populations are effective in the black community. That is another question that must be answered.

I look forward to hearing the testimony of today's witnesses as we seek to make governmental policies more responsive to addressing the AIDS crisis in the African-American communities.

Let me begin by saying that I have been told that many people have now requested to testify, and I wish we could accommodate you, but this is not a town hall meeting. This is an official hearing of the U.S. House of Representatives, and we will not be able to allow you to testify at this time. However, I must say that as a result of the interest that I have seen that I think we will be looking at this issue a lot further and a lot closer, because you know as well as I do that this is a very serious, serious matter.

The other thing that I would also do is that I will leave the record open for 10 days to allow people that did not have the opportunity to testify, if they would like, to enter a statement into the record. We will hold the record open for that information, as well.

And just before I call up our first panel of witnesses, let me thank my former State senator, Anna Jefferson, who suggested very strongly that we do something in this area at this time, and also we would like to recognize Dr. Norma Goodwin from Health Watch in New York, who also encouraged me down through the months to begin to get more involved in this issue. So I would like to thank both of them for their help and their participation.

May I add that the reason we had some reservations about moving forward is that the ranking member of the subcommittee, who happens not to be here because of the fact that he is Jewish and it is his holiday, he has been very active in these issues along with me; and I salute him for his cooperation and his efforts, and only for that reason is he not here.

Other than that, he is always here at every hearing. He comes in the beginning and he stays till the very end. So I just want to sort of share that with you. Because the fact that the chair next to me here is open, that is the reason for it and the only reason for it.

At this time, I would like to call forth our panel of witnesses for the first panel. I would like to call Anita Genous. I would call Eric Turner, and also Veronica Everett-Jones.

Let me say that, due to the time constraints, you will have 5 minutes to make a statement. You can summarize it, because your entire statement will be included in the record, so if you would just summarize in 5 minutes. And what we will do—just to help you recognize 5 minutes, we will turn the light on; and it starts out green, and then when it turns red, that means your 5 minutes have expired. So please, please keep your eye on the light and—as well as your testimony.

So thank you very, very much.

Why don't we begin with you, Mr. Turner, being you are closest to the light.

STATEMENT OF ERIC L. TURNER, HIV POSITIVE PERSON

Mr. TURNER. Good afternoon, Mr. Chairman, distinguished Members of the House of Representatives and all that are present. My name is Eric Lanell Turner; and if you notice, I did not write a formal testimony due to the fact that I want to testify from the heart.

I am a person who is living with HIV disease, and has been ever since 1986; and I found out in the Federal Correctional Facility in F.C. Raybrook in New York. I come here today to testify at the appalling status of the African-American community, not only just in DC, but in our Nation. Upon last night from 6 to 9 p.m., Lifelink, Inc. sponsored a champagne reception in honor of the Congressional Black Caucus. It was the second annual event, and several Congress individuals confirmed attendance. We did not see there Congressmen or Congresswomen that showed up at our event. This was a very alarming piece of information to me, because in our United States of America, as you just said, between the age of 25 and 44, AIDS is the leading killer among African-American men.

I am also a recovering alcoholic and a substance abuser of 9 years. I am an ex-felon offender. I fit several categories when it comes to diagnosed persons living with HIV disease and/or dual diagnosis. So I have a "lot of strikes against me," society says.

I just want to state that I am really appalled at the response of our government when it comes to HIV infection.

I want to commend you on having this hearing.

I have been to several meetings with FDA and ASAP, which will testify later, in regard to a diagnostic testing tool which—tests for HIV infection through saliva, and has been held up for several years, for whatever reason—I will just get blunt: They just held it up—and it is a tool that will provide great opportunity, great promise to local community-based organizations as far as testing individuals for HIV infection. It will free up dollars for smaller, community-based organizations so that they can provide tests so then that we can move into a preventative state.

I would hope that it would be Congress' final foundational move to not just wait until a person is infected, but to want to prevent a person from ever having to become infected. With this tool, I believe that could be achieved. I am just—I come here to plead with Congress, to plead with whomever I possibly can, as a person living with this disease, that something needs to be done.

I know for a fact that HIV and AIDS has become a multimillion-dollar business. I would just like to say, I am tired of people getting rich off of my pain and grief, my suffering, my friends' suffering. I watch my friends die a drastic death, and I am just tired.

Mr. TOWNS. Thank you very much, Mr. Turner, for your testimony.

Mrs. Jones.

STATEMENT OF VERONICA EVERETT-JONES, PROJECT DIRECTOR, WE THE PEOPLE ONE DAY AT A TIME, ON BEHALF OF THE NATIONAL MINORITY AIDS COUNCIL, ACCOMPANIED BY GREGORY ADAMS, DIRECTOR, PUBLIC AFFAIRS

Ms. EVERETT-JONES. Mr. Chairman, members of the subcommittee, my name is Veronica Everett-Jones. I was diagnosed as being HIV positive in 1983. In addition to being a wife and a mother of a 1-year-old son, who keeps talking back there, I am the project director of a 24-hour extended service center in Philadelphia called "We the People One Day at a Time." We provide referrals, case management, and other critical services to people in recovery.

I am accompanied today by Gregory Adams, the director of public affairs for the National Minority AIDS Council, who was also the driving force behind the poster campaign that you see around the room. Gregory is also living with HIV, and is an advocate for people of color impacted by this disease.

On behalf of the National Minority AIDS Council, I want to thank you for giving us this opportunity to testify. My remarks will focus on the issues of secondary prevention.

AIDS secondary prevention refers to the use of low cost, effective preventative measures against AIDS-related diseases so individuals living with HIV can prevent the development of opportunistic infections and improve their quality of life and live longer. Early in the epidemic, pneumocystis carinii pneumonia, commonly referred to as PCP, killed the majority of people infected with HIV. In the mid-1980's, the medical community began using drugs to prevent this pneumonia, and today, over 80 percent of gay white males who are HIV positive and have significantly compromised immune systems to get the treatment. However, recent studies show that people of color are far less likely to receive treatment for this common but largely preventable form of pneumonia.

Even worse, many people of color don't even find out that they are HIV positive until they are diagnosed with PCP. We have scientific proof that PCP is a preventable and treatable opportunistic infection. The use of preventative therapies against AIDS-related diseases in combination with HIV early intervention measures have proven to be the most critical life-sustaining strategy for those infected with HIV.

In response to these realities, the National Minority AIDS Council has developed a multimedia AIDS–PCP prevention education campaign. The idea for the campaign originated with Moises Agosto, NMAC's treatment and research advocacy director, who is himself a person living with AIDS. Moises felt strongly about the need of such a campaign because of his personal experience with friends getting PCP unnecessarily, due to not knowing that they should be taking prophylactics for it.

This week NMAC unveiled its PCP prevention campaign. The campaign specifically targets communities of color with the message that AIDS-related pneumonia is largely preventable by taking inexpensive widely available drugs. The bilingual print video, audio, and outdoor media campaign is entitled "Live Long, Sugar," and features Grammy award-winning singer, Patti LaBelle, and four different people of color living with HIV. I am proud to be one of those individuals and to know that my work in the campaign will help to save lives. NMAC is producing and distributing the campaign in cooperation with the U.S. Public Health Service.

This campaign is using a social marketing strategy to get the message across. What we have learned from past campaigns is that general information-only messages don't work because they don't take into account the various cultural and community issues that have to be addressed.

Thank you for this opportunity to testify. I will be happy to respond to any questions.

[The prepared statement of Ms. Everett-Jones follows:]

Testimony
before the Subcommittee on
Human Resources and Intergovernmental Relations

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AIDS AND HIV INFECTION IN THE AFRICAN AMERICAN COMMUNITY

Friday, September 16, 1994
2:00 pm

Veronia Everett-Jones
on behalf of

The National Minority AIDS Council
Developing Leadership to Address HIV Infection in Communities of Color Since 1987

Mr. Chairman and members of the subcommittee, my name is Veronica Everett-Jones. I was diagnosed as being HIV positive in 1983. In addition to being a wife and mother of a one-year-old son, I am the project director of a 24-hour extended service center in Philadelphia called *We the People.* We provide referrals, case management and other critical services to people in recovery. I am accompanied today by Gregory Adams, the Director of Public Affairs for the *National Minority AIDS Council.* Gregory is also living with HIV and is an advocate for people of color impacted by this disease.

On behalf of the *National Minority AIDS Council (NMAC),* I want to thank you for giving us this opportunity to testify. The National Minority AIDS Council was formed in 1987 to develop leadership within communities of color to address issues of HIV infection. Our members are nearly 500 community-based organizations that deal with AIDS on the front lines -- in hospitals, clinics, shelters, schools, store fronts and streets. NMAC's goals are to lend visibility, leadership, comprehensive technical assistance and a powerful national voice to these front line AIDS workers.

I am particularly pleased that you Mr. Chairman, and the Congressional Black Caucus have decided to focus attention on the issue of AIDS in the African American community. This is an issue that has been overlooked by our community for too long. Therefore it is refreshing that a black member of Congress has decided to put the issue on the forefront and Mr. Towns, we commend you for this critical action.

My remarks will focus on the issue of secondary prevention. AIDS secondary prevention is the utilization of low-cost, effective preventative measures against AIDS related diseases so individuals living with HIV can prevent the development of opportunistic infections, improve their quality of life, and live longer.

In the early years of this epidemic, the life expectancy of people with AIDS was six months after diagnosis. Early in the epidemic, *pneumocystis carinii pneumonia (commonly referred to as PCP)* killed the majority of people infected with HIV. In the mid-eighties, the medical community began using sulfa-based drugs to prevent this pneumonia and today, over 80 percent of gay white males who are HIV positive and have significantly compromised immune systems get the treatment.

However, recent studies show that people of color are far less likely to receive treatment for this common, but largely preventable form of pneumonia. Even worse, many people of color don't even find out that they are HIV positive until they are diagnosed with PCP. This is especially true for women. Because physicians still do not expect women to be infected with HIV, symptoms of diseases such as PCP tend to be misdiagnosed.

We have scientific proof that PCP is a preventable and treatable opportunistic infection. The use of preventative therapies against AIDS related diseases in combination with HIV early intervention measures has proven to be the most critical life-sustaining strategy for those infected by HIV.

In response to these realities, the National Minority AIDS Council has developed a multi media AIDS/PCP Prevention Education Campaign. The idea for the campaign originated with Moises Agosto, NMAC's Treatment and Research Advocacy Director, who is himself a person living with AIDS. Moises felt strongly about the need for such a campaign because of his personal experience with friends getting PCP unnecessarily due to not knowing that they should be taking prophylaxis for it. He felt that it was a tragedy to see so many friends die knowing that there was a relatively inexpensive preventative treatment.

On Tuesday of this week NMAC unveiled its PCP prevention campaign to the national media. This is the first national public education campaign designed to keep people living with HIV healthy for as long as possible. The campaign specifically targets communities of color with the message that AIDS-related pneumonia is largely preventable by taking inexpensive, widely preventable drugs.

The bilingual print, video, audio and outdoor media campaign is entitled "*Live Long, Sugar,*" and features Grammy Award-winning singer Patti LaBelle with four different people of color living with HIV. I am proud to be one of those individuals and to know that my work in the campaign will help to save lives. NMAC is producing and distributing the campaign in cooperation with the U.S. Public Health Service.

This campaign is using a social marketing strategy to get its message across. What we have learned from past campaigns is that general, information-only messages don't work because they don't take into account the various cultural and community issues that have to be addressed. By using the exchange principles of social marketing -- giving the consumers something in return for what we're asking them to do -- we hope that *Live Long, Sugar* will be as effective as ads selling alcohol, tobacco and fast food products have been in our communities.

The next phase of the campaign, which will take place over the next eight months, is its dissemination in at least ten major metropolitan areas where people of color live. This will be accomplished through the development of public/private partnerships with city, state and local health departments, private industry and other non-profit organizations. Also, NMAC will provide technical assistance and training to community-based organizations (CBOs) to enable them to use the campaign more effectively.

While our campaign is an ambitious effort, it is but a first step and broader measures are needed. Most efforts designed around AIDS secondary prevention are grassroots. It is time to institutionalize the concept of AIDS secondary prevention. The federal government has public health responsibility regarding accessibility to AIDS secondary prevention information. There is an urgent need to create public policy that provides an infrastructure in which people living with AIDS, care givers, case managers, and primary providers can access AIDS secondary prevention information.

AIDS treatment activists and community leaders have been very vocal on this issue. While we applaud the support from the U.S. Public Health Services with the NMAC campaign, the federal government has not taken primary responsibility in addressing the matter. There is no single, centralized, well coordinated program supported by the federal government that provides comprehensive AIDS secondary prevention education to people living with AIDS, their care givers and case managers. Moreover, none of the major federal agencies under PHS want to take responsibility for this identified need. Therefore, even though we know AIDS related pneumonia and other opportunistic infections can be prevented, we still have AIDS related pneumonia defined as the main killer of people with AIDS. That is unconscionable with the science that now exists.

Action needs to be taken around this issue and a more aggressive strategy needs to come from the leadership of the federal government. People with AIDS are dying unnecessarily of diseases that can be prevented. Not taking action on that situation means overlooking the most critical life-sustaining measure for the one million of us living with this disease.

Other steps are critical as well. Funding increases for prevention efforts targeting people of color are sorely needed. Input from members of the affected minority communities is needed in both the design of the new prevention community planning process and the development and implementation of effective secondary prevention programs in communities of color. Finally, we desperately need more research to better understand behavioral patterns in communities of color and certain subgroups such as women, youth, injection drug users and gay men of color.

In closing, we cannot overlook the critical impact that HIV/AIDS has had on the African American community. While we account for only 12 percent of the U.S. population, we represent 31 percent of all reported AIDS cases. That number grows even higher when only looking at AIDS cases among African American females. Out of the cumulative totals reported through December 1993, 54 percent of the AIDS cases among women were African American. To put this is another context, during 1990, the number of reported deaths per 100,000 population was 29.3 percent for African Americans as compared with 8.7 for whites.

Mr. Chairman, members of the subcommittee, thank you for this opportunity to testify. I will be happy to respond to questions.

Mr. TOWNS. Let me first thank both of you for your testimony. I must say that it is very moving testimony. We would sort of wish that the entire Congress could hear what you said at the moment that you were saying it. However, this information will be shared with the Congress as an official record of a government hearing.

Let me ask both of you, very quickly, what more could government do? Do you have any specific kinds of suggestions or recommendations, you know, that you can make to those of us who serve in the Congress?

Mr. ADAMS. I would like to respond to that. I think this prevention campaign that we have here, the secondary prevention campaign, is critical to reaching people of color. It uses marketing tools that have been used to sell us alcohol, tobacco, tennis shoes that light up in the dark; and what we are trying to do is to get the Federal Government to give us more money to do this kind of targeted messaging, to get our people to pay attention to the fact that we can save our own lives.

Mr. TOWNS. Thank you very much.

Mr. Turner.

Mr. TURNER. Mr. Towns, I really believe that there was someone else that was supposed to testify here, Mr. Gregory Hutchings, who is the executive director of Lifelink. Lifelink is an advocacy organization, but it is a coalition for people living with HIV disease. The unique thing is that it is run by people who live with HIV disease, though.

I also sit as an alternate on the Ryan White-title I planning council. I believe that the government could better serve us—one, people living with HIV disease can better tell other individuals who are less than newly diagnosed what they can do to better live, not just what you would call the "quantity of life," but more so the "quality of life," and I have to honestly say to free up dollars that we can better provide for our own communities.

We know how to take care of our communities, and it is us that need to stand up and stand forward and do that. And the only way that is going to be done is through the availability of more funds.

Mr. TOWNS. Let me thank both of you for your testimony. I think you have been very, very helpful; and I think that if I understand your last statement, you are saying now money must be targeted to those areas that really have the serious, serious kinds of problems.

Thank you. Thank you very, very much.

Our next panel is Dr. Helene Gayle, associate director of the Washington, DC office of the Centers for Disease Control and Prevention; accompanied by Dorothy Triplett, Acting Assistant Director of Minority and Other Special Populations; Dawn Smith—Dr. Dawn Smith, medical officer, division of HIV/AIDS, National Center for Infectious Diseases; Carlton Duncan, program analyst, Office of the Director of the National Center for Chronic Disease Prevention and Health Promotion; and Dr. Samuel Taveras, team leader, the National Minority Organizations, the National Center for Prevention Services.

Mr. TAVERAS. I am not a doctor.

Mr. TOWNS. I promoted you. I am happy to promote you, not demote you.

On that note, why don't I start with you.

STATEMENT OF HELENE D. GAYLE, M.D., M.P.H., ASSOCIATE DIRECTOR, WASHINGTON, DC OFFICE, CENTERS FOR DISEASE CONTROL AND PREVENTION, U.S. PUBLIC HEALTH SERVICE, ACCOMPANIED BY DOROTHY TRIPLETT, M.Ed., ACTING ASSISTANT DIRECTOR FOR MINORITY AND OTHER SPECIAL POPULATIONS

Dr. GAYLE. Actually, if it is all right with you, I am Dr. Helene Gayle. And I will be reading from our statement, and I have all of my colleagues here to answer questions. We wanted to be as time efficient as possible, given the number of people who are also going to be testifying today.

As you mentioned——

Mr. TOWNS. Without objection, the format will be followed. There can be no objections because I am the only Member present.

Dr. GAYLE. First of all, we would like to thank you for the honor and the opportunity to participate in this hearing, and we think that it is particularly important that this subject be addressed in this Congress.

As you mentioned, I am accompanied by four other colleagues from CDC whose names you have mentioned and they will be available as panel members to answer questions on epidemiologic data, describe the HIV/AIDS epidemic in the African-American community, key CDC efforts in preventing HIV infection and AIDS, and the important lessons that we have learned from these activities.

I would like to start by thanking our first panel. I think it is always important that in meetings of this sort and in a forum of this sort we do have the opportunity to hear from the people who are most affected by this epidemic. I think it centers us and makes us very aware of what it is we are working for.

First, I would like to begin by providing some perspective on the scope of the HIV/AIDS epidemic in the United States; and, Mr. Chairman, you gave some very important facts, and I will just add to some of those 13 years of collecting and monitoring AIDS cases has demonstrated increasing diversity among people with HIV infection. From 1982, when the vast majority of AIDS cases were in a few communities among gay and bisexual men, the epidemic has evolved into a composite of multiple epidemics in different regions and among different population subgroups. Cumulatively, since the beginning of the epidemic, more than 360,000 AIDS cases have been reported through the end of 1993. Of these, African-Americans accounted for 32 percent of the total number of cases, 54 percent of women, 28 percent of men, and 55 percent of children with AIDS. In 1993 alone, more than 100,000 AIDS cases were reported. Of these cases, 36 percent were among African-Americans, indicating the rising proportion of black persons with AIDS. In 1993, African-Americans were among the group with the greatest, fastest-growing rate in AIDS cases and were disproportionately represented among people who acquired AIDS through heterosexual contact. In 1993, the rate of AIDS cases for African-American females was approximately 15 times greater than that for white females; and for black men, the rate was nearly 5 times greater than that for white men.

The increase in the number of persons with AIDS has greatly affected death rates for African-Americans and particularly young adults. Provisional mortality data for 1992 indicated that HIV infection was the second leading cause of death among African-American females 25 to 44 years of age and remained the leading cause of death among African-American males in that age group. Although we all know race and ethnicity are not risk factors themselves for HIV transmission, they are markers for underlying social, economic, and cultural factors that affect health.

Low socioeconomic status in particular is associated with morbidity and premature mortality. Unemployment, poverty, racism, and illiteracy can be barriers to accessing health education, preventive services and medical care, resulting in an increased risk for disease. Clearly, the social, economic and cultural context of HIV must be considered when designing and implementing prevention programs.

Let me turn then to discuss a little bit about CDC's prevention activities. CDC's HIV prevention programs include collaborating with and providing financial assistance to State and local health and education agencies, national and local minority organizations, other national organizations, community-based organizations, academia, business and labor, and religious organizations.

The largest component of CDC's prevention efforts is financial and technical support for State and local health department programs, including publicly funded counseling and testing sites. CDC manages a national AIDS public information system consisting of mass media, educational efforts; the CDC National AIDS Hotline, the CDC National AIDS Clearinghouse, and partnerships with national organizations. These systems help ensure public and professional access to information about HIV and improve social support to at the community level for people to maintain or adopt behaviors that will keep them from acquiring HIV. If you will permit me to go past the red light since I am reporting for all of us.

Mr. TOWNS. Being it is that only two of you that are reporting, I will be delighted to do so.

Dr. GAYLE. CDC's program provides support for the Nation's school and out-of-school youth. CDC provides financial support and technical assistance to 57 States and territorial educational agencies and to 24 national organizations to help schools and other institutions that serve youth implement effective HIV education within comprehensive school health programs.

Finally, CDC conducts the more traditional epidemiologic behavioral and laboratory studies that add to our Nation's and our world's basic scientific understanding of the epidemic and the virus itself.

I am going to for a few minutes just to talk about what we have done in the area of education, because I think along the way and as things have evolved, it has been very important to make sure that we are constantly looking at what we are doing and evaluating that. Although there have been many demonstrations that HIV prevention efforts reduce high-risk behavior, it is still important to ask the following questions: What mix of HIV prevention interventions works best? For whom? Under which circumstances? For how long? And qualitatively, by how much? Quantitatively, by how much? Because of the extent of the epidemic and the urgent need for prevention efforts, we have made evaluation of these efforts a high priority.

I will talk just for a moment about some of the programs and some of the types of efforts that we think have been successful in evaluating our programs. Analysis of several studies indicate that publicly funded information programs have, in fact, led to an overall increase in basic HIV knowledge in the general population. In particular, data show that basic knowledge about how HIV is transmitted has increased greatly over the last several years. In addition, findings indicate that HIV education in the context of comprehensive school-based health education has significantly increased knowledge among school and college-age youth. Programs for high risk or already-infected persons have received the most extensive study. According to CDC analysis, evaluation of counseling and testing programs indicate that such programs tend to reduce HIV-related risk behaviors in specific populations.

Mr. TOWNS. Let me add that your entire statement will be included in the record.

Dr. GAYLE. Right. I am not reading the entire one.

Mr. TOWNS. So if you would summarize that, I would appreciate it.

Dr. GAYLE. All right. And I am actually not reading it although it may seem like it. I am not reading the entire statement, but I will summarize quickly.

So those are some of the findings that we have found through our evaluation.

I just want to close by touching on a couple of new activities that we are currently involved in, and one—and I hope some of the other panelists will talk about this as they have been involved—is HIV community planning. HIV prevention community planning represents a significant step forward in planning of scientifically sound programs that address unique community needs. Community planning provides a systematic approach to involving communities in planning HIV prevention programs that affect them.

The second new initiative is the prevention marketing initiative and uses what was talked about in the last panel, the well-known and well-proven marketing strategies to sell safe behavior that we use to sell so many other things in our consumer-oriented society.

I will just close by saying that in doing HIV prevention, we believe that it is important to consider the specific challenges presented by the multicultural and multiracial nature of our society. We must consider communities' needs, characteristics of the epidemic and resources in determining appropriate prevention programs. In meeting these challenges, we have sought, particularly in the last few years, to develop closer links and greater partnerships with both private and public and community-based partners, and think that this is going to be increasingly important in the way that we do our prevention efforts.

Thank you.

[The prepared statement of Dr. Gayle follows:]

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TESTIMONY of

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Before the

SUBCOMMITTEE ON HUMAN RESOURCES
AND INTERGOVERNMENTAL RELATIONS
COMMITTEE ON GOVERNMENT OPERATIONS
U.S. HOUSE OF REPRESENTATIVES

SEPTEMBER 16, 1994

Mr. Chairman, members of the Subcommittee, I am Dr. Helene Gayle, Centers for Disease Control and Prevention (CDC) Associate Director for Washington. I and other members of the CDC staff are honored to have this opportunity to comment on the HIV/AIDS epidemic in the African-American community.

I am accompanied today by Ms. Dorothy Triplett, the Assistant Director for Minority and Other Special Populations in CDC's Office of the Associate Director for HIV/AIDS; Dr. Dawn Smith from CDC's National Center for Infectious Diseases; Mr. Samuel Taveras from the Center for Prevention Services; and Mr. Carlton Duncan from the National Center for Chronic Disease Prevention and Health Promotion. They will be available as panel members to answer your questions on the epidemiologic data describing the HIV/AIDS epidemic in the African-American community, key CDC efforts in preventing HIV infection and AIDS, and the important lessons we have learned from these and other activities.

Status of the Epidemic

I would like to begin by giving the Subcommittee some perspective on the scope of the HIV/AIDS epidemic in the United States.

Thirteen years of AIDS case surveillance has documented increasing diversity among people infected with HIV. From 1982, when the vast majority of AIDS cases were in a few communities among men who have sex with men, the epidemic has evolved into a composite of multiple epidemics in different regions and among different population subgroups. Cumulatively, more than 360,000 AIDS cases had been reported through December 31, 1993.

In 1993 alone, more than 100,000 AIDS cases were reported, reflecting both the expansion of the AIDS surveillance case definition and overall trends in the epidemic. Of these cases, more than half (58,538) were reported among racial/ethnic minorities, 66 percent among African Americans, 32 percent among Hispanics, 1 percent among Asians/Pacific Islanders, and 1 percent among American Indians/Alaskan Natives.

Also during 1993, for the first time, cases reported among homosexual/bisexual men did not represent the majority of cases reported in a calendar year. From 1985 through 1993, the proportion of persons with AIDS who reported heterosexual contact with a partner at risk for or with documented HIV infection increased from 1.9 percent to 9 percent. In 1993, the rate of increase in case reporting was greatest for women, racial/ethnic minorities, adolescents, injecting drug users, and persons infected through heterosexual contact. Although the pediatric AIDS case definition remained unchanged in 1993, the number of children reported with AIDS increased and paralleled the increase in AIDS among young women.

Among persons with heterosexually acquired AIDS, adolescents and young adults, women, African Americans, and Hispanics have been disproportionately affected. Persons at highest risk for heterosexual HIV transmission are those who have multiple sex partners, sex with a high-risk partner, or STDs. The highest proportion of cases associated with heterosexual contact during 1993 was reported in the South (42 percent) and Northeast (31 percent).

HIV/AIDS in the African-American Community [Attachments 1-3]

In 1993, the number of AIDS cases reported among racial/ ethnic minorities increased 135 percent over that in 1992, while the number among whites increased 114 percent. Although much of the increase was due to the 1993 expansion of the AIDS surveillance case definition, the greater increase in cases among racial/ ethnic minorities is consistent with trends in the number of AIDS cases reported in previous years, representing a continued increase in the epidemic among certain minority populations, particularly African Americans and Hispanics.

In 1993, the rate of AIDS cases was 73 per 100,000 population for African-American females, approximately 15 times greater than that for white females; for African-American males, the rate was 266 per 100,000 population, or nearly 5 times greater than that for white males.

The increase in the number of persons with AIDS has greatly affected death rates for African Americans, and particularly young adults. Provisional mortality data for 1992 indicate that HIV infection was the second leading cause of death among African-American females ages 25-44 years, and remained the leading cause of death (since 1991) among African-American males in that age group.

In the United States, through December 31, 1993, more than 5,000 children under the age of 13 have been reported with AIDS. Of that total, 2,866 (nearly 55 percent) are African American.

Although we all know race and ethnicity are not risk factors for HIV transmission, they are markers for underlying social, economic, and cultural factors and personal behaviors that affect health. Low socioeconomic status in particular is associated with morbidity and premature mortality; unemployment, poverty, racism, and illiteracy can be barriers to accessing health education, preventive services, and medical care, resulting in an increased risk for disease. In 1992, 33 percent of African Americans lived below the Federally defined poverty level, compared with 29 percent of Hispanics, 13 percent of Asians/ Pacific Islanders, and 10 percent of whites. Therefore, the social, economic, and cultural context of HIV infection must be considered when designing and implementing prevention programs for diverse populations.

CDC's HIV Prevention Activities

CDC's HIV prevention programs include collaborating with and providing financial assistance to State and local health and education agencies, national and local minority organizations, other national organizations, community-based organizations (CBOs), academia, business and labor, and religious organizations. In fiscal year 1994, nearly 75 percent of CDC's HIV prevention funds are being distributed through cooperative agreements, grants, and contracts primarily to State and local health and education agencies.

The largest component of CDC's prevention efforts is financial and technical support for State and local health department programs, including publicly funded counseling and testing sites.

CDC manages a national AIDS public information system, consisting of mass media educational efforts, the CDC National AIDS Hotline, the CDC National AIDS Clearinghouse, and partnerships with national organizations. This system helps ensure public and professional access to information about HIV and improve social support at the community level for people to maintain or adopt behaviors that will keep them from acquiring HIV.

CDC's programs include support for education programs in the nation's schools and for out-of-school youth. Specifically, CDC provides fiscal support and technical assistance to 57 State and territorial education agencies, and to 24 national organizations to help schools and other institutions that serve youth implement effective HIV education within comprehensive school health programs. CDC also works with the health departments in four major U.S. cities heavily affected by the HIV epidemic to establish coalitions among health, education, social services, and other programs to prevent behaviors that result in HIV infection among youth aged 10-24 years who are in high-risk situations (for example, homeless or runaway youth).

In its international role, CDC actively seeks opportunities to bring scientific and programmatic lessons learned into the domestic arena, and vice-versa.

Finally, CDC conducts the more traditional epidemiologic, behavioral, and laboratory studies that add to our Nation's basic scientific understanding of the epidemic and the virus itself.

Evaluation of HIV Prevention Efforts

Although there have been demonstrations that HIV prevention efforts reduce high-risk behaviors, it is still important to ask the following question: What mix of HIV prevention interventions work "best," for whom, under which circumstances, for how long, and quantitatively by how much? Because of the extent of the epidemic and the urgent need for prevention efforts, we have made careful and timely evaluations a high priority. This information about program effectiveness and efficiency is critical for decision-making about future HIV prevention priorities, at both the Federal and local levels.

A review of data from program evaluations does indicate that behaviorally-based HIV prevention programs have a positive impact on behavioral outcomes in specific populations, particularly when these programs have sufficient resources, intensity, and cultural competency. In addition, economic evaluations to date indicate that HIV prevention efforts appear to be cost-effective. Thus, we believe in a continued commitment of public funds for behaviorally-based HIV prevention programs.

CDC scientists recently looked at studies evaluating "what works" in HIV prevention. The results of their review are in press; I would like to summarize some of their findings.

In reviewing the general characteristics of reported successful, behaviorally-based HIV prevention programs, the CDC scientists noted that common elements of such programs are:

- A basis in real, specific needs and community planning;
- Cultural competency;
- Clearly defined audiences, objectives, and interventions;
- A basis in behavioral and social science theory and research;
- Quality monitoring and adherence to plans;
- Use of evaluation findings and mid-course corrections; and
- Sufficient resources.

The CDC researchers looked at programs directed to persons at relatively low risk of HIV infection, those at potential risk of infection (such as adolescents), and persons at high risk or who were already infected. Following are a few examples of successful prevention programs.

Analysis of several studies indicated that publicly funded information programs have led to an overall increase in basic HIV knowledge in the general population. In particular, data from the National Health Interview Survey showed that basic knowledge about how HIV is transmitted has increased greatly over the last several years.

In addition, findings indicate that HIV education in the context of comprehensive school-based health education has significantly increased knowledge among school- and college-aged youth, and that HIV prevention programs in educational settings can delay the onset of or reduce the practice of high-risk behaviors. Effective adolescent HIV prevention programs were generally found to be those that are based on social learning theories; focus on reducing sexual risk behaviors; provide accurate information on risks of and methods for avoiding unprotected sex (i.e., without a condom); address social influences on sexual behaviors; support values that discourage unprotected sex; and provide communication and negotiation skills.

Programs for high-risk or already infected persons have received the most extensive study. According to the CDC analysis, evaluations of counseling and testing programs indicate that such programs tend to reduce HIV-related risk behaviors in specific populations--especially among heterosexual couples in which one partner is HIV infected and the other is not, and among gay men testing HIV seropositive. However, there seems to be little evidence that counseling and testing leads to favorable behavior change among persons who are engaging in risky behavior but receive *negative* test results. These findings would indicate a need to strengthen the length, intensity, and quality of the counseling and other preventive services for selected high-risk persons who test negative and to evaluate these improved efforts. Several studies of individual or small group risk-reduction counseling interventions completely unlinked to testing indicate that such interventions increase knowledge about HIV and AIDS and decrease high-risk drug- or sex-related activities among different specific high-risk populations, at least in the short term.

Evaluations indicate that community-level interventions are particularly promising for changing risky behaviors. Community-level interventions are those which (a) target the community (which may be defined by gender, geography, high-risk behaviors, race/ethnicity, or sexual orientation) rather than a specific individual, (b) involve community members in the actual design and delivery of the intervention, and (c) attempt to change community norms about high-risk behaviors as well as modify individual behaviors.

External Review of CDC's Prevention Activities

Recognizing the changing patterns of the HIV/AIDS epidemic, and concerns from outside groups to determine what has, and what has not, been effective in prevention efforts to date, in February 1993, CDC requested that its Advisory Committee on the Prevention of HIV Infection (ACPHI) convene subcommittees of outside experts to review CDC's key HIV program areas. The Advisory Committee, in its general findings, acknowledged that HIV prevention is necessary and urgent, that prevention efforts should be guided by science, and that partnerships and collaboration are key to the success of prevention programs. The Committee also advised that "prevention interventions must strike a balance between targeted efforts and efforts to change general community norms." All Americans are potentially at risk, but it is important to maximize limited resources and minimize new infections by targeting those whose behaviors place them at highest risk.

Concurrent with the external review of its programs, as a result of lessons learned to date and in response to the Secretary's direction, CDC had also begun two new initiatives--HIV Prevention Community Planning and the Prevention Marketing Initiative--which are designed to target prevention efforts better and to more closely involve its prevention partners and, particularly, communities affected by the epidemic.

HIV Prevention Community Planning

HIV Prevention Community Planning represents a significant step forward in the planning of scientifically sound programs that address unique community needs. Past experience has shown that we must be responsive to the needs of African-American and other racial/ethnic minority communities, for example, by using language that is culturally appropriate within those communities and by involving community members themselves in planning and evaluating programs. This will ensure that HIV prevention programs are well received and accepted at the local community level.

The HIV Prevention Community Planning Guidance, issued in December 1993, is being implemented in fiscal year (FY) 1994 and applies to all of CDC's 65 State, territorial, and local health department grantees. In addition to including representatives of affected populations, the process embraces the notion that the behavioral and social sciences must play a critical role in the development, implementation, and evaluation of HIV prevention programs within a given community. By using this and other scientific information, such as scientific-effectiveness and cost-effectiveness literature, successful interventions can hopefully be translated for use in other geographic areas and demographic groups.

CDC is providing technical assistance and training to health departments and community planning groups through a network of governmental, nongovernmental, and private providers. This assistance and training focuses on the following areas:

- Parity, inclusion, and representation;
- Surveillance and the uses of epidemiologic data;
- Community planning processes and models;
- Evaluation of effective and cost-effective HIV prevention efforts;
- Access to behavioral and social science expertise; and
- Conflict of interest and dispute resolution.

Prevention Marketing Initiative

In January 1994, CDC formally announced the Prevention Marketing Initiative, or PMI. This initiative represents a large-scale effort to influence behaviors which contribute to the sexual transmission of HIV and other STDs among young people 18-25 years of age. PMI uses proven social marketing principles and consumer-oriented health communications technologies to shift from previous mass media health communications programs, aimed at increasing general awareness of HIV infection and AIDS, to activities designed to influence behavior changes among persons at high risk of HIV infection or transmission.

To date, the most visible aspect of PMI has been the first component, the national health communications program. A series of public service announcements (PSAs) have been produced and distributed to major networks and their local affiliates. These PSAs deliver two main HIV prevention messages: (1) abstaining from sexual activity is the most effective HIV prevention strategy; and (2) individuals who are sexually active can significantly reduce their risk by using latex condoms consistently and correctly.

The second component focuses on the establishment of a national prevention collaborative among governmental and nongovernmental partners to facilitate the interchange of technical assistance and promote and facilitate support for the objectives of PMI at the local level. With the assistance of this prevention collaborative, CDC will continue to develop and distribute materials, planning guides, data gathered for the national program, case studies, and other materials to State and local communities.

In the third component, community demonstration sites, CDC is assisting five communities in taking the lead to plan and implement innovative, data-driven prevention marketing programs to prevent the sexual transmission of HIV and other STDs among young people. CDC will closely monitor and evaluate these demonstrations sites, and lessons learned will be distributed through the Prevention Collaborative Partners and will impact the National Health Communication Component.

In the fourth PMI component, CDC will specifically work to facilitate the application of prevention marketing principles in CDC-funded HIV prevention community planning efforts by promoting guidelines and providing technical assistance for incorporation of these principles at the local level.

PMI is an important example of how we base prevention efforts on increasing scientific knowledge. Although we have known for some time that condoms were effective in reducing transmission of HIV and other STDs, recent studies have provided compelling evidence that latex condoms are highly effective in protecting against HIV infection when used properly for every act of intercourse. In a study of discordant couples (in which one member is infected with HIV and the other is not) in Europe, among 123 couples who reported *consistent* condom use, *none* of the uninfected partners became infected. In contrast, among the 122 couples who failed to use condoms *consistently*, 12 of the uninfected partners became infected.

Conclusion

The challenge of preventing further spread of HIV infection in *all* affected U.S. communities will require our greatest efforts. We must continue to direct our prevention programs toward people infected with the virus (to help them avoid the behaviors that transmit the virus), those who are at highest risk of becoming infected, those who have not yet adopted the behaviors that put them at risk for infection (such as adolescents), and others who have an occupational risk for infection.

We must consider the special challenges presented by the multicultural and multiracial nature of our society, and we must consider communities' needs, characteristics of the epidemic, and resources in determining appropriate prevention programs. To meet these challenges, we must work closely not only with communities, but also with our State, national, and international partners, in supporting programs found to be most effective and in implementing new strategies to prevent the spread of HIV infection.

Our HIV prevention strategy has evolved into one that recognizes the complexity of human behavior change, the diversity of partners needed to combat this common enemy, and the importance of integrating HIV prevention efforts into other prevention, medical, and social services. We will continue to work closely with other Public Health Service agencies and Congress to evaluate our activities carefully, build upon those that are most effective, and develop new strategies where needed to make the best use of our resources and achieve the important goal of HIV prevention.

Mr. Chairman, this concludes my testimony. I will be glad to answer any questions that you or any other members of the Subcommittee may have. Thank you.

Attachment #1

AIDS in Black Americans

Of the 361,164 AIDS cases reported to CDC in residents of the United States by December 1993, Blacks accounted for:

- 32% of the total
- 54% of the women
- 28% of the men
- 55% of the children

Blacks accounted for 36% of the total AIDS cases reported in 1993.

NCID/DHA

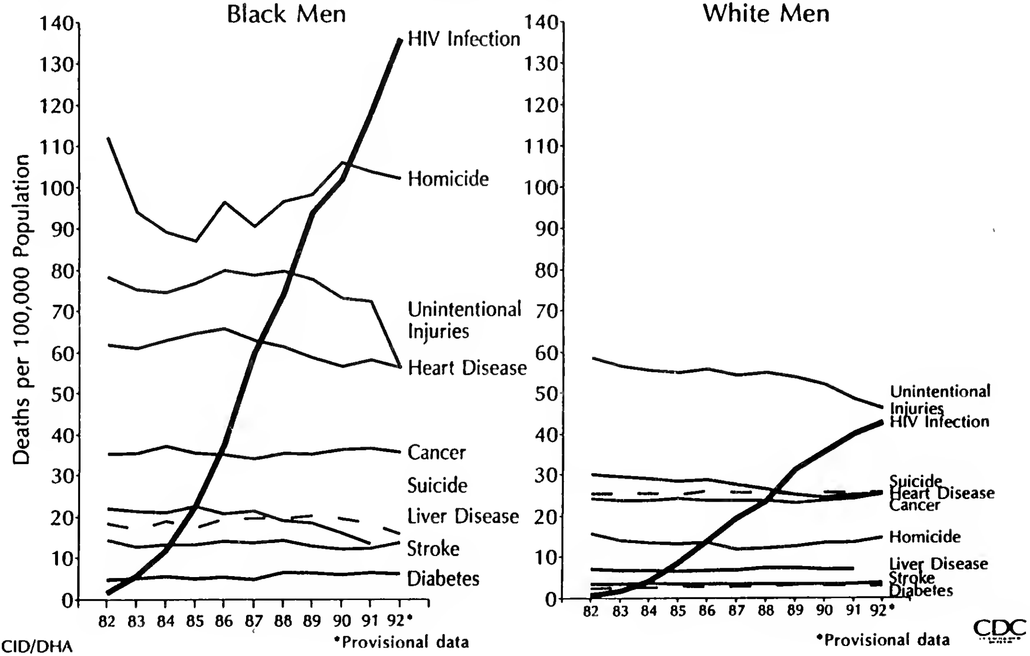
CDC

B:MINOTIL, DEAN, H., MINORIRT SERIES, 04/93

Updated 9/94 Dawn Smith

Attachment #2

Death Rates for Leading Causes of Death in Men Aged 25-44 Years, USA, 1982-1992*



*Provisional data

NCID/DHA

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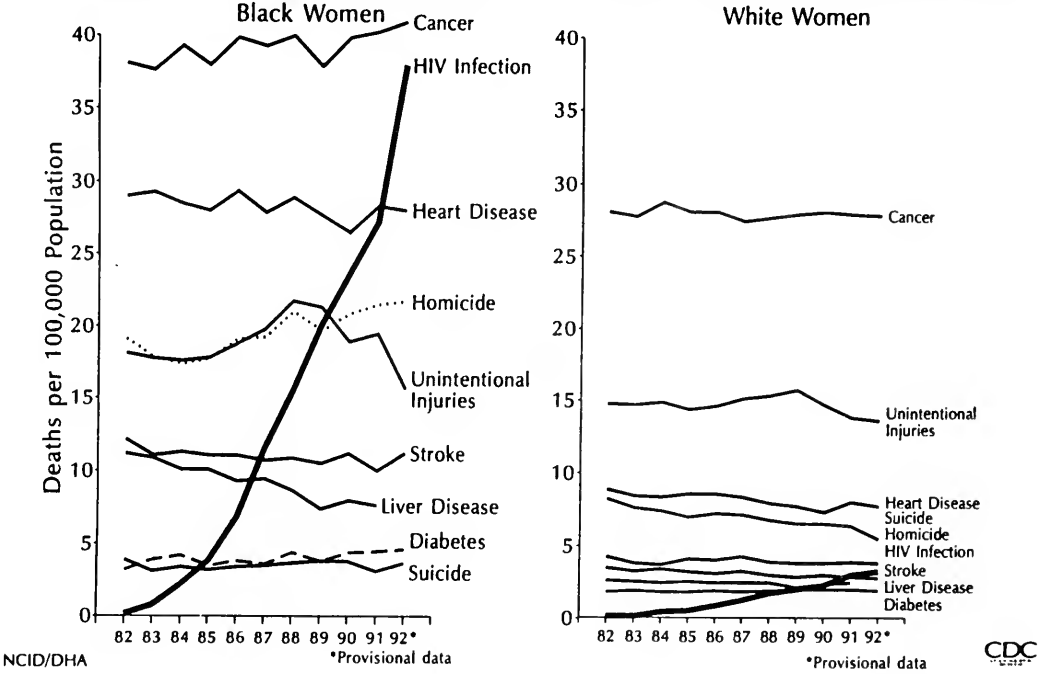
Attachment #3

Death Rates for Leading Causes of Death in Women Aged 25-44 Years, USA, 1982-1992*



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Mr. TOWNS. Thank you. Is Dr. Smith going to testify?

Dr. GAYLE. We were going to open now for questions.

Mr. TOWNS. Sure.

Dr. GAYLE. Generally, we have, as we mentioned, four experts here—Carlton Duncan, who has worked extensively with adolescent programs; Dawn Smith, epidemiologist; Dorothy Triplett, who is our minority HIV prevention expert; and Sam Taveras, who is working with community prevention programs.

Mr. TOWNS. Thank you very much, Dr. Gayle.

According to your testimony, you say blacks account for 36 percent of all the total AIDS cases reported in 1993. Correct?

Dr. GAYLE. Thirty-six percent.

Mr. TOWNS. Thirty-six percent. Are 36 percent of CDC's prevention funds actually devoted to programs targeted for African-Americans?

Ms. TRIPLETT. That is a very good question, and I would like to respond. And I am very willing to respond.

I think internally CDC—as the Nation's prevention agency, we actually have some work to do, because the planning activities of the different centers, institutes and offices must reflect communities of color as one of the priorities. Now, if you call me to task on that, I couldn't say if that were so. So I think we have got to do some homework internally to look at the shift in the virus and see if our funds are shifting accordingly. So—because if we are not doing that, then we are—a cliché I like to use is, we are pushing water uphill with a rake. So we have got to do some internal work before we can start looking externally to see if, in fact, our priorities reflect our epidemiology.

And then, second of all, with PHS, Public Health Service, we have got to look at collaboration, with the shrinking resources, to plan our activities with the epidemiology in mind and then fund those programs accordingly. So we have got some work to do in terms of shifting, Mr. Chairman, in terms of the way the epidemic looks now.

Mr. TOWNS. Let me just say that I indicated earlier on that I would hold the record open for 10 days.

Ms. TRIPLETT. OK.

Mr. TOWNS. I would like to hold it open and get that information.

Ms. TRIPLETT. OK.

Mr. TOWNS. Because I think it is important.

Let me just say the reason I think it is so important is that sometimes I think we don't learn from our vicarious experiences, either positive or negative. I think we don't learn from them. I look at the drug epidemic that is now—we are overwhelmed by.

I remember—I have been long enough now where it was basically a problem in the ghetto in terms of like Harlem, Bedford-Stuyvesant, and Watts. Someone said there is a drug problem in those communities and everybody else just drove by and waved. They didn't do anything about it.

Then all of a sudden they woke up, and it was in the suburbs. Now everywhere you go there is a drug problem. If they paid attention to it then, we would not have the problems we have now, there is no question about it.

I think we might be making the same kind of mistake here, that if there is a problem that we need to address it in a—in a very, very outgoing and courageous kind of fashion, which means that we have to put the dollars where the problems are.

Ms. TRIPLETT. That is exactly right. That goes internally into our organization, but we have also got to look at ways of working with the community.

Now, we can't just sit up in government and say, we can do this and solve this. We have got to figure out initiatives of working with the religious community. We have got to figure out ways of working with the minority health professional foundation schools, the Tuskegees, the Florida A and Ms, the Morehouse Schools of Medicine. These institutions are sitting right in our neighborhood, and they should play an integral part in HIV prevention. We have got to start looking at our youth and getting them involved along with our school leaders, our teachers, our principals. We cannot afford to let anyone off the hook here.

And I think in addition to looking internally, we have also got to look externally. So we have got some work to do.

Mr. TOWNS. I agree with you, and I say to you that I will hold the record open to see in terms of getting information to me, in terms of the amount of resources that are actually being targeted into these areas. I think that is very, very important.

Dr. GAYLE. We will provide that.

Mr. TOWNS. Your written testimony says CDC knows HIV prevention programs work and can change behavior in specific populations. Can you give me a specific example of an HIV prevention program that has reduced the rate of infection within the African-American community? Either one of you.

Mr. TAVERAS. Well, they are—there are certainly many examples that we could cite in terms of organizations that are grassroots and community based. And there are some folks here that represent those agencies and could perhaps better speak to some of these outcomes and results.

And I can cite, for example, many agencies, ranging from one side of the East Coast to the other side of the West Coast. But I think what is more important is to talk about the characteristics of organizations that work for our communities. And I think we heard a little bit about that in the first panel. But if I may, I would like to share with you some of these.

First, programs that are science based and that are based on behavior change practice, theory, and experience. I think community-based organizations and other agencies that are involved in the forefront of fighting this epidemic have other specific characteristics, for example, that the programs are accessible to folks in our community, but they involve persons who are infected and affected by HIV in terms of involvement in decisions that are related to planning, designing, implementing programs and delivering programs. Also that these programs provide ongoing opportunities to reinforce prevention messages, that they provide opportunities to acquire and practice prevention skills, such as negotiating condom use or safer sex, that they provide opportunities for referrals and that these referrals have been proven to work for our community, that the folks that are developing those services are sensitive, cognizant of the many cultural, social, economic issues and needs that our communities have, and that the programs are well-funded.

So those are some of the characteristics that I think work for our programs. And I think that should be of help in terms of this hearing.

Mr. TOWNS. Well, it helps, but that really didn't answer my question.

Mr. TAVERAS. OK.

Mr. TOWNS. It helps. Because we are dealing with a very serious problem. But could you give me the name of the—the name of the program, the director's name, and maybe we could use that as a model.

Mr. TAVERAS. OK.

Mr. TOWNS. That is what I am saying.

Mr. TAVERAS. OK. Sure.

Mr. TOWNS. Do you have that for me?

Mr. TAVERAS. I will give you a number of examples. We have in Oakland, CA a program called AIDS Project of the East Bay. That project is run by Valerie Papaya Mann and A.J. Napolis. It involves people who are from the community. It involves team peer educators. It involves three young men who are gay men of African descent who are out in the community. Their motto is "home and loans, bar-education," and reaching out to the community in specific places where individuals are—that are high risk. That is an excellent model.

Dr. GAYLE. Just—and also just to add—I mean, I think your question is specifically about examples where we have seen HIV infection actually decrease as a result of the programs. I think we all have to—we all probably have to recognize that rates are still growing. We know that.

I think what we have learned is, as Mr. Taveras outlined very nicely, we have learned what it takes to reduce the behaviors that will lead to reduction in HIV infection. That is a long chain; that is not an instantaneous change. I think that we have to be willing to accept that prevention takes time.

What we are talking about is a long—being in this for the long haul, and this is a sustained effort and a sustained battle. We are not going to see decreases in HIV infection tomorrow, even though we know that we are on the right road. We need to do more, and we need to do it longer.

But I think we do feel confident that we, working with communities—increasingly, that we know the right way to do a lot of the things that it takes to decrease the behaviors that lead to HIV infection.

Mr. TOWNS. Let me just say that I hear of that, traveling around, from community-based organizations—that they are left out of the process, that they are shut out of the process. So is that real or imaginary?

Dr. GAYLE. I think that is—I think that—and I will let some of my colleagues answer, as well. I think that we are evolving and developing our partnerships. The community planning process that is a recent process is a process of inclusion. It is a process that we hope will include increasingly a more diverse range of groups than we have worked with in the past.

But I think it is fair to say that we are evolving in our development of partnerships with community-based organizations. It is something that is a high priority to what we do and increasingly, the future of how we do prevention.

Mr. TAVERAS. Mr. Chairman, let me say that not only are they kind of left out of the process, but not enough community-based organizations are funded.

And I will say this: In 1991, we put out a program announcement. In 1992, we put out a second program announcement for community based, grassroots organizations. The first announcement, we had about 398 grassroots organizations respond to our proposal. We could only fund 42, to the tune of close to $10 million. In the second program announcement that went out in 1992, we got a response of about 348 organizations. We could only fund 49, to the tune of about $9 million.

There were many organizations that we could not fund that were well justified in terms of capabilities, in terms of the needs that they were addressing. I might add that some of those organizations have representatives here that were excluded from receiving funding. So it is a major problem.

Ms. TRIPLETT. Also, Mr. Chairman, in terms of the infrastructure that is in place now, CDC and other organizations fund national organizations. Many of our CBOs are not national organizations, so they are not included in the process. It is very important. And government has recognized that we can't do it from a top-down level and then let it trickle to the bottom. It has to be a bottom-up process.

CDC and other governmental employees are learning that this paradigm shift must take place in terms of inclusion, parity and representation of the communities. Now, in order to get that done—the infrastructure that is in place did not happen yesterday. The infrastructure to redo this is not going to happen this evening. We are clear that we have to have the community's involvement that tells us what is needed in their particular community as opposed to us telling them what they need in their community.

So it is taking a different shift here. Community planning is one effort that I know includes parenting inclusion and representation, and it is a start, but is not a cure-all. So we are going to have to look internally and externally to make major changes in the way we do business.

Mr. TOWNS. I am happy to hear that.

Let me say I plan to help you, because in the next Congress I am going to look at legislation to see in terms of how we can get money down to grassroots organizations that are dealing with the problem on a day-to-day basis.

Ms. TRIPLETT. Your point is well taken. I think it is extremely important for those of us that are here for the Caucus and those of us that are here for the National Minority AIDS Congress, for you to take the time to make this a priority of yours. It is already a priority of ours. I am very proud to be a part of the Caucus that has now decided that we must take a very good look on a day-to-day basis at HIV and AIDS.

Mr. TOWNS. Let me thank all of you.

I think that we really have to work together to try and bring about an end to this; $10 million is not enough. You know it, I know it, and anybody else will know that this is not enough money. My son would say, you would know that this is not enough dollars, $10 million we are talking about to the community organizations. Is that the number I heard from somebody?

Mr. TAVERAS. No. Let me correct a statement.

I said $9 million for one program announcement in which we funded 42 organizations and close to $10 million for another program announcement where we funded 49 organizations. So that is $19 million.

Mr. TOWNS. Let me ask a question.

How much per annum are you spending for these community-based kinds of programs? That is what I am trying to ask.

Mr. TAVERAS. We have—let me tell you in terms of what I am aware of. We fund through Health Department Minority Initiatives to the tune of $14 million.

Mr. TOWNS. How many million dollars?

Mr. TAVERAS. $14 million. So, for community-based organizations, we are talking $19 million. And in terms of our support, financial and technical support for national and regional minority organizations, that serve and represent and provide technical assistance and capacity building to community-based organizations and health departments, we are talking $8.5 million. So approximately $40 million are going to efforts to support minority communities in terms of HIV prevention. Not all that money goes directly to organizations that are for and by folks of color, and that is an issue.

Mr. TOWNS. Let me ask a follow up to that. How much do you think it costs us to treat them when they are sick?

Mr. TAVERAS. I am not prepared to answer that.

Mr. TOWNS. What I am really saying——

Dr. GAYLE. I think clearly the point that is being made is that prevention obviously is much less costly than taking care of somebody once they are already infected. We believe that will, and I think this could get into a long discussion about how overall AIDS funding is distributed.

What we can do for you is to provide a much more detailed breakdown of CDC's prevention funding. It is difficult to explain, and clearly funds that are general prevention funds also have a huge effect on minority populations since many of those are public funds as well. So we will do the best we can to give you a thorough breakdown of the funding overall for prevention, that is earmarked specifically for minority communities and that has a major effect because it reaches minority communities even though not earmarked for a minority community. We will give you a breakdown.

Mr. TOWNS. Thank you very much. I think you can see where I am trying to go.

Dr. GAYLE. We appreciate it.

Mr. TOWNS. Thank you very much for your testimony. You have been very helpful.

Thank you very much.

Our next panel is Joyce Hughes, deputy director of the division of HIV prevention, AIDS Institute, New York State Department of Health; Ronald Johnson, chair of the HIV planning council, coordinator of citywide AIDS policy, New York City, NY; Catherine Correa, special assistant, Office of the County Manager, Union County, NJ.

Your entire statement will be included in the record. If you could summarize in 5 minutes, it would allow us to have an opportunity to have a dialog.

STATEMENT OF JOYCE HUGHES, DEPUTY DIRECTOR, HIV PREVENTION, AIDS INSTITUTE, NEW YORK STATE DEPARTMENT OF HEALTH

Ms. HUGHES. Thank you for the opportunity to allow the New York State Department of Health AIDS Institute to testify today. We are grateful for your time and energy in this very important topic.

I am going to do exactly what you asked. I am going to leave you our testimony but summarize a few points. And what I really want to do is to give you a picture of AIDS in New York State. There is no doubt that African-Americans are disproportionately affected by the AIDS virus, and I will highlight some of the statistics.

In New York State, African-Americans account for 14 percent of the overall population and yet we account for 40 percent of the actual AIDS cases; 52 percent of the State's AIDS cases affecting women are African-American women and 53 percent of the pediatric cases and injecting drug use cases are African-Americans.

Of the cases 47 percent are contracted through heterosexual contact and nearly 24 percent of the male homosexual cases are in the African-American communities; 1 in 55 African-American women giving birth in New York City are HIV infected, and as many as 1,700 African-American infants have been born with the virus since the beginning of the epidemic.

I think that the New York State Department of Health has been proactive in addressing HIV/AIDS in our State, and I would like to share a few of the models that we have designed to reach the African-American community. The one that I am most proud of and I think the State is most proud of, is our multiservice agency initiative. This initiative, which we started approximately 2 years ago, was borne out of community forums and focus groups with communities of color.

Out of those focus groups, we were told by the community that they often come to the table late for seeking funding mainly because they didn't have the infrastructure or the expertise to write grants; also that oftentimes they didn't have the infrastructure even to provide services; so that their funding was low, their infrastructure was nonexistent and they didn't have the capability to hire capable staff.

With that in mind, we designed what we call the MSA initiative which funds that infrastructure piece which is vital to community-based organizations, particularly in the small grassroots organizations such as CBO's and the community health centers. We also made sure that the community-based organization reflected the community, so therefore the board and the senior management staff must be—must represent the community, and we also strongly encourage that people indigenous to the community are hired to provide the services.

One of the things that we can't do is talk about HIV and AIDS in the black community without addressing the fears and the skepticism that folks have on the origin of HIV/AIDS and AIDS, particularly how it came about and the so-called treatment availability for people of color. So therefore we felt the MSA model would allow us to address those fears and those skepticisms so that people would come into the services.

I think that we have done an effective job in doing that. This is only 2 years into the program and the program got off the ground about 1 year ago. So I hope that at the end of a year or two we will be able to share with you what we have done there.

In closing, I would like to leave a couple of recommendations with you. I think we have done great things with the drug treatment program and with women's services, and I hope you will take time to read our testimony to see that.

A couple of recommendations: One, you need to increase the prevention funding. We have not received increased prevention funding in over 2 years through the CDC cooperative agreement, while the health care side has grown consistently over the last 2 or 3 years.

We have to have prevention funding because that is the only thing which will stop transmission of the HIV/AIDS virus. Also, drugs are killing our communities and AIDS is the largest—AIDS is affecting the substance abuse community more than any other group.

The needle exchange programs and substance abuse programs must be funded using Federal dollars. There are no Federal dollars going into it. Also, many of our children are going to be orphans and we need to provide for those children by providing programs for not only the mothers to get ready to put those kids in State homes, but also that the programs are well-rounded.

We also are not doing very much, as you heard from CDC, in the area of evaluation and clinical research for people of color. When you talk about effective models, we can't talk about what works and what doesn't, when there are no moneys allocated to provide that sort of evaluation.

I close saying that we need additional funding, we need to dedicate dollars to behavioral science, to clinical research which is really going to impact on communities of color.

Thank you.

Mr. TOWNS. Thank you, Ms. Hughes.

[The prepared statement of Ms. Hughes follows:]

STATEMENT

OF

JOYCE HUGHES

DEPUTY DIRECTOR FOR HIV PREVENTION

AIDS INSTITUTE

NEW YORK STATE DEPARTMENT OF HEALTH

BEFORE

SUBCOMMITTEE ON HUMAN RESOURCES AND INTERGOVERNMENTAL RELATIONS

COMMITTEE ON GOVERNMENT OPERATIONS

U.S. HOUSE OF REPRESENTATIVES

WASHINGTON, D.C.

SEPTEMBER 16, 1994

Testimony of Joyce Hughes

Deputy Director, Division of HIV Prevention

New York State Department of Health AIDS Institute

Congressman Towns, members of the Congressional Black Caucus and members and staff of the Subcommittee on Human Resources and Intergovernmental Relations; thank you for the opportunity to present testimony on HIV infection and AIDS in the African American community.

My comments will focus on several areas: the devastating impact of the AIDS epidemic on African Americans; the HIV prevention and health care programs we at the New York State Department of Health AIDS Institute have developed to respond to the HIV epidemic in the African American community, and the necessity for multiple approaches focusing on the unique needs of African Americans.

Let me begin by giving a picture of the terrible impact HIV infection and AIDS are having on black Americans. The Centers for Disease Control and Prevention (CDC) recently reported that black women are almost 15 times more likely than white women to have AIDS. In New York State, AIDS has been the leading cause of death among African American women aged 25 to 44 since 1987. Black men are five times more likely than white males to have the disease, which is now the leading cause of death among black, and Hispanic men aged 25 to 44.

New York State's HIV epidemic is growing most rapidly and disproportionately in the African American community. Although African Americans represent 14 percent of New York State's population, they account for 40 percent of the State's cumulative AIDS cases reported through July of this year. African Americans account for more than half (52 percent) of AIDS cases among the State's women, more than half (53 percent) of pediatric AIDS cases, more than half (53 percent) of cases among injection drug users, nearly half (47 percent) of cases acquired through heterosexual contact, and nearly one-quarter (24 percent) of cases acquired through male homosexual contact.

Also, one in 55 African American women giving birth in New York State is HIV positive. Assuming that approximately 25 percent of the infants born to infected mothers will themselves be infected, as many as 1,700 HIV-infected African American infants have been born in New York State since the beginning of the epidemic.

By the year 2000, it is estimated that AIDS will have orphaned 82,000 children and adolescents. Again, African American and other minority communities will disproportionately bear the burden of this devastating adjunct to the AIDS epidemic. These children may themselves be at high risk for HIV infection, and have likely experienced numerous other health and social problems. The ability of their remaining family members to care for them and to provide a nurturing environment may be compromised by age, poverty, illness, and other factors.

New York's African American community faces an HIV epidemic that has become increasingly complex, affecting entire families and generations. This situation is exacerbated by other coexisting and longstanding epidemics of substance abuse, tuberculosis, youth violence, infant mortality, and teenage pregnancy, all eroding the fabric of family and community life.

The New York State Department of Health AIDS Institute has responded by developing and funding a spectrum of comprehensive, integrated services ranging from programs to prevent the spread of HIV to care for those who are infected and ill.

African Americans and other communities of color receive HIV services through all Institute-funded programs, but particularly through several major initiatives: multiple service agencies, community-based health centers, women's services, and substance abuse treatment, each providing some or all components of a continuum of services comprising HIV prevention education, HIV counseling and testing, case management, and primary care.

The AIDS Institute also believes in the empowerment of African American and other communities of color to combat the HIV epidemic. The Institute's Multiple Service Agency, operating on the principle of community empowerment, supports the development and expansion of comprehensive HIV care and support services provided through a "one-stop shopping" model. The Community Development initiative supports AIDS advocacy and policy development activities among African American and other communities whose voices are frequently not heard by government policymakers.

With injection drug use having become the primary risk factor for HIV infection in New York State, the AIDS Institute, in collaboration with the State Office of Alcohol and Substance Abuse Services, has implemented HIV medical care and support services in 25 of the largest drug treatment facilities statewide.

Because the AIDS Institute recognizes that not all persons whose drug use puts them at risk for HIV infection will seek substance abuse treatment, we have developed a harm reduction initiative that provides needle exchange and offers counseling and medical and support services to persons who cannot or will not enter into treatment or cannot abstain from drug use.

Women at risk for HIV or who are already infected with the virus can receive care for themselves and their children through hospital and community-based programs providing HIV counseling and testing, community-based follow-up health care, case management, and support services such as day care and medical respite.

As you no doubt are aware, the Federal clinical study ACTG 076 found that zidovudine (AZT) given to HIV-infected pregnant women significantly lowers the risk of HIV transmission to their babies. In light of this finding, The AIDS Institute has embarked on a major effort to identify infected women as early as possible and bring them into care. We have also developed state of the art clinical guidelines for the use of AZT in pregnancy that will greatly reduce the chances of perinatal HIV transmission. This development will largely benefit African American and Latina women, who together account for some 80 percent of seropositive women in New York State.

The AIDS Institute developed a Community HIV Prevention and Primary Care initiative to establish comprehensive HIV medical care and support services in health centers located in African American communities. Last year more than half of persons who received HIV counseling and testing through this program, and nearly 80 percent of those receiving follow-up primary care, were African American or Latino. These community health centers provide accessible, community-based care in a manner that fosters a close relationship between patients and care providers. It is also important to note that a significant percentage of patients receiving care at these centers have symptomatic HIV infection.

Besides the community-based, women's, and substance abuse programs, New York has developed the most extensive grant-funded insurance program providing free medications, home care, and primary care for persons who lack health insurance but are not eligible for Medicaid, many of whom are African American or Latino.

While accomplishments in New York have been significant, we continue to meet with those in the minority community, both infected and affected by this epidemic, and with health care providers, social and behavioral scientists, clinicians, and others to develop new program approaches to slow the spread of HIV. However, while we continue to work on program development, our experience in New York thus far is useful in providing a basis for making specific recommendations for Congressional action.

We recommend the following steps:

- **Increase funding for HIV risk reduction and prevention education.**

With the prospects for an AIDS cure looking so dim, I cannot overemphasize the importance of preventing the further transmission of HIV. There is a basic, critical need for increased federal prevention funding. Without new prevention funding all those at risk for HIV are harmed, but particularly African Americans and other minority populations so disproportionately affected by this epidemic. The single most important step that you can take is to push your colleagues on the Labor/HHS Appropriations Subcommittee to provide the maximum possible increased funding for HIV prevention when the House and Senate conferees meet next week.

Once new funding is received, CDC should work harder to provide the flexibility to permit funding of organizational infrastructure so that indigenous, community-based programs that have credibility among and access to African Americans can develop the capability to provide HIV prevention and education services.

- **Lift the Congressional prohibition on the use of federal funds for needle exchange.**

No one should accept needle exchange as a substitute for drug treatment programs. But neither should we ignore the scientifically valid findings that point to needle exchange programs as a means to engage drug users in HIV prevention, harm reduction, health care, drug treatment, and other services which they otherwise might never have a chance to access. Needle exchange provides us with the means to talk with active drug users about changing their behavior, referring them to other services, and educating them to prevent the spread of HIV.

- **Provide funding to begin programs to assist the children who survive their parents and siblings who die from AIDS.**

A massive infusion of funding is needed to provide health, social, psychological support and other services to these children. In addition, funds are required to provide permanency planning, entitlement and legal counseling, and other services.

- **We can no longer allow the continuation of insufficient clinical and behavioral research on HIV and AIDS and African Americans.**

More funding should be directed to the African American community for research into African Americans' knowledge, attitudes, and beliefs about HIV and AIDS, as well as about the behaviors that contribute to the continued spread of the virus among blacks and other people of color. Research that not only identifies those factors that promote HIV transmission but also how risk behavior can be changed. The roles of peer education, the black church, and mentoring programs in promoting and sustaining behavior change are research issues of critical concern to African Americans.

Clinical trials of new AIDS treatments sometimes have been designed with the result that blacks, and particularly black women, have been underrepresented or even excluded. Alternative forms of treatment embraced by members of the African American community, often in the belief that they are less toxic than conventional approaches, need to be understood by the medical and advocacy communities.

Black women urgently need research on means other than condoms to protect themselves from heterosexual transmission of HIV infection. Development of effective viricides would truly be a life-saver for women who lack the power to make their male partners consistently use condoms.

- **A national action agenda by and for African Americans should be developed and funded to facilitate open and frank dialogue relative to the devastation of AIDS in communities of color, including research, prevention, and treatment.**

Representatives should include leaders of scientific, religious, educational, entertainment, government, non-government and other organizations. We must conscientiously and deliberately address the suspicions and concerns of the African American community in dealing with this disease.

Mr. TOWNS. Ms. Correa.

STATEMENT OF CATHERINE CORREA, PROJECT DIRECTOR, RYAN WHITE, TITLE I, PATTERSON, NJ

Ms. CORREA. Just a classification in terms of title. I am the project director for Ryan White in the northern region of New Jersey, and my background is community-based organizations for the past 10 years. My presentation is on behalf of children whose parents have died and are dying with AIDS-related conditions and their caregivers.

Thank you for having these hearings during the National Congress State of HIV/AIDS in Racial Communities, as well as during the Congressional Black Caucus. I will present a quick overview on the orphans, the needs of the affected, not infected children, and conclude with further research needs as it correlates to prevention and service.

The epidemic has hit hard among women and men during their primary productive years. It is the leading cause of death for African-Americans between 25 and 44. For African-American women, it is 15 times greater than for white women. Children of color account for about 80 percent of all AIDS-reported cases among children in their age group in the United States.

As hetero transmission tends to dramatically increase, becoming the primary transmission among women, we have to ask ourselves how many children and adolescents will survive the AIDS-related death of a parent. By the turn of the century, between 72,000 children and 125,000 children and teenagers in the United States will have lost their mothers to AIDS, and an additional 60,000 young adults will have lost their mothers.

For the vast majority of the youth whose care-giving parent has died to AIDS, for the most part, it has been the mother. In communities where the extended family is fortunate to have connected the extended family, it is increasingly observed that the grandmother with limited resources continues the nurturing role.

The graphs that are presented give you an estimate of children who will survive by the year 2000, left motherless in the six major epicenters in the country by the year 2000. By the year 2000, in New York City alone, 30,000 children will be orphaned.

These major centers that I mention of the six cities, account for approximately 60 percent of all the total number of orphans. The unmet needs of the affected youth, a vast majority of orphans are not HIV infected, but are affected, and are at a high range for behavioral developmental problems.

Although a broad range of long-term continuum of care is required which includes health care, the most urgent needs are for mental health services, including bereavement counseling, transitional services for that reorganized family, legal services and standby guardianship, housing supports and appropriate evaluations and referrals by the juvenile justice system and the schools must be directed to community services. Although there are many innovative programs that target the affected families, it is the needs of the well orphaned by AIDS which have not been met, have gone unrecognized and undocumented.

My recommendations, looking to further research needs, in the attached appendix you will note research needs documented in the publication, "The Orphan Project: The HIV Epidemic," among the six cities. Further research consideration in the affected and infected of orphans to AIDS within African-American families must be documented and evaluated.

This study should be sensitive to the issues of confidentiality, including statistical analysis on interracial children, African-American/Caucasian and African-American/Latinos. The data collected is instrumental for policy planning and evaluation. Public policies and practice must be respectful of tradition and cultures in order for a reduction of barriers.

The research really, as we heard, must be integrated at the community-based level and involve and draw on the educational institutions, but researchers must be accountable to the people they study, allowing for feedback from the findings. The information can be most effective once collected in forums that respect the community-based local levels for the development of programs at that level.

The goal is to alleviate human suffering and allow for a greater rite of passage from one generation to the next. We need to minimize loneliness, to articulate the silent voices, understand the fears and rejection, the tears of the motherless, our caregivers, our spiritual mothers.

This important subcommittee is uniquely positioned to provide leadership to advocate legislation and funding toward a systematic needs assessment of orphaned children to HIV/AIDS so that limited resources can be directed to appropriate prevention. I would like to encourage the committee to continue dialog with the speakers you have heard today, to review the newsletter that is attached to your—to the document which is a newsletter that came out today regarding the state of AIDS among ethnic minorities, and documents very well African-American families and the plights, and solutions.

Thank you for allowing me this opportunity to speak.

[The prepared statement of Ms. Correa follows:]

Statement of Catherine Correa
before
The Government Operations Subcommittee
on Human Resources and Intergovernmental Relations
Hearing: "AIDS in the Black Community"

Friday, September 16, 1994

ORPHANS OF THE HIV/AIDS EPEDMIC

On behalf of the children whose parents have died and are dying with an AIDS related condition (ARC) and their caregivers, I would like to thank your committee for having these hearing during the week of the Congressional Black Caucus Convention and the National Congress State of HIV/AIDS in Racial and Ethnic Communities. For the next few moments I will present an overview of **ORPHANS OF THE HIV/AIDS EPIDEMIC, UNMET NEEDS OF THE HIV AFFECTED-NOT INFECTED CHILD,** and conclude with **FURTHER RESEARCH NEEDS** as it correlates to prevention/education and services.

The epidemic has hit hard among women and men in their prime reproductive years. It is the leading cause of death for African Americans between the ages of 25 and 44. Sixty- six percent of all U.S reported cases have been among Blacks. For African American women, the rate was 73/100,00, or 15 time the rate for white women, and 5 times greater among African American men comparatively. Children of color account for about 80 percent of all reported AIDS cases among in the U.S. Heterosexual transmission trends is dramatically increasing, becoming the primary transmission among women. Yet only recently has the question been asked: HOW MANY CHILDREN AND ADOLESCENTS WILL SURVIVE THE HIV RELATED DEATH OF A PARENT? By the turn of the century between 72,000 and 125,000 children and teenagers in the U.S. will have lost their mothers to HIV/AIDS. An additional 60,000 young adults (18 yrs and older) will have also lost their mothers. For the vast majority of youth whose caregiving parent dies to an ARC, that parent is the mother. In communities, where the extended family still remains connected, it is increasing observed that the grandmother, with limited resources continues the nurturing role. **FIGURE** 2 show three estimates of children and adolescents left motherless by HIV/AIDS, based on a range of values including: proportion of HIV related death; incidents of pediatric AIDS and overall infant mortality rates; and projected deaths among women. Using a different model the Centers for Disease Control arrived at a similar estimate, predicting between 93,000 and 125,000 by the year 2000. **FIGURE** 3 compares the six cities hardest hit by the epidemic between 1990 and 2000 of the number of orphaned children and adolescents to survive:

New York City - 30,000; Newark - 7,200; Miami - 4,900; San Juan - 4,200; Los Angeles - 1,900; and Washington, D.C. - 1,400 by year 2000.

These major urban centers account for approximately 60 percent of the total number of orphans. The subsequent **FIGURES 4 to 15** provide a specific breakdown of the approximate number of children who will be orphaned by HIV/AIDS in the respective cities, and notable low and high trend projections. Local geographic variables are involved in defining the magnitude of the problems. However it is also understood that problems such as, institutional racism, systemic barriers, availability of appropriate support models and systems further reinforces and complicates the crisis that orphans and their primary care takers confront.

UNMET NEEDS OF HIV-AFFECTED YOUTH. A vast majority of orphaned youngsters are not HIV-infected, but are affected, and are at a high risk for a range of behavioral developmental problems. Although a broad range of long term continuum of care services is required which includes health care, the most urgent needs are for mental health services, including bereavement counseling, transitional services for the reorganized family, legal services and standby guardianship, housing supports, and appropriate evaluations and referrals by juvenile justice and school staff to community-based services. Although there are many innovative and successful service models, the needs of well children orphaned by AIDS have not been met, and have gone unrecognized and undocumented.

FURTHER RESEARCH NEEDS. In the attached appendix are notable research needs as documented in the publication of **THE ORPHAN PROJECT: THE HIV EPIDEMIC**, Unmet needs in six U.S. Cities, by Carol Levine, and Gary L. Stein, 1994. . Further research consideration of the infected and affected orphans to HIV/AIDS within African American families must be documented and evaluated. The study should be sensitive to the issues of confidentiality, and include statistical data and analysis on inter-racial children African American/Caucasian, African American/Latinos, etc. The data collected is instrumental for policy, planing, programming and evaluation. Public policies and practices that are respectful of traditions and cultures reduces barriers and promotes improved access to the delivery of a comprehensive continuum of services. The research must be integrated with community-based organizations, and educational institutions. Researchers must be accountable to those studied, allowing for feedback on outcomes and findings. The information collected can be most effective in forums at the respective community-based levels in order to process the development and implementation of support systems. Interventions models must be shared at a national level bringing a symposium of multi-disciplinary professions together for a collective approach.

The goal is to alleviate human suffering, and allow for a greater right of passage from one generation to the next: to minimize loneliness, to the articulate the silent voices; to understand the fears and rejection. The tears of the motherless, of our caregivers, our spiritual mothers and grandmothers, who in spite of their own disabilities, will survive, holding onto an inner strength, existing to serve. This important subcommittee is uniquely positioned to provide leadership, to advocate legislation, and funding towards a systematic needs assessment of orphaned children to HIV/AIDS, so that limited resources can be directed to appropriate prevention and intervention models. Help us to take care of our babies, our affected children, so that together we can take care of our communities.

I would like to encourage the committee to keep a continual dialogue with those who gave testimonies today. To review the daily newsletter of the National Congress on the State of HIV/AIDS in Racial and Ethnic Communities for vital recommendations and solutions - the Bridge to cross over the assess gaps and services barriers our ethnic communities face.

In closing, I would like to thank Congressman Payne and his staff Maxine James, and Patricia Crawford, for their continual community support and leadership. And of Michelle Doran McBean who has tirelessly continued the Mission of sacrifical giving to our affected and infected communities. It is leadership and support as this which keeps the Mission going, knowing that without a vision our people will perish.

Catherine Correa
(201) 977-8872

APPENDIX

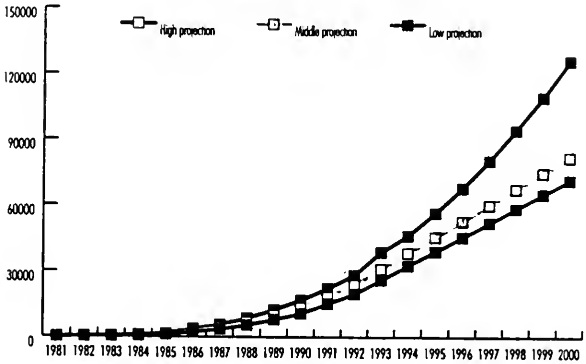
THE ORPHAN PROJECT: THE HIV EPIDEMIC, Unmet needs in six U.S. Cities,
Carol Levine, and Gary L. Stein, 1994.
Executive Summary
FURTHER RESEARCH NEEDS.

1. Further refinements of epidemiological data to take into account the lack of data on fathers, changes in the epidemic, treatment advances, migration patterns, and the aging of children.
2. Follow-up and analysis of family cases to determine who cares for orphaned children and adolescents, the number and ages of children in foster care, the legal status of new guardianship arrangements, the extent to which siblings are separated and long term outcome.
3. Anthropological/ethnographic studies to describe the cultural and acculturation milieu of families, and how these factors affect custody arrangements.
4. Studies examining the impact on adolescents of caring for younger siblings without parental supervision.
5. Studies of bereavement in children of different cultural back-grounds.
6. Data on how and where families access services.
7. Evaluation of strategies to promote more public support for programs that assist families affected by HIV.
8. Psychosocial research on strategies to document family histories.
9. Studies of different patters of disclosure of HIV status within the family.
10. Research on the impact of the growing number of orphans in smaller cities and rural areas, which may lack the range of services found in larger cities.

New York City New York City is the hardest-hit city in the nation. By the end of 1994, approximately 7,000 children and 6,700 adolescents will have been orphaned by HIV in New York City (Figure 4, facing page). As projections move further into the future, they inevitably become less precise; however, by the year 2000, the cumulative total is estimated to include 15,000 who were orphaned as children and another 15,000 orphaned as adolescents. The low estimate is 29,000; the high estimate 34,000; and the medium-range estimate is 30,000 (Figure 5

Figure 2

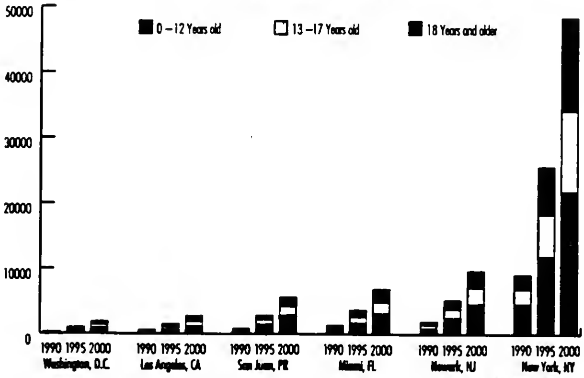
Motherless Children and Adolescents Orphaned by HIV/AIDS
Cumulative US, 1981–2000



Source: The Orphan Project 1993

Figure 3

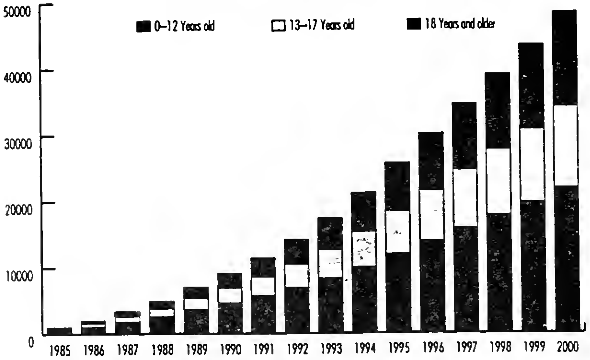
Motherless Youths Orphaned by HIV/AIDS, Cumulative by Age Category
6 Cities, 1990/1995/2000



Source: The Orphan Project 1993

Figure 4

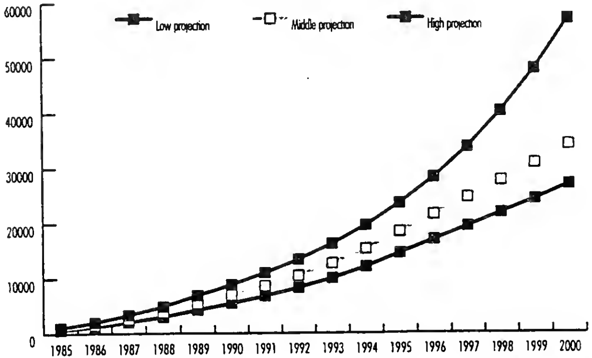
Motherless Youths Orphaned by HIV/AIDS
NYC Cumulative by Age Category, 1985–2000



(1990 population under 18 years old: 1,700,000)

Figure 5

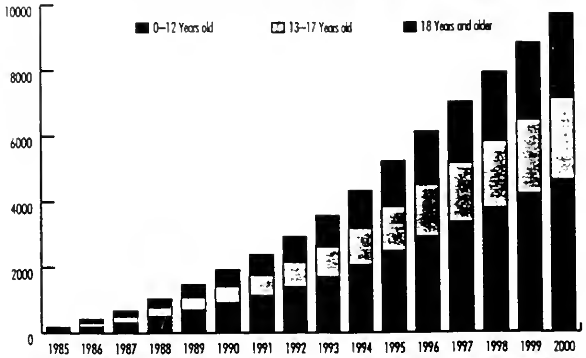
Motherless Children and Adolescents Orphaned by HIV/AIDS
Cumulative New York City, 1985–2000



Source: The Orphan Project

Newark The city with the next highest numbers is Newark. By the end of 1994, 2,100 children and 1,100 adolescents will have been orphaned in Newark (Figure 6). By the year 2000, those numbers will reach 4,700 children and 2,500 adolescents. The estimates of the total number of orphaned children and adolescents by that year range from a low of 5,800 to a high of 11,600, with a medium-range estimate of 7,200 (Figure 7).

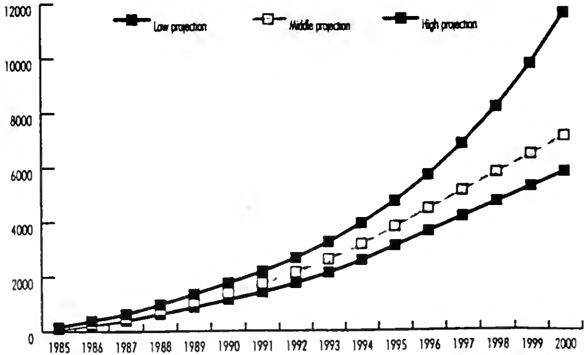
Figure 6 **Motherless Youths Orphaned by HIV/AIDS Newark Cumulative by Age Category, 1985–2000**



(1990 population under 18 years old: 78,000)

Source: The Orphan Project 1993

Figure 7 **Motherless Children and Adolescents Orphaned by HIV/AIDS Cumulative Newark, 1985–2000**

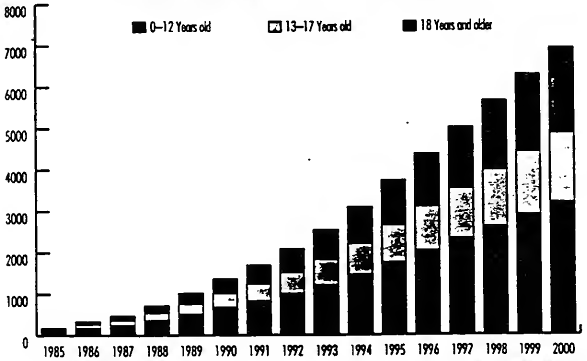


Source: The Orphan Project 1993

Miami Miami, another city with a high proportion of HIV-infected women, will have 1,500 orphaned children and 700 adolescents by the end of 1994 (Figure 8). Miami can expect those numbers to increase to 3,200 children and 1,700 adolescents by the year 2000. The range for Miami runs from a low of 3,800 children and teens to a high of 8,200, with a medium estimate of 4,900 (Figure 9).

Figure 8

Motherless Youths Orphaned by HIV/AIDS
Miami Cumulative by Age Category, 1985–2000

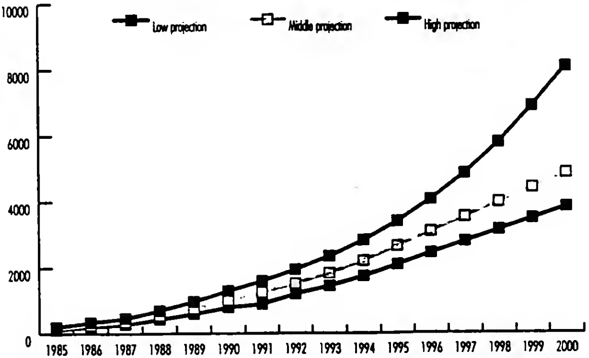


(1990 population under 18 years old: 82,000)

Source: The Orphan Project 1993

Figure 9

Motherless Children and Adolescents Orphaned by HIV/AIDS
Cumulative Miami, 1985–2000

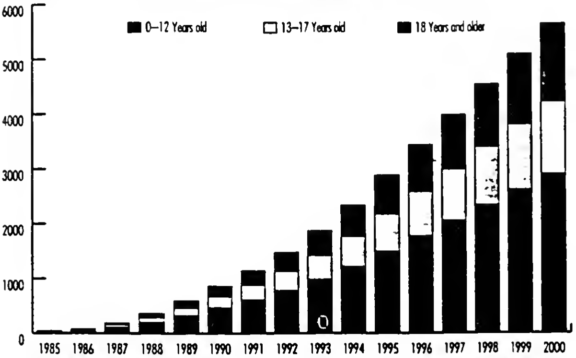


Source: The Orphan Project 1993

San Juan San Juan is not far behind Miami. About 1,200 children and 550 adolescents will have been orphaned by the end of 1994 (Figure 10). By the year 2000 there will have been 2,900 orphaned children and 1,300 adolescents. A low total estimate for San Juan is 3,300 while the high is 7,200; the medium-range estimate is 4,200 (Figure 11).

Figure 10

Motherless Youths Orphaned by HIV/AIDS
San Juan Cumulative by Age Category, 1985–2000

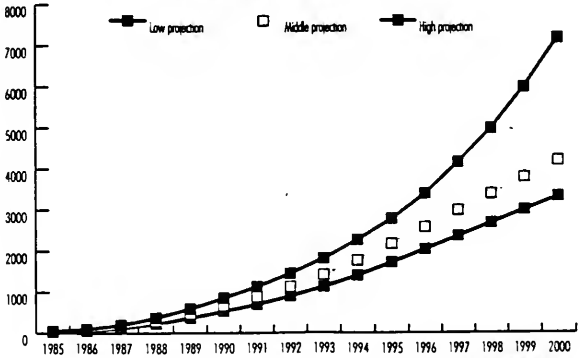


(1990 population under 18 years old: 113,000)

Source: The Orphan Project 1993

Figure 11

Motherless Children and Adolescents Orphaned by HIV/AIDS
Cumulative San Juan, 1985–2000

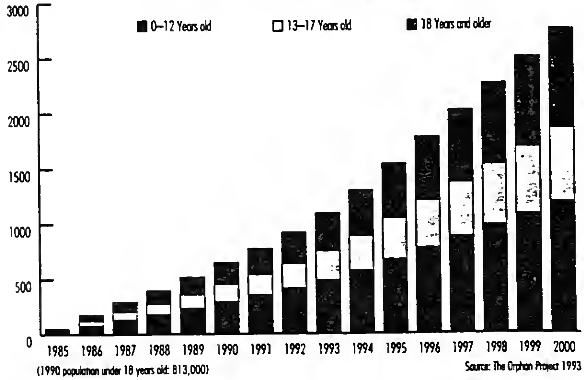


Source: The Orphan Project 1993

Los Angeles By the end of 1994, about 600 children and 300 adolescents in Los Angeles will have been orphaned, growing to 1,200 children and 700 adolescents by the year 2000 (Figure 12). The total low estimate for Los Angeles is 1,500, with a high of 3,100 and a medium-range estimate of 1,900 (Figure 13).

Figure 12

Motherless Youths Orphaned by HIV/AIDS
Los Angeles Cumulative by Age Category, 1985–2000

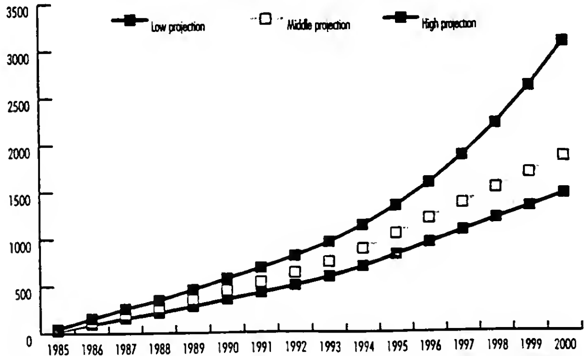


(1990 population under 18 years old: 813,000)

Source: The Orphan Project 1993

Figure 13

Motherless Children and Adolescents Orphaned by HIV/AIDS
Cumulative Los Angeles, 1985–2000

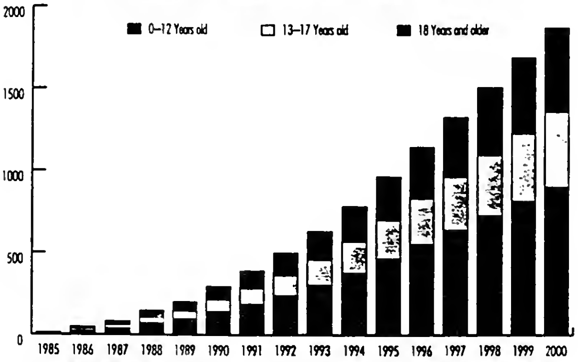


Source: The Orphan Project 1993

Washington, D.C. In Washington, a much smaller city than the other five, 400 children and 200 adolescents will be orphaned by the end of 1994; those figures will rise to 900 children and 500 adolescents by the year 2000 (Figure 14). The low estimate for the total is 1,100; the high is 2,200 and the medium-range is 1,400 (Figure 15).

Figure 14

Motherless Youths Orphaned by HIV/AIDS
Washington, D.C. Cumulative by Age Category, 1985–2000

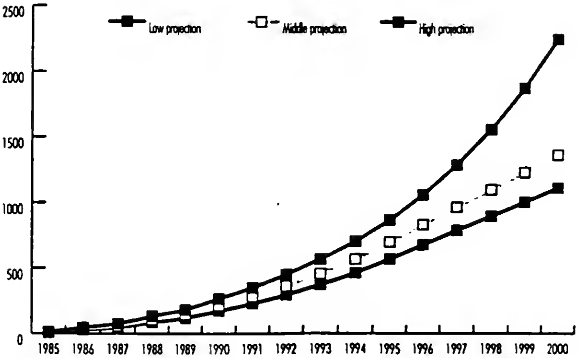


(1990 population under 18 years old: 117,000)

Source: The Orphan Project 1993

Figure 15

Motherless Children and Adolescents Orphaned by HIV/AIDS
Cumulative Washington, DC, 1985–2000



Source: The Orphan Project 1993

BREAKING BARRIERS
BUILDING BRIDGES

BRIDGES

The Daily Newsletter of the National Congress on the State of HIV/AIDS in Racial and Ethnic Communities

Friday, September 16, 1994

Elders Challenges Congress to "Lead the Charge!"

With those words, Surgeon General Joycelyn Elders challenged all congress delegates to lead the way to comprehensive HIV/AIDS prevention, education and treatment programs for communities of color.

Greeted with a standing ovation, Dr. Elders acknowledged the expertise of her audience, "I know," she said, "that the people in front of me know more about HIV/AIDS in racial/ethnic communities than I do." She thanked the delegates for their commitment to all the communities affected by the HIV/AIDS epidemic.

Dr. Elders urged the delegates to unite to break down barriers and build bridges over the rivers of ignorance, racism, sexism, turfism, skepticism and hopelessness that impede the battle against HIV/AIDS. "We must be willing to communicate," she emphasized. "Communication and talking are two different things. We must really listen and communicate."

She stressed the importance and difficulty of collaboration. Citing an African proverb that says when spiderwebs unite they can bring down the lion, Elders asked delegates to help build a health care system that will serve all people and all their diverse needs.

Pointing out that HIV/AIDS is not just a "sex problem," but also incorporates other issues such as drug and alcohol use, Dr. Elders tied the needs of those affected by HIV/AIDS to the national need for comprehensive health care coverage. Health education and primary preventive health care are not adequately covered in our existing system, she said. "We must change our expensive sick care system to a health care system."

Dr. Elders outlined several critical prevention needs. We need to begin comprehensive health education at an earlier age. Parents also need health education so that they can educate their children. We need to make better use of our schools to provide primary health services. Finally, more people of color need to be recruited into the medical profession.

Dr. Elders concluded her remarks with an affirmation of her help and support. "You have the power of my bully pulpit," she promised.

PHS Director Lee Addresses Opening Plenary Session

In his remarks at the Opening Plenary, Philip R. Lee, M.D., HHS assistant secretary for health and director of the U.S. Public Health Service, declared, "We (the federal government) are your employees."

Dr. Lee discussed the glaring disparities in HIV/AIDS and race and stressed that we must overcome the barriers to effective health care policies, including racism. He suggested that we build community partner-

Continued on page 2

INSIDE

Overcoming the Barriers

The Non-Minority Institute was facilitated by Neil Tashima and Cathleen Crain of LTG Associates, Rev. Ted Karpf of the National Episcopal AIDS Coalition and Richard Klein of the FDA. It brought together representatives from federal and state governmental agencies, community service providers and researchers. The institute focused on the following problem statement:

There are barriers to HIV service effectiveness and accountability in every arena of activity, whether one is a grantee, researcher, policy maker, regulator or administrator. The challenge for this institute will be to begin the process of identifying those barriers, and to enhance participant skills to reduce those barriers.

HIV/AIDS research, prevention and treatment programs are often designed by non-minority people. It is therefore critical that they have an understanding of the needs of all the client populations they may need to serve. In addition, before even that work can begin, the non-minority community must understand itself. This involves an examination of patterns of thinking in the dominant culture, a look at stereotypes and assumptions that are prevalent. Also, non-minority organizations can benefit from examining the barriers that exist to agency cooperation and effective programming.

The institute began with an examination of stereotypes that affect the way we think about and classify other people and institutions. Participants rapidly discovered that they held stereotypical impressions of governmental entities and service providers and that these impressions were both positive and negative. Stereotypes, although often founded in kernels of truth, can be used in ways that disadvantage or dis-empower others. They become harmful when they cause people who are "out of type" to be ignored in the construction and implementation of service programs. For example, if there is a perception that Asians do not have an HIV/AIDS problem, a service provider may not have any outreach mechanism for that community.

Participants also identified barriers to effective service delivery and accountability. Nearly 100 different barriers were identified and then grouped into five major categories: turf issues, organizational structure issues, funding/resource issues, politics, and effectiveness/accountability issues. As these issues were discussed by the group, it became clear that government and private agencies face similar barriers, particularly in the area of funding/resources and organizational structure issues.

In addition to formal institutional barriers to service delivery, participants also identified several unwritten rules that dictate the actual day-to-day operations of their organizations, as well as the way their organizations interact with other organizations. These rules often involved values of "not rocking the boat," and communicating only good news. Although one participant noted that, "If there are no disagreements, then no work is being done."

Finally, the facilitators led a discussion of how to promote accountability both within and between agencies. Several people mentioned the need for freedom to take creative risks, and at the same time have permission to fail. The point was made that we often can learn a great deal from a program's apparent failure, but that such programs may not receive additional funding. In addition, accountability was seen to be linked to issues of communication, listening and feedback. It was noted that "communication should be a loop, not a direction."

Another area of concern was the issue of community versus individual accountability, and the cultural context of each. Finally, it was noted that accountability needs to go in all directions, even as far as the U.S. Congress.

Federal Agency Meetings

Congress participants will be afforded the opportunity to meet informally with representatives of numerous federal agencies. Participants will be able to learn more about the missions and programs of the agencies, ask questions and share their concerns about agency programs.

Lee...

Continued from page 1

ships and stay actively involved in making health policy decisions for our communities.

According to Dr. Lee, the goal of the Public Health Service is, "Healthy people in healthy communities." With that in mind, he promised to come back on Sunday for the Closing Plenary to listen to the variety of suggestions and decisions developed by the Congress. He will consider those suggestions in developing his own action plan — just as all participants in the congress are urged to do.

African Americans Stress Common Culture

Members of the African American diaspora must recognize their common heritage, their common culture and come together to stop the spread of HIV and AIDS. That was the conclusion of the African American Institute held yesterday. In the United States, AIDS is the number one killer of all Blacks between the ages of 25-44. Sixty-six percent of all U.S. cases reported have been among Blacks. African Americans must take responsibility for the direct impact of HIV and AIDS in their community. The statistics demand us to act now.

Key leadership skills that can bridge communities of color were recognized in the Leadership Breakout Session. Spencer Allen and the breakout participants decided that HIV and AIDS leadership promotes positive growth within the African American community. Specific positive elements include nurturing, co-sharing, assurance and an emphasis on quality.

Another focus of this institute was "The Black Church, Faith Communities and other Institutions." This session looked at the role of the Black Church and its responsibility to the community. Given the power that the Black church has, it was decided that religious leaders must have a shared commitment in facing the realities of AIDS and HIV in the Black community. Elias Frajaje-Jones stressed the importance of prevention and education within the church structure and acknowledged the contribution of those who take up HIV/AIDS ministries, combatting an often blatant disregard for the issue by many churchgoers.

Barriers that exist within the Black church include a lack of dialogue about the human body and sexuality and a lack of government agencies working with Black churches to establish prevention and educational programs.

The group decided that churches across the nation need to become health advocates and network with each other and with public and private health agencies. Without the support of churches, a vast group of people may potentially miss HIV/AIDS prevention messages and services.

The Sexual Politics and Behavior session concentrated on community issues, research and policy perspectives. The group agreed that people should be able to define who they are themselves and that others have no right to label them. Labels, such as "gay" or "bisexual" can sometimes interfere with understanding behavior patterns and creating effective prevention messages.

All agreed that African Americans must create respect for diversity within the community and empower each other.

Deya Smith, a young peoples advocate, gave an emotional talk on compassion and the need for people to reach out and do something to help in the HIV and AIDS movement. She stressed the importance of positive peer education programs and the role of young people. She suggested that there be support groups for young people living with HIV/AIDS and support groups for young people who have family and friends with the disease.

Overall, this institute served as an instrument for dialogue and positive feedback by and for members of the African American community.

TIDBITS

In 1993...

- 55 percent of all cases of AIDS were in minority populations. This is up from 51 percent in 1992.
- The AIDS case rates for all American populations per 100,000 were as follows:

Whites	30
Blacks	162
Hispanics	90
Native Americans	24
Asian and Pacific Islanders	12

- For Black women, the rate was 73/100,000, or 15 times the rate for white women.
- For Black men, the rate was 266/100,000, or 5 times the rate for white men.
- In the Northeast U.S., AIDS in Blacks and Hispanic men is predominately spread by IV drug use, while homosexual contact is the greater risk elsewhere for Blacks and Hispanic men.

(Source: *Washington Post*, September 9, 1994, Page A20)

Welcome to the Congress!

Substance Abuse and Mental Health Services Administration

SAMHSA

- HIV/AIDS Outreach for Substance Abusers and the Mentally Ill
- Linkage of Community-based Health Care Services
- Early Intervention Services for Substance Abusers with HIV/AIDS
- HIV/AIDS Training and Technical Assistance for the Mental Health/Substance Abuse Field

SAMHSA
13C-05
5600 Fishers Lane
Rockville, Maryland 20857
1-800-729-6686

CMHS
Center for Mental Health Services

CSAT
Center for Substance Abuse Treatment

Center for Substance Abuse Prevention
Prevention*WORKS!*

Hispanic/Latinos: Unity Within Diversity

Fifty-one Latinos are diagnosed with HIV per day, while another 17 per day die from an HIV/AIDS-related disease. Latinos are two-and-a-half times more likely than the general population to be infected with HIV. In spite of these numbers, there is little knowledge of the mental health needs of Latinos. Thus began Dr. Nelda Chavez, director of the PHS Substance Abuse and Mental Health Services Administration, in her keynote address to the Hispanic/Latino(a) Institute.

The institute continued with an overview of the state of HIV/AIDS in the Hispanic/Latino community. Panel discussions were led by active Latino(a) members within the HIV/AIDS field sharing their experiences and views on such issues as immigration policy, research, services, and prevention as they affect the Latino population. The panel discussions were followed by three breakout sessions divided into prevention, services and research focus groups. There were a number of themes identified by all three groups which affect the effective delivery of HIV/AIDS services and programs to the Latino community.

Latinos are systematically overlooked and discriminated against in such areas as immigration policy, HIV/AIDS research, prevention and services. One of the main indications of this discrimination is the glaring lack of culturally and linguistically relevant HIV/AIDS programs which address the Latino community. Panelists and participants gave numerous examples of such occurrences. Everyone emphatically agreed that the Latino community must unite to develop HIV/AIDS prevention and service programs that will specifically address their needs.

Another significant issue for the group was the lack of sufficient funding for the already existing HIV/AIDS programs. The panelists stressed the need for prevention and case management programs to work together in order to develop and provide comprehensive services. Once again the emphasis was on unity not only within the Latino community itself, but on the integration of all the different factors involved within the HIV/AIDS field. Panelists and participants felt that if the funding for each program was not so restricted, then the development of a comprehensive HIV/AIDS prevention and service program would be that much more feasible.

Fifty-one Latinos are diagnosed with HIV per day, while another 17 per day die from an HIV/AIDS-related disease. Latinos are two-and-a-half times more likely than the general population to be infected with HIV.

Another topic was the exclusion of Latinos from HIV/AIDS research. Issues of race and class are major determining factors in the research process. Once again the overwhelming consensus was that the Latino community needs to unite behind one strong voice when discussing and demanding changes within the often Eurocentric stance of the medical and behavioral research fields.

After six hours of detailed and at times heated discussions, members and participants from the breakout groups of the Hispanic/Latino Institute developed a list of strategies and policies that will provide comprehensive HIV/AIDS programs for the Latino community. Some of the suggestions included the development of a national Latino research policy, redefining the funding mechanisms to better meet the needs of community based organizations and the redefining of numerous terms in order to incorporate cultural and age-appropriate terminology.

The institute ended with an eloquent summary by Chris Sandoval, who also reiterated the importance of unity not only within the Latino community, but also within each individual Latino(a) as well. Mr. Sandoval ended with the advice, "Do not let global advocacy dilute Latinos in the process."

PLEASE NOTE

Summaries of the Asian and Pacific Islander and the American Indian/Alaskan Native Institutes will be in tomorrow's *Bridges* newsletter.

Affinity Group Meetings

Affinity group meetings have been made an official component of the program in order to allow up to 20 different groups to meet to discuss issues important to them. Parties interested in holding an affinity group meeting should register at the registration desk. Affinity groups are scheduled to meet both Friday and Saturday, 4:00 - 5:30 pm.

Treatment Options

On Saturday at 8:30 am, participants will be able to critique a new AIDS Treatment Information System currently being developed by the PHS. Participants will be able to provide feedback on how the system should be structured to better meet their needs. The system is still in its development stage, so community input is important. The system is a toll-free telephone service for HIV-infected people and for those who provide care and services for them and who want to know about treatment options. (See workshops CC-2, page 41 of the program.)

ATTENTION

Sponsored Participants and Scholarship Recipients

For those participants who require on-site reimbursement of travel expenses, payments will be made Saturday as stated in correspondence sent to you. We do ask that claim forms be turned in at the REGISTRATION DESK as soon as you can complete them. Thank you.

POSTER SESSIONS

Poster sessions are held Friday, September 16, from 4:00 pm to 5:30 pm, and Saturday, September 17, from 10:30 am to 12:00 pm, in the Cotillion Ballroom. Poster session presenters will be available during this time, and participants are encouraged to attend these sessions at their leisure.

The Research Track has two additional sessions:

- *HIV-Positive Adolescents-Cultural Issues in Research and Treatment,* by Lauren Wood and Rebecca Parks (NCI/NIH)
- *Recruitment and Outreach of Study Participants, especially Women of Color,* by Reggie Caldwell

SCHEDULE/ROOM CHANGES

Friday, 8:30 - 10:00 am

Research Plenary: Margaret Kadree replaces Wayne Greaves.

Friday, 10:30 am - 12:00 noon

[P-13] HIV Education: The inclusion of Ms. Ford's name was a mistake. We apologize to Ms. Ford for the confusion.

[R-1] Clinical Trials A: Wafaa el-Sadr could not attend.

[R-15] AIDS: Time to Turn to Basic Science: Owen McMaster, FDA, replaces Henry Chang. Martin Delaney could not attend.

[S-1] Culturally Competent Services: Amanda Houston-Hamilton is both facilitator and speaker. Walter Shervington could not attend.

[S24] HIV and Primary Care: Early Diagnosis: Jeanette Gandionco Lazam added as speaker. Kevin Fong could not attend.

[S-27] Policies That Promote Effective Services For Youth of Color: Donald Babb-Maldonado added as facilitator.

Friday, 2:00 - 3:30 pm

[P-32] HIV and TB: This workshop is cancelled. Please attend R-11 for discussion of TB and HIV/AIDS.

[R-6] Creating Partnerships: Martin Delaney could not attend.

[S-2] Culturally Competent Services: Walter Shervington could not attend.

BRIDGES
The Daily Newsletter of the
National Congress on the
State of HIV/AIDS in
Racial and Ethnic Communities
September 15 -18, 1994
Washington, DC

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For more information on
HIV/AIDS among racial and ethnic
communities, please contact:

CDC National AIDS Clearinghouse
1 800-458-5231

OMH Resource Center
1-800-444-6472

Mr. TOWNS. Let me thank both of you for your testimony. And let me sort of make certain that we have something clear here because I want to make certain that the record reflects it if it is what you are saying.

I understand that you said that you have not received any increase in terms of prevention dollars in the last 3 years?

Ms. HUGHES. At least in 1992 and 1993—CDC has not received additional prevention dollars in the last 2 years. Therefore, all of our programs have been really at the 1991–92 level and we have not been able to expand into new initiatives. There has been increased funding on the health care side to Ryan White, and there is a bill that is now I believe in the House that has an additional supplemental funding for prevention, and we encourage you folks to support that increase on the prevention side.

Mr. TOWNS. I just find that a little strange that we are saying that prevention is important, but at the same time we are not showing that it is important, because I think the best way to show that it is important would be to increase the funding.

Ms. HUGHES. That is exactly right. You will get no argument from us.

Mr. TOWNS. And I will also go a step further, that with our behavior that we are not saving any money. They have a saying in my neighborhood in Brooklyn: "We are hustling backwards."

Ms. HUGHES. Unfortunately, in addition to not having any money, and it is not just in the African-American community, but any of our programs, whether at the State or Federal level, we are not devoting dollars to what works in any of the programs. As CDC said, there are a lot of innovative programs out there and everybody is doing something and they think it works, but there is not enough money or energy going into seeing whether it works or whether different models work in certain populations or communities. With those lack of dollars, we continue to reinvent the wheel wherever we go.

Mr. TOWNS. In your testimony, Ms. Hughes, you discussed the problem of dealing with orphan children and adolescents of AIDS victims. How big a problem is this in New York?

Ms. HUGHES. It is a major problem in New York. The figures Ms. Correa shared with you are very similar for New York State. It is predicted that over 30,000 children will be orphans by the year 2000.

Mr. TOWNS. Are you getting any Federal or State dollars to deal with this?

Ms. HUGHES. We have recently, and this is just in New York State being proactive in terms of trying to identify programs, the Orphan Program, the Permanency Planning Program for a lot of women who want to make arrangements for their children after they are deceased. They are trying to place these children in homes with their families or in stable foster homes.

The State has taken $500,000 to $600,000, which is minimal, to work with legal agencies and community-based agencies to make these arrangements for these women, but there is no Federal dollars and there is very little State dollars going into this sort of preparation. If I can stress, it is prevention. We do a lot of funding based on the AIDS numbers and in communities of color, whether

Pacific Islanders, Native Americans, Asians, whatever, we wait to see the numbers before we react.

Prevention to me means we get in and do something beforehand. There are a lot of precursors that tell us we are in trouble, the teenage pregnancy, the violence we have—why do we have to wait to see increasing numbers of AIDS cases to redirect dollars? It is ludicrous. We have to—and it has to come out of our elected officials.

But the black community is not a community like the gay community which put all this on the table for HIV and AIDS. It is not mobilized and it is not strong enough to come in every time there is a new budget coming down the line. We have to ask our elected officials to take the stand for us and make sure you are at the table advocating for the dollars that come out rather than waiting until the numbers increase and we have to do something about the crime and AIDS that has devastated our communities.

Ms. CORREA. With regard to prevention—and I heard your concern over prevention, and education starts at a much earlier level. It does begin before 12. A lot of our prevention programs begin possibly at the teenage years and on. But for true prevention, and if we are looking at prevention education, it begins at an earlier age. Because the dollars are so limited, you have to hit who is hardest impacted upon, and it is teenage youth and adolescents, and whatever money is left over trickles to our younger children.

Technically, there are different phases of a prevention, and if you want to start where it begins, it is with younger youth. I am sorry we didn't get to hear enough about that. There are successful models. You have peer training, peer support, usually at that age adolescents are more receptive to hearing from other adolescents. So there are effective prevention methods which I have observed nationally, programs that begin in the schools that trigger over to school-based programs that involve and encourage the family to be community oriented and take a community approach.

Mr. TOWNS. Let me thank both of you for your testimony. I think you pointed out one thing, that, yes, we have a lot of work to do at every level, on my side and in terms of the community side as well.

Thank you for your testimony—because when you look at the number of children that will be orphaned over the next 2 years, 3 years, 4 or 5 years, that should be enough to motivate us all to move to do something.

Thank you very much for your testimony.

Our next panel consists of Patricia Ware, Americans for a Sound AIDS/HIV Policy; and Raquel Whiting, National Pediatric HIV Resource Center.

I am sure that you probably have heard the fact that your entire statement will be included in the record and every "i," every period, every "t," everything will go in the record.

If you will summarize in 5 minutes and allow us an opportunity to raise some questions with you, we could accomplish a lot more.

Ms. Ware.

STATEMENT OF PATRICIA WARE, AMERICANS FOR A SOUND AIDS/HIV POLICY

Ms. WARE. Thank you, Congressman.

I do appreciate the opportunity to testify. After listening to the previous testimony, there are some things in my testimony I would like to highlight rather than what I thought I might originally.

I concur with Ms. Hughes who just came before me. It is significant that we have to wait until the AIDS numbers are counted before we can determine the AIDS money given to each State. And it is my conjecture that is where the problem begins, not only waiting until the AIDS numbers are counted, but that indeed we just count AIDS, end-stage AIDS cases, that if we begin to look at where the epidemic is today, because these AIDS cases represent where the epidemic was 10 years ago.

We have to start looking at where the HIV index is today, and that has shifted. The problem is that the government formulas for determining how we allocate this money provide inequity for us as a people. If the formulas look at end-stage AIDS prevalence cases and oftentimes count those who are no longer alive who are living with AIDS, that brings up the issue of diagnosing.

If we don't begin to diagnose on a voluntary and routine basis in our community, we do not have the critical data necessary to know where those HIV infections are and consequently to use to determine where the funding might go. I think that is a very, very significant issue.

You know, we talk a lot about AIDS cases now, but it should come as no surprise that we have a lot of AIDS in the black community. As early as 1985, the military and Job Corps had data that showed that blacks were disproportionately affected by HIV infection as early as 1985. Nothing significant was done then. Instead we waited to see when the HIV cases became AIDS cases and then we start saying there is a tragedy in the black community. So this is not really a new bit of information for us. However, the dollars must shift with where the epidemic is today.

I would also like to talk about prevention. As I kept pondering this issue of where is an effective model, where is a model that has worked, we took a look at the—CDC had some data that we pulled out from a group that I think has a perfect prevention model from the gay community. This is a study that was done from 1977 onward and a hepatitis B cohort of 6,800 gay men in San Francisco—it was learned in 1980, the average number of sexual partners per month, this cohort exceeded 16 and dropped by the mid-1980's to only 1 per month. I think the elimination of 180 sexual partners per year on the average of this average of this cohort, was one of the most significant things to help the gay community in the early stages of this disease to save lives.

What is happening in the gay community today may be different, but limiting partners worked. It is believed that a significant number of gay men were not infected because they limited the number of sexual partners. And the CDC studies show us—they say the No. 1 indicator of who will get an STD, including AIDS, is number of sexual partners. In addition, they show that the earlier you start, the more sexual partners you will have over a lifetime.

How does that translate into HIV prevention for us and especially for young people? I think our first line of defense for young people is, No. 1, to help them learn to delay sex. That should be our No. 1 line of defense. We spend millions of dollars talking about strengthening the black family, black family reunions, but yet we are talking about alternative lifestyles, alternative families and that kind of schizophrenic message here.

We agree with President Clinton when he says this community would be better off if babies were born into two-parent families. How can we have that happen if we don't help our young people learn to delay sex and take them out of that risk group of those who become infected with HIV.

My statement is here. Thank you.

Mr. TOWNS. Thank you.

[The prepared statement of Ms. Ware follows:]

TESTIMONY BEFORE THE

SUBCOMMITTEE ON HUMAN RESOURCES & INTERGOVERNMENTAL RELATIONS
U.S. HOUSE OF REPRESENTATIVES

"AIDS and HIV Infection in the African American Community"

September 16, 1994

by

Patricia F. Ware
and W. Shepherd Smith

Good afternoon Mr. Chairman, and members of the committee. Thank you for allowing me to address this critically important issue: "AIDS and HIV Infection in the African American Community". I am Director of Educational Services for Americans for a Sound AIDS/HIV Policy (ASAP), a culturally diverse organization giving primary focus to communities of color. With me is Shepherd Smith, President of ASAP.

A few weeks ago, the Centers for Disease Control and Prevention (CDC) reported that 55% of AIDS cases in 1993 came from communities of color, with African Americans having the worst rate of all groups.[1] The AIDS rate in 1993 among whites was 30 cases per 100,000 people. The rate was more than five times as high among blacks, 162. Black women, with an AIDS rate of 73 per 100,000 were roughly 15 times more likely than white women to acquire the disease. Black males, with a rate of 266 per 100,000 were nearly five times more likely than white males to get AIDS. It is the number one cause of death for black men between the ages of 25-44, and the second leading cause of death for black women in the same age group.[2]

These figures are startling, but should come as no surprise to the U.S. Public Health Service (PHS). This AIDS data represents HIV infections that happened ten years ago. For many of those years there was overwhelming evidence that the black community was being disproportionally affected by this virus.

The CDC reported in the July 26, 1990 New England Journal of Medicine[3] that of nearly 90,000 Americans tested anonymously for HIV in 1988 and 1989 at twenty-six hospitals in twenty-one cities, the rate of infections in blacks was approximately twice that of infections in whites. The CDC's response to this report was to allocate only 10% of its 1991 AIDS budget to communities of color and to bring together several hundred minority AIDS groups to discuss these pertinent issues. Even though the number of these meetings with AIDS organizations continued to increase over the years, a significant reappropriation of dollars did not.

Data have shown high HIV infection rates among blacks since HIV testing began in 1985. Job Corps test results in 1988[4] showed African American men to have HIV infection rates roughly four times higher and African American women seven times higher than their white counterparts. Even more alarming was civilian military applicant data because much larger numbers of young people from more diverse communities were being tested.

From 1985 to 1988, military data[5] showed not only much higher rates of HIV infection among African Americans applying for active duty, but among those presently serving their country as well. The rates for blacks exceeded four times that for whites. Incredibly, even then, black women had a higher rate of HIV infection than white men. Again, these infection rates were never reflected in terms of shifting of significant resources to fight the epidemic in its present primary location...the African American community. Unfortunately, there was little change in attitude within our government that this was anything other than a white gay disease.

Other early data also showed a critical HIV problem among African Americans which we now see reflected in astounding numbers of AIDS cases. While we are only now beginning to acknowledge this as a tragedy of immense proportions for our people, we have not yet been given adequate tools to fight this scourge.

Several factors have contributed to this inequity. To begin with, our community is culturally different from the community first affected by AIDS. I would like to share some of those differences in order to help us better understand how we have responded in the past, and how we must respond in the future if we are to head off the full wrath of this disease in the African American community.

First of all, for us as a people, the disease is another significant problem to be combatted along with unemployment, health care, homicide, teen pregnancies, drug and alcohol abuse, and sadly, so many more. When faced with these other overwhelming concerns, our ability to summon inordinate amounts of energy and time, to understand a disease that did not initially appear to be a real threat to our numbers, is limited. To raise money for this, another cause; to access the media; and, to reach influential decisions makers, pales considerably compared to the abilities of those first infected.

Secondly, African American women and children in particular are at considerable risk for acquiring this disease.[6] Because women and children were not a conspicuous part of the early infected, they have largely been overlooked until very recently in this epidemic. They are also the least empowered constituencies and have great difficulty being heard as HIV continues to spread among us.

Third, the African American community is investing millions of dollars in "Strengthening the Black Family" conferences and "Black Family Reunion" celebrations to refocus our people on the values of the established family...father, mother and children, living and loving together in the same home. Simultaneously, much of the existing AIDS education information reflects the need to redefine "the family" in a way that encourages the development of alternative structures. Based on the devastation that out-of-wedlock births have brought to our communities, we resoundly agree with President Clinton when he says, "This country would be better off if babies were born into two-parent families."[7] This can only happen to a profound degree when life-long monogamous relationships are encouraged.

Debate over family definition which embodies the one life-long partner concept is consequential in respect to the AIDS' issue. Many in the established gay community contend that a message to discourage multiple sexual partners is unrealistic and inconsistent with their lifestyle. However, the gay community, in the early years of the virus, set an example of behavior change from which we could all learn. In a hepatitis B cohort of 6800 gay men studied from 1977 onward, it was learned that in 1980 the average number of sexual partners per month of this cohort exceeded 16 and dropped by the mid 1980s to only 1 per month.[8] The elimination of 180 sexual partners per year on average of this cohort, arguably, was the most pivotal behavioral change in respect to reducing new transmissions.

This is consistent with the CDC's findings that the greatest predictor of a sexually transmitted disease, including HIV/AIDS, is the number of sexual partners one has; and, the earlier one begins sexual activity, the more partners one is likely to have.[9] Regrettably, the break-down of the African American family unit in many of our communities, has helped to create environments where there are numerous opportunities for multiple sexual partners.

What we have is a schizophrenic message that on one hand promotes establishing any kind of family that feels right for you, and on the other hand presses with all its might to promote the establishment of the two-parent family. It directly contributes to the prevailing confusion around HIV prevention education, especially for our young people, and indirectly contributes to the unnecessary transmission of this disease.

HIV prevention education is the fourth area of concern. What is appropriate for one community may not be for another. In July, 1993, Central State University in Wilberforce, Ohio sponsored a conference titled, "Abstinence and the African American Youth".[10] In opening remarks, President Arthur Thomas explained why the event was necessary: "To save our children and our communities because our children have been stripped of their dignity and respect...to teach them how to date and not date rape, to teach them how to delay gratification, and how to develop a meaningful relationship...and to teach them about marriage and parenting".

Dr. Thomas and the diverse group of attendees clearly saw the promotion of delaying sexual activity for unmarried teens and college age students as a realistic activity...one that has great potential to positively impact other societal problems such as drug abuse, violence and school dropout rates that plague our communities. It is extremely irresponsible and discriminatory to imply to our young people that they can control their passions in the area of violence, drugs and other abuses but cannot control their sexual urges. If young people are having sex...with or without a condom...they are still placing themselves at critical risk of unwanted pregnancies, disease (including HIV), economic and educational poverty...a breeding ground for violence, substance abuse and welfare.

Kimi Gray, president of Kenilworth Parkside Resident Management Corporation in Washington, DC says that over a decade ago, the adults in her inner city community began telling their young people that using drugs and having sex were not acceptable behaviors for them. "We set guidelines and boundaries and we found ways to help them be excited about learning. Instead of watching them suffer from HIV infection, go to jail, a drug rehab center or the welfare office, like we used to do, we are now sending hundreds of them to college."

AIDS prevention education, especially for our young people, should always begin with the message of helping them to delay sex and emphasize it throughout. The focus should be on developing resistance skills, self-control, delaying self-gratification, respect for self and others. It should involve developing support from peers, parents, teachers and other role models to help youth follow through on their decision to delay; and, to find something positive the young person can say 'yes' to as they say 'no' to sex. Our primary goal should always be to decrease the numbers of adolescents who are sexually active, consequently, decreasing the numbers who are at risk of disease and pregnancy.

This approach can and does work for black youths as effectively as significantly limiting the number of sexual partners worked for gay men during the early stages of the epidemic. For example, Best Friends in Washington, DC reports only one pregnancy out of the nearly four hundred inner-city elementary through senior high girls in its seven year old, school based, abstinence focused program.[11] Charles Ballard, president of the Cleveland headquartered National Institute for Responsible Fatherhood and Family Development is quick to share the impressive outcomes of his twelve year old program. He tells of not distributing condoms or encouraging sex outside of marriage.[12] Of the nearly 2,000 primarily African American young men, most of whom were already unwed fathers, 75.3% have not caused an additional out-of-wedlock pregnancy since participating in the program. There are other such successful programs that should be closely explored by this committee.

To reduce the risk of HIV infection, clear secondary messages would include limiting the number of sexual partners, knowing your HIV status and that of your partner(s), and information about condom use.

A fifth uniquely important difference is in regard to diagnosis of HIV. Diagnosing, or testing for a disease, is a medical practice which is the foundation of prevention for any epidemic.[13] Diagnosing for HIV, per se, does not carry the same negative connotation among African Americans as it invokes in some other groups. Randy Shilts explains in his book turned t.v. movie, And the Band Played on, that gay men feared an HIV positive result might expose one's lifestyle and lead to discrimination. That fear was the foundation upon which national policy for HIV diagnosis was based. As a result, African Americans have often been denied access to routine voluntary and confidential testing in medical settings.

The lack of voluntary and routine diagnosis can present several major problems: (1). Persons who do not know they are HIV positive do not receive optimal medical care that could enhance prevention of opportunistic infections and delay of disease progression. (2). These persons may, unknowingly, transmit the virus to others; and, (3). The ability to provide necessary data used in calculating the distribution of critically needed resources is limited.

Government formulas for making funding decisions to HIV/AIDS prevention and care programs are most often based on end-stage AIDS prevelance numbers, rather than on new HIV infections that reflect where the epidemic is today. For example, Ryan White care dollars are distributed based on AIDS prevalence; which counts not only those living with AIDS, but those who have died from the disease as well. Care money should be based on only recent AIDS prevalance - those living with AIDS today. It should not surprise us that the New England Journal of Medicine reported March 12, 1994,[14] that "there were racial disparities in the receipt of antiviral therapy."

Committee composition for federally funded programs, organizations, working groups and task forces also inadequately represent those from communities where the virus is presently having the most negative impact. Care committees should be more representative of people living with AIDS today, and prevention focused committees need to be more reflective of new HIV infection statistics. A revised funding formula is greatly needed to bring equity and fairness to distribution of dollars and other resources.

Finally, unlike most other groups, African Americans have a general distrust of government programs that collect blood samples. This is commonly attributed to several historically tragic occurrences, most noteably the Tuskegee incident. Consequently, the most effective HIV diagnostic tool that has been documented to be highly acceptable for use in our community is one that does not require taking a blood sample.[15]

We congratulate you, Mr. Chairman, for having the courage to help speed the approval process for an easy-to-use, non-invasive, safe and accurate HIV saliva-based diagnostic tool that is urgently needed. We have been extremely disappointed in the Food and Drug Administration's attitude towards our long standing appeals and support for an oral fluid sampling device.

Had this product been approved in 18 months, for example, we would have had this useful tool available to those facing the brunt of the epidemic today. If just a million of these tests had been used in the last year in hard-to-reach communities and we applied the 4.7% rate of infection found by the CDC in its 1992 hospital study,[16] we would have found approximately 47,000 people who carry the virus and don't presently know it. Had just a modest percentage of those people not infected others, we would have saved literally thousands of lives. In spite of the fact that many African American AIDS activists, physicians and health care workers have overwhelmingly encouraged the agency to provide for such a device, this product is still unapproved after nearly forty months of review. The needless delay by the FDA has cost predominately people of color many, many lives. It is knowledge of infection, rather than ignorance, that will empower us to deal effectively with HIV disease.

In closing, I would like to reiterate the need for radical change to correct what many of us believe are inequities in distribution of resources. This is largely as a result of not better defining our infection problem through making routine voluntary diagnosis of HIV more readily available to our people. Moreover, we call for a realistic change in much needed HIV educational messages especially targeted to our young people...messages that also have a positive impact on other debilitating social ills with which we are confronted.

Many African Americans are working towards educating and unifying our community to join the fight against HIV/AIDS. It is our desire to encourage support for, rather than isolation and judgement of, those who are infected or affected by this disease; and to bring maximum resources to these efforts. I again thank the chairman and this committee for the opportunity to testify. Your support for an easy-to-use diagnostic tool will help save lives as well as provide information that will assist in generating vitally needed resources. Your giving us a public forum to articulate our concerns will create much needed awareness. Your genuine interest and action in respect to this issue will help empower our brothers and sisters in the battle we all face with HIV and AIDS.

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2. MMWR," Death Rates* From Leading Cause of Death Among Men and Women aged 25-44 years, United States, 1982-1992" Figures 1 and 2.

3. The New England Journal of Medicine, "Seroprevalence Rates of Human Immunodeficiency Virus Infection At Sentinel Hospital In The United States", Vol. 323, No. 4, July 26, 1990

4. Department of Labor, "Figure 14. HIV seroprevalence among Job Corps entrants by sex and race/ethnicity, United States", January 1988 through December 1990.

5. U.S. Army HIV Force Testing Positivity Rates* Race/Ethnic Group, November 19, 1987

6. JAMMA, "Characteristics of, and HIV Infection Among, Women Served by Publicly Funded HIV Counseling and Testing Services-United States, 1989-1990, Vol 265, No. 16 pp. 2051-2052, April 24, 1991.

7. USA Today, December 14, 1993

8. Testimony from December 1987 Presidential Committee hearing by Don Abrams, M.D. of San Francisco.

9. CDC, "Morbidity and Mortality Weekly Report", Jaen. 4, 1991/v01. 39/Noe. 51 & 52.

10. Central State University in Wilberforce, Ohio, July, 1993

11. ADVANCES, Newsletter of the Robert Wood Johnson Foundation, "Best Friends Program Provides Positive Choices", Spring/Summer 1994.

12. Washington Post, Study by Dr. G. Nixon and Dr. A. King, September 1993.

13. The New England Journal Of Medicine, "The Case For Wider Use Of Testing For HIV Infection", Vol 320, No. 19, pp. 1248-1254, May 12, 1994.

14. The New England Journal Of Medicine, March 12, 1994.

15. "OraSure an Oral Specimen Collection Device for HIV Testing: A Preference Survey Analysis Interim Report", Conducted by People of Color Consortium Against AIDS with Jackson State University National Alumni AIDS Prevention Program, pp. 8-11, 1993.

16. The New England Journal of Medicine, "HIV Infection Among Patients In U.S. Acute Care Hospitals", Vol. 327. No 7, pp. 445-452, August 13, 1992.

Mr. TOWNS. Ms. Whiting.

STATEMENT OF RAQUEL B. WHITING, POLICY ANALYST, NATIONAL PEDIATRIC HIV RESOURCE CENTER

Ms. WHITING. Good afternoon Mr. Chairman. My name is Raquel Whiting, and I am testifying on behalf of the National Pediatric HIV Resource Center where I serve as the policy analyst.

I am grateful for the opportunity to speak to you this afternoon not as an HIV policy analyst, but as a 22-year-old African-American woman who is at risk for contracting HIV infection. I hope to bypass rhetoric today and provide you with facts, community voices and recommendations to address the growing problem of HIV in the young African-American population.

You know the statistics, but you may wonder why young African-Americans are continuing not protecting themselves. But when you think about how the prevention message is being phased it is clear why. In the media they are telling you, if you are not white, if you are not gay, if you are not a drug user, you are not at risk and that is not true. Our community has not until recently addressed this issue or educated our young people.

The second problem with the current prevention message is the way it is delivered. Research tells us scare tactics do not work. Young people require honest, consistent and concrete prevention messages.

Programs in the past have lacked credibility with young people, especially urban youth. It is a white middle-class message which does not take into account any issues that are specific to our community. Messages like get high, get stupid, get AIDS do not take into account that many young African-Americans live with the threat of dying from a drive-by shooting or drugs everyday. Young African-Americans doubt the establishment's concern about their health and their welfare, and in many cases see AIDS as a way of the government controlling the African population. If we are to reach this group, we must reshape our message and change the messenger.

I have come here not only with my views but with the views of other young African-Americans. In anticipation of my testimony, I conducted a short survey of 10 young African-Americans between the ages of 15 and 25, with all different sexual orientations and from different socioeconomic classes, to give you a real picture of what the prevention efforts are and the struggles that we face everyday.

The three major findings were on the whole, none of these participants had received any HIV/AIDS education in their schools. Second, was that only two of them consistently used condoms. And the third, they felt a general abandonment from the black community as well as the Federal Government and felt that the Federal Government had neglected their issues when talking about HIV.

It is apparent from the results of this survey and my own personal and professional comments, that the prevention messages that we are sending are not reaching this group and many times it is because we are speaking a whole different language. There needs to be greater prevention research to outline why certain behaviors persist among certain groups, and I am a proponent of race and culturally specific research aimed at understanding how a number of issues, for example, poverty, drugs, crime and discrimination affect the way people of color think about HIV infection.

I also believe that in order for any campaign to work, we must send a message which young people can relate with. The Federal Government also needs to be more visible about their support of these activities. And the Congressional Black Caucus also needs to be more vocal about their support of the community planning initiatives at the CDC, as well as drafting and supporting legislation which increases prevention efforts, and monitoring present activities in their communities.

The Federal Government has a responsibility to educate its young people. There needs to be more extensive HIV programming in our schools. And since many of our young African-Americans are not in school because they are in the disenfranchised youth population, for example, runaways, the homeless and dropouts, we need to support community organizations that work with this group.

Many outreach programs today are on shoestring budgets and have high levels of burnout. There needs to be an infusion of support and dollars in order to revive these programs.

I would like to close by commending this Congress for its support of the community planning initiatives at CDC. I know, because I work on AIDS policy, of the tremendous changes and accomplishments that we have made in prevention, but our work is far from successful. We have laid down many seeds but must nurture our programs in order to ensure success.

My final recommendations are that the Federal Government needs to publicly demonstrate its concern and commitment to the problem of HIV in young African-Americans. The black community must start to address this problem and work actively to engage young people at risk into discussion. Prevention messages must be modified with an urban focus which also addresses alternative sex lifestyles, and Congress needs to ensure that more race-specific research on prevention is conducted, and we need to bring young people to the table to do that.

I hope that you will consider my recommendations as I speak to you as a young African-American woman who has taken the prevention message to heart. I work in this epidemic and have benefited from the experiences of my colleagues as well as grassroots activists. However, there are many young people like myself who have not gotten the message and it is up to us to modify the message and make it more culturally specific.

With commitment and action, we can guarantee successful prevention, but this needs everyone's action and we as African-Americans cannot just take up the AIDS during the Congressional Black Caucus weekend or during the Minority AIDS Congress, but we must take it up every day because young people are at risk every day and people are dying every day.

[The prepared statement of Ms. Whiting follows:]

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HIV PREVENTION AND AFRICAN AMERICAN YOUNG PEOPLE

TESTIMONY OFFERED BY RAQUEL B. WHITING BEFORE THE UNITED STATES HOUSE OF REPRESENTATIVES

COMMITTEE ON GOVERNMENT OPERATIONS
SUBCOMMITTEE ON HUMAN RESOURCES AND INTERGOVERNMENTAL OPERATIONS

SEPTEMBER 16, 1994

A project of the University of Medicine & Dentistry of New Jersey New Jersey Medical School and Children's Hospital of New Jersey

Good Afternoon Mr. Chairman. My name is Raquel Whiting. I am testifying on behalf of the National Pediatric HIV Resource Center where I serve as the Policy Analyst. I also work with an affiliate of the Pediatric Resource Center, the AIDS Policy Center for Children, Youth and Families. I am grateful for this opportunity to speak not as a Washington based HIV policy analyst, but as a 22 year old African American woman who is at risk for contracting HIV infection. I hope to bypass rhetoric today and provide you with facts, community voices, and recommendations to address the growing problem of HIV in the young African American population.

AIDS is now the leading cause of death of African American men between the ages of 25 and 44. African American women in this age group are at the highest risk of contracting HIV and now represent 53% of the total US population of infected women. Even though we know this group has become an emerging high risk population, studies show that they do not perceive themselves to be at risk and consequently engage in risky behaviors. I know this not from studies, but from the experience of growing up with many peers who continue to take their lives in their hands when they have sexual intercourse.

You may wonder in the light of all of the information in the media about HIV and the effectiveness of condoms why African American young people are not protecting themselves. There are two major problems with the current prevention message and how it relates to African Americans: the way the message is delivered and who the target audience is. And many times young people hear the prevention message and lack the negotiation skills to effectively use the information.

In 1994, the media and larger society continue to portray images of gay white men as the face of HIV. People of color regardless of their sexual orientation are absent from the picture. There has also been a limited federal response which has left the onus on the private community and thus far grassroots organizations have targeted many of their prevention efforts to the gay, white community. By large, federal agencies have missed many opportunities to reach out to communities of color. Until recently, most of what the federal government called prevention was extensive counseling and testing services. Communities of color have also been neglectful of HIV and its impact on the African American community, many times as a result of the stigma associated with the modes of transmission and the disease itself. Therefore they have not participated actively in the discussions around how the prevention message should be shaped and presented. In a recent study by the Center for Youth Development, adolescents were characterized as the invisible constituency in AIDS and because of the above mentioned reasons, African American adolescents are completely absent from the dialogues around prevention.

The second problem with the current prevention message is the way it is delivered. Research tells us that scare tactics do not work and it is important to have honest, consistent and concrete prevention messages. Programs in the past have lacked credibility with young people, especially urban youth. Even the recent PSAs and programs geared to young people have not effectively reached the urban African American community. It is a white middle class message which does not take into account any of the issues specific to this group. I showed the PSAs to a group of African American young people whom to tutor and found that many of these young people did not feel compelled by the images that were being presented and were not in anyway moved to change their behaviors. The abstinence ads in particular evoked laughter and jokes. This group represents part of the supposed target audience and their reactions were unfavorable. Prevention messages about HIV need to take into account other aspects of young people's lives, particularly people who live with the constant threat of death from drive-by shootings and drugs everyday. On the whole, young African Americans are very distrustful of anything they perceive as the party line and honestly doubt whether the government even cares about the devastations in their community. They doubt the establishment's concern about their health and welfare and in many cases see AIDS as a way to control the population of African Americans in this country. If we want to reach this group, we must reshape our message and change the messenger.

The third issue I would like to raise is the apathy, lack of support and awareness of the larger African American community. In a report of Key Findings from interviews by the Select Committee on Children, Youth and Families it was concluded that community support for HIV prevention and services for teens is critical to a program's success. Community support snowballs when key groups are recruited. As a community we have closed our eyes to the horrors of AIDS. Our black churches have shut the doors on the issue due to the stigmas of homosexuality and drug use, our supposed black leaders have ignored the issue because they have too much on their plate and many of our black Congressional Representatives have not visibly supported any changes in federal policy. All in all we have allowed AIDS to wreak havoc on our community and take an unprecedented number of lives and we have failed to accept responsibility for our young people.

I have come here today with not only my views, but the views of other young African American women and men with different sexual orientations in order to help you understand the struggles that we face. In anticipation of this testimony, I conducted a short, informal survey of 10 African Americans between the ages of 15 and 25 , representatives from all socioeconomic classes. Four of the respondents were female and the other six were male. There were two gay men surveyed and one lesbian. I would like to highlight some of the more important findings for you today. When asked what type of HIV/AIDS education they received in high school an astounding 100% reported none. Out of all the respondents only 2 had comprehensive health/sex education programs in their schools. Even the youngest of the participants, a young man who is now in 10th grade had very limited exposure to materials on HIV. When asked whether or not they engaged in protected sex every time they had intercourse only two subjects responded positively. The excuses ranged from "my partner and I are monogamous" to "I rationalize that I don't know anyone who would have HIV therefore I am not at risk". One male respondent reported only using a condom once in 3 years. When asked if he was involved in a monogamous relationship, he replied "no but you can just tell if someone has HIV." I also asked the respondents why they thought African American young people comprised one of the growing risks groups and 6 of the 10 subjects believed that the message about prevention had not reached the urban centers of our nation and people of color in lower socioeconomic backgrounds had been completely ignored in the debate. Two subjects reported that they believed the federal government had intentionally ignored communities of color because they do not care if the welfare recipients and drug addicts die. What they do not realize is many young African Americans who are in college are also contracting HIV. The two gay men of color both reported a lack of respect and information on alternative sex lifestyles in the black community which leads to a feeling of isolation by young men of color. This isolation works adversely with any prevention messages. Finally, I asked my peers how they thought the federal message could be changed to better relate to African American young people. Five of the respondents believed that it is important to get the information out to more communities and send the message in the form that urban communities can relate to. Three of the subjects said they would like the government to be more direct and honest about the message and increase educational opportunities. I would like to reiterate that this was a small sample and results can not be generalized to the larger population of young African Americans, however I sought to get a wide variety of subjects from diverse backgrounds in order to make the findings more credible.

In my short, yet insightful study, a few significant issues became apparent. There is a greater need for HIV/AIDS education in our schools, young people would like to see a more visible federal response especially from their African American representatives and in general young blacks still do not perceive the risks and, therefore, do not protect themselves. It is apparent from the results of the survey and my own personal and professional comments that the prevention message is not reaching this group and many times it because they are speaking a whole different language. There needs to be greater prevention research to outline why certain behaviors persist among certain groups and I am a proponent of race and culturally specific research aimed at understanding how a number of issues ie, poverty, drugs, crime, and discrimination affect the way people of color think about HIV prevention I also believe that in order for any campaign to work, we must send a messenger who our young people can relate with and admire. Magic Johnson, a man who has been one of the more effective prevention advocates for young black Americans, remains as an abstract person in their lives Our black churches and leadership need to get on the prevention band wagon There are some black churches who have risen to the occasion and have begun to sponsor community wide activities and we have many lessons to learn from them However, they remain the minority in the larger picture The Congressional Black Caucus also needs to be more vocal about their support of Community Planning Initiatives at the CDC as well as drafting and supporting legislation which increase prevention efforts as well as monitoring present activities in their community.

The larger federal government also has a responsibility to educate its young people about the risks and an effective vehicle is the public school system. More extensive HIV programming is necessary in our schools. As a young person who went to high school in the late eighties when people were still convinced that only gay men and drug users were at risk, I know that there is a generation out there who is lost My generation although growing up with the threat of HIV has never understood our risks. We must not miss out on my younger brother's generation who is in school now We have the opportunity to promote school based programs to reach him and his peers. However, we know that many young blacks are completely disenfranchised from the system and would not be reached in the schools These are the runaways, the homeless and the dropouts. They are a huge concern In order to reach this group, community activities are critical. Many street outreach programs today run on shoestring budgets with high levels of burnout. There needs to be an infusion of support and dollars in order to revive these programs.

I would like to close by commending this Congress on its support of the Community Planning Initiatives at CDC. I know because I work on AIDS policy the tremendous changes and accomplishments in prevention. But, our work is far from successful. We have laid down the seeds, but we must nurture our programs to ensure their success. My final recommendations are for 1) the federal government needs to publicly demonstrate its concern and commitment to the problem of HIV and young African Americans, 2) the black community must start to address this problem and work actively to engage young people at risk into the discussion, 3) the prevention messages need to be modified with an urban focus which also addresses alternative sex lifestyles, and finally 4) Congress should encourage more race specific research on prevention. The Congressional Black Congress can play a pivotal role in ensuring the federal response by educating their colleagues and keeping their constituents apprised of the new developments and upcoming debates.

I hope that you would seriously consider my recommendations as I speak to you as a young African American woman who has taken the prevention message to heart. I fortunately work in this epidemic and have benefited from the experiences of my colleagues as well as grassroots activists. However, there are many young people like myself that have not gotten the message and will not until it is modified and becomes culturally specific. As I consider the issues of African Americans trying to stay healthy, I am reminded that the U.S. is a multi-cultural society and within various cultural groups there is diversity. As we develop our prevention message we must incorporate these differences, i.e. sexual orientation, socioeconomic class, and environment in order to effect substantive changes in behavior.

Your request for my testimony today demonstrates your commitment to understanding the perspectives of young African Americans. Your immediate response to these concerns is necessary. Many lives are hanging in the balance and I am convinced that you will devote your attention and time to working to implement changes in the programs to date and the support of community based interventions. With commitment and action, we will guarantee successful prevention.

Mr. TOWNS. Let me thank both of you for your testimony.

Let me begin by asking you, Ms. Ware, you mentioned I think about the formula. Specifically, how should CDC change its funding formula for community-based organizations? Do you have any ideas as to what should happen? We want to get as much information in the record today as possible.

Ms. WARE. As I mentioned, a lot of the dollars are based on the prevalence cases of AIDS and that may include the numbers now living with AIDS as well as the numbers of those who have died with AIDS in a particular community. The black community may not have as large a number of AIDS prevalence cases but in terms of the new infections of HIV, which is the epidemic today, our numbers or at least percentages, rates are greater. That is where the epidemic is today. That is what we want to stop, the epidemic. We want to provide care for those who are already infected and as a community of people be compassionate about that.

In terms of formulas for how the money is determined, we have to look at the incidence rate, the number of cases, because we don't aggressively diagnosis on a voluntary and routine basis. And I do thank you for your efforts with the FDA to try to get the saliva-based diagnostic approved, because it has shown to be acceptable in the black communities, where a lot of black people have problems with drawing blood.

They would use a saliva-based product even in hard-to-reach communities so we can count the numbers. When we do that, then we have the hard data that is necessary to determine the funding. The diagnosis is not just to get money but also that people who are infected and don't know it, they don't get optimal medical care, they don't have an opportunity to get the care to stop opportunistic infections, and oftentimes they unknowingly infect other people, so we have this epidemic moving and moving.

Again, back to your question. The formula has to change. It has to look at where this epidemic is today, not only in terms of dollars but also in terms of representation on committees, panels, advisory boards, all of that. They have to reflect where this epidemic is today, because our agenda is a little different than the agenda of those who may have been in the first wave of those infected. As we have heard, you have got to go right to the source to say what can we do in your community to end this epidemic and save lives.

Mr. TOWNS. Thank you very much, Ms. Ware.

Ms. Whiting, what is the best way to change the risky sexual behavior of African-American youth? What is the best way to do that?

Ms. WHITING. I think that is a really tough question, but I will try to answer from my personal and professional experience. I think African-American youth, as do other young people, see themselves as being invincible, they don't see anything as being able to kill them.

When you think about the gangs in Philadelphia, the female gangs that have engaged in the risky behavior of having sex with other members who they know are HIV positive, because they say the ones that don't turn out positive are strongest, best, kind of survival of the fittest, we need to change how we talk to our young people. We can't try to tiptoe around the issue. We have to give them honest, concrete messages saying OK, use a condom. That is not working because people aren't wearing that condom.

Our young black people have so many excuses they go as far as to say I know what people with HIV look like. I can't get HIV, I am not gay, how can I get HIV? We need to make sure that we are educated on their risk. We need to get information about how many people are dying, how many are actually infected.

Infection rates are very important when we deal with young people. And we can't try to scare them by saying people are dying, so you should protect yourself. We have to actually help them develop the skills to negotiate in their sexual lives as well as to educate them on self-esteem and how they should care about themselves and want to protect themselves because they are beautiful, wonderful people.

We don't teach our young people that as African-Americans they are beautiful people and are wonderful and we love them. They are told by the media that they are bad and if you walk on the street with a white woman that she is going to walk across the street because you are black and basically you mean nothing to her. So until we teach them to love and respect themselves rather than give them just parts of information, young people of African-American descent will not protect themselves.

Mr. TOWNS. I just wanted to raise this issue—would you give me your age again after that very powerful statement?

Ms. WHITING. I am 22 years old.

Mr. TOWNS. Let me thank you. That was what the discussion was about. I said you said you were 22 and he said he wasn't sure.

Let me say that I appreciate your testimony. I think both of you have been so helpful, because I think that the formula is something that we really must address and there is no question, in terms of behaviors is another area that we have to talk strongly about.

Thank you very much for your help. Thank you.

Ms. WHITING. Thank you.

Ms. WARE. Thank you.

Mr. TOWNS. Our next panel is Mr. Gregory Hutchings of Lifelink—come forward—Dr. Noel Braithwaite, director of HIV/AIDS project, Association of Black Psychologists; C. Alicia Georges, president of the National Black Nurses Foundation.

It is good to see you again.

Let me begin with you, Mr. Hutchings. You have 5 minutes to summarize.

We have been joined by Congressman Donald Payne from the great State of New Jersey, who is a member of the committee who has just joined us here.

STATEMENT OF GREGORY HUTCHINGS, DIRECTOR, LIFELINK, INC.

Mr. HUTCHINGS. Before I start, I want to offer a little bit of education. A couple of panels ago, you made a reference to the fact of AIDS victims, and I would like to point out that people that are living with HIV are productive members of this society and shouldn't be referred to as AIDS victims. I wanted to offer that to you.

Mr. TOWNS. Let me say, victims of the disease.

Mr. HUTCHINGS. We are not victims. Victims is a very negative issue. People that are fighting for their lives and going through with an issue of living their lives.

Mr. TOWNS. No, the statement was, if I remember, was people who had passed away, that there were victims, that had died. That was the understanding I had.

If you understand it differently, we will have to wait until the record comes back.

Mr. HUTCHINGS. I will stand corrected.

My name is Gregory C. Hutchings, and I am the director of Lifelink, Inc., which is an organization that is committed to the empowerment, support and advocacy for people living with HIV and AIDS and their families.

I would like to thank you for the opportunity to testify with respect to increasing treatment and other services, developing educational and prevention programs, and unique research approaches that the government should explore to address this disease in the African-American community.

Let me first ask an important question: Is anyone sitting up there now infected with HIV or have you all been tested?

Mr. TOWNS. I can't answer that. I can only speak for myself.

Mr. HUTCHINGS. I am asking anyone that is sitting there. Have you been tested?

Mr. TOWNS. The thing about it, you can only ask it to the Members, not the staff. I have been tested.

Mr. PAYNE. Oh, yes.

Mr. HUTCHINGS. I cannot effect——

Mr. TOWNS. The staff can remain silent. You didn't vote for them.

Mr. HUTCHINGS. OK. I cannot effectively discuss these issues until the basic obstacle to mobilizing our community is overcome. This obstacle is the personal commitment required of every member of every segment of the African-American community in order to bring this raging epidemic to its feet.

Let me take a minute to share with you my personal commitments to this effort. I am an African-American gay father, grandfather, son, brother, uncle, cousin, nephew and friend living with HIV.

As you can see, I am a clear representation of many segments of the community. Not only am I an individual who is infected with this dreadful virus, but one of many related individuals affected by this epidemic.

It must be understood that the lasting effects of this disease will span generations within our communities. Throughout this time that I have been infected, I have had to endure the personal pressures of lack of life insurance, lack of sensitivity and virtual termination from my employer, limitations placed upon me by the effects of this disease, friends and associates—sharing this information with friends and associates while fighting the possibility of being stigmatized and shunned by the rest of the community, being concerned with receiving adequate medical care, reaching out for spiritual support and empowerment, and dealing with the inevitable point of a suffering and painful death.

With all of these issues hovering over my every waking day, I cannot put aside the cultural values that were instilled in me as an African-American living in this country, including the teachings of the black church to embrace and exhibit compassion for our brothers and sisters along with the strong and immediate extended family support and love.

Fortunately, my life has been blessed with understanding friends and family. However, everyone has not been provided this type of emotional and physical support. Through my involvement in this epidemic, there have been virtual horror stories regarding various peoples' experiences within their individual lives and health.

I have endured the loss of more than 35 good friends over the last 4 years and hold the confidence of many more who are enduring the struggle alone. It is for this reason that I speak out on the issue of HIV and AIDS with the hope of raising the awareness and compassion of our community to effectively battling this epidemic.

Originally, I stated that the major obstacle to be overcome was gaining the personal commitment of each and every member of our community. It has been only recent that the black church has acknowledged the need for compassion for individuals and families undergoing the devastating effects of this epidemic. Consequently, throughout our community, from student to lawmaker, there has existed a great amount of denial and resistance to understanding and accepting the depth of this epidemic among our fellow brothers and sisters. As a result, we have adopted a comfort level in discussing and exhibiting an adequate amount of support, commitment and efforts at battling this epidemic.

Too often our community has emphasized the evidence of genocide attempts through the raging force of this epidemic, but fail to recognize the need for support, compassion for those living with HIV and AIDS and the greater need for awareness and education of those greatest at risk. Let's take a reality check.

Recent reports indicate that the leading cause of death among African-American men between the ages 25 and 44 in this country is AIDS. We must stop from taking a noninclusive or comfortable approach to this problem by publicly making personal commitments to this battle. This topic should continue to be one of the top priorities of the Congressional Black Caucus legislative weekend throughout this epidemic.

To my dismay, among the many planned receptions and events of the weekend, there is no reception that was planned to network with the workers associated with this virus or the people infected with this virus to enhance your commitment, even though this weekend is also the enactment of the first National Racial and Ethnic HIV Congress, and being held in this city with over 1,000 participants from across the Nation.

As leaders and teachers of the African-American community, I challenge you to embrace the task of teaching by example. You must use every opportunity to speak out on this issue not as a health epidemic but as a socioeconomic problem within our community. You must utilize the African-American media to bring attention to this problem on an ongoing basis. You must reach out to the fraternities, sororities, professional and social organizations that hold your membership to ensure an active level of awareness and commitment.

You must rally your constituents to an active role. You must convince your churches to enact their compassion clause to the affected populations of this epidemic, and you must encourage your own family members to become actively involved in this battle. Each one teach one is the order of the day.

As a person living with HIV, I long for the attention and support from my community that I remember as a child. It is through these means that we will teach the world how to permanently eradicate this devastating disease, AIDS, from the face of this earth. Therefore, as a role model and mobilizer, I challenge you to voice your commitment at every possible occasion.

Once this challenge is met, we can begin to network on further methods appropriate to our community. We can then begin to talk about housing situations, medical conditions, unique outreach strategies, alternative testing methods and equitable funding strategies.

Thank you very much for the opportunity to address your body.

[The prepared statement of Mr. Hutchings follows:]

[illegible] Lay in

TESTIMONY BEFORE SUBCOMMITTEE ON HUMAN RESOURCES AND
INTERGOVERNMENTAL RELATIONS

24th Annual Congressional Black Caucus Legislative Weekend

September 16, 1994

Good afternoon.

My name is Gregory C. Hutchings and I am the Director of Lifelink, Inc., which is an organization that is committed to the empowerment, support and advocacy for people living with HIV/AIDS and their families. I was thank you for the opportunity to testify before the Subcommittee on Human Resources and Intergovernmental Relations in respect to increasing treatment and other services; developing educational and prevention programs; and unique research approaches the government should explore to address this disease in the African American community. Let me ask first ask an important question? IS ANYONE ON THIS SUBCOMMITTEE INFECTED WITH HIV AND HAVE YOU ALL BEEN TESTED ? Therefore, I can not effectively discuss these issues until the basic obstacle to mobilizing our community is overcome. This obstacle is the personal commitment required of every member of every segment of the African American community, in order to bring this raging epidemic to its feet.

Let me take a minute to share with you my personal commitment to this effort. I am an African American Gay father, grandfather, son, brother, uncle, cousin, nephew, and friend living with HIV. As you can see, I am a clear representation of many segments of the community. Not only am I an individual who is infected with this dreadful virus, but one of many related individuals that are affected by this epidemic. It must be understood that the lasting effects of this disease will span generations within this community. Throughout the time that I have been infected, I have had to endure the personal pressures of lack of life insurance; lack of sensitivity and virtual termination from my employer; adjustment to the physical limitations placed upon me by the effects of this disease; sharing this information with friends and associates while fighting the possibility of being stigmatized and shunned by the rest of the community; being concerned with receiving adequate medical care; reaching out for spiritual support and empowerment; and dealing with the inevitable point of a suffering and painful death. With all of these issues hovering over my every waking day, I can not put aside the cultural values that were instilled in me as an African American living in America, including the teachings of the Black Church to embrace and exhibit compassion for our brothers and sisters along with the strong immediate and extended family support and love.

Fortunately, my life has been blessed with understanding friends and family. However, everyone has not been provided this type of emotional and physical support. Through my involvement in this epidemic, there have been virtual horror stories regarding various people's experiences within their individual lives and healthy. I have endured the loss of more than thirty-five good friends over the last four years and hold the confidence of many more who are enduring this struggle alone. It is for this reason that I speak out on the issue of HIV/AIDS with the hope of raising the awareness and compassion of our community to effectively battling this epidemic.

Originally, I stated that the major obstacle to be overcome was gaining the personal commitment of each and every member of our community. It has been only recent that the Black Church has acknowledged the need for compassion for individuals and families undergoing the devastating effects of this epidemic. Consequently, throughout our community, - from student to lawmaker -, there has existed a great amount of denial and resistance to understanding and accepting the depth of this epidemic among our fellow brothers and sisters. As a result, we have adopted a comfort level in discussing and exhibiting an adequate amount of support, commitment, and effort to battling this epidemic. Too often, our community has emphasized the evidence of genocide attempts through the raging force of this epidemic, but failed to recognize the need for support and compassion for those living with HIV/AIDS and the greater need for awareness and education of those greatest at risk.

LET'S TAKE A REALITY CHECK ! Recent reports indicate that the leading cause of death among African American men between the ages of 25 and 44 in this country is AIDS ! We must stop from taking a non-inclusive or comfortable approach to this problem by publicly making our personal commitment to this battle. This topic should continue to be one of the top priorities of the Congressional Black Caucus Legislative Weekend throughout this epidemic. To my dismay, among the many planned events of the weekend, there is no reception planned to network with the workers in this field or people infected with this virus to enhance your commitment; even though this weekend is also the enactment of the first National Racial and Ethnic Minority HIV Congress and being held in this city with over 1,000 participants from across the nation.

As leaders and teachers of the African American community, I challenge you to embracing the task of " teaching by example ". You must use every opportunity to speak out on this issue; not as a health epidemic, but as a major socio-economic problem within our community. You must utilize the African American media to bring attention to this problem on an ongoing basis; you must reach out to the fraternities, sororities, professional and social organizations that hold your membership to ensure an active level of awareness and commitment; you must rally your constituents to an active role; you must convince your churches to enact their compassion clause to the affected populations of this epidemic; and you must encourage your family members to become actively involved in this battle. " Each one, teach one " is the order of the day.

As a person living with HIV, I long for the attention and support from my community that I remember as a child. It is through these means that we will teach the world how to permanently eradicate this devastating disease, AIDS from the face of this earth. Therefore, as a role model and mobilizer, I CHALLENGE YOU TO VOICE YOUR COMMITTMENT AT EVERY POSSIBLE OCCASION. Once this challenge is met, we can begin to network on further methods appropriate to our community. We can then begin to talk about housing situations, medical conditions, unique outreach strategies, alternative testing methods and equitable funding strategies.

Thank you for the opportunity to address this body and I only hope that you will not hesitate to call on my assistance at other times outside of this yearly convergence of accomplishments.

Mr. TOWNS. Thank you for your powerful and profound statement.

Before I forget it, I want to correct one thing. There is a reception immediately after this where we can do some networking.

Mr. HUTCHINGS. How many PWA's have you invited?

Mr. TOWNS. We invited all the participants in this program to network, that is the reason for the reception. If we want to expand it at another time, I would be delighted with you to do it. But this is a form of networking and that is the purpose.

Will someone give us the room number on the record? 2203.

Thank you again for your testimony.

Dr. Braithwaite.

STATEMENT OF NOEL BRAITHWAITE, Ph.D., DIRECTOR OF HIV/STD PROJECT, ASSOCIATION OF BLACK PSYCHOLOGISTS

Dr. BRAITHWAITE. Doctor and Chairman Towns and Representative Payne, I would like to describe a unique training program that is done by the Association of Black Psychologists, an effort to prevent the spread of HIV/AIDS in the African-American community.

I will begin by making a statement. The statement is this: There is a widening gap between the growing number of African-Americans with HIV and AIDS and culturally specific programs that address education, prevention and psychological services within the African-American community. Because this statement is true, the association decided to take a stand to assist in the information efforts. So since 1987, the association has been involved in HIV prevention by training over 70 of its member psychologists who then returned to local communities to provide technical assistance and training for the affiliate chapters, hundreds of community-based organizations, local health departments, small businesses, social service organizations, churches and other groups that serve African-American adults and adolescents.

Specific prevention services included providing culturally appropriate HIV education and public information, conducting small support discussion groups for African-Americans infected and affected by HIV, organizing and conducting workshops to train local professionals and service providers regarding how to plan and deliver culturally specific relevant HIV education and services to African-Americans, and developing a collaborative network system with local health departments and CBO's to enhance the effectiveness of their services to African-Americans. So between 1987 and 1993, the association has been conducting these efforts in cities such as Boston, New York, Washington, DC, Jacksonville, FL, Atlanta, Miami, Houston, New Orleans, Chicago, Denver, Los Angeles, San Diego, and San Francisco.

The association has felt it necessary by developing this network system to collaborate with institutions such as Howard University, the Red Cross, National Urban League, National Organization of Black County Officials, National Council of Negro Women, National Association for Equal Opportunity and Education, Health Watch out of New York, and many other local and regional organizations. In the local sectors we have worked with churches, jails, barber and beauty salons, hospitals, clinics, schools, universities, even homeless shelters.

For the next 5 years the association is going to be involved in the second level of its efforts in HIV/AIDS prevention. The association will receive another 5-year grant from the Centers for Disease Control and Prevention to provide technical assistance to community-based organizations and AIDS services organizations.

Our technical assistance consultants are now being trained by the Progressive Life Center of Washington, DC, and there are a number of critical areas that have been based on a needs assessment that organizations involving HIV/AIDS prevention indicated they need technical assistance in. These areas include: proposal development, team building, cultural competency, networking, collaboration, recruitment and retention of staff and volunteers, program evaluation, program planning and implementation, and also needs assessment.

The purpose of this technical assistance initiative is to build and strengthen organizations' capacity or ability to deliver a comprehensive range of HIV prevention services to African-Americans. In the second phase of our involvement we have trained over 60 consultants and have been providing technical assistance to over 100 agencies in 20 cities nationwide.

What are some of the lessons that we have learned from our 7-year involvement in HIV/AIDS prevention? Six lessons: One, a theoretical framework that includes a cultural element or component for attempting to explain factors that influence behaviors is critical. The framework has been used successfully since 1987.

Two, a community-based needs assessment is another key in attempting to understand communities at risk.

Three, recruiting and training individuals from the target community has been essential in our efforts. This has enhanced our project planning and implementation and also reduced the reluctance of people to pass up education and training.

Four, networking and agency collaboration have been decisive in our efforts over the past 7 years.

Five, including evaluation personnel in our program planning and design who then provide program staff with feedback on consultation has been rewarding.

The last lesson that we have learned, not necessarily in terms of order, but it is a recognition that AIDS prevention is a slow process. The approach must be comprehensive, theoretically sound and needs driven.

The test over the next 5 years is to see a significant decrease in behaviors that place individuals and communities at risk for infection that causes AIDS. Another test over the next 5 years will be the decrease in new infections. Another test to determine success will be a decrease in mortality from AIDS and sustained social and economic development of African-American communities.

We are hoping that by our efforts over the next 5 years we will see a significant decline in HIV/AIDS in the African-American community.

Mr. TOWNS. Thank you very much.

[The prepared statement of Dr. Braithwaite follows:]

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HIV Prevention and African Americans

Testimony of

Noel Brathwaite, Ph.D., MSPH
Director of the HIV/STD Project of the
Association of Black Psychologists

before the
Subcommittee on Human Resources and Intergovernmental Relations

Congress of the United States
House of Representatives

Friday, September 16, 1994
2:00 pm

The Association

The Association of Black Psychologists (ABPsi) is a National minority, professional, and social action organization. It consists of over 1300 Psychologists and mental health professionals, 32 affiliated chapters, a 12 member Board of Directors, chaired by a nationally elected president.

Founded in 1968, ABPsi's objectives are to enhance the psychological well-being of African Americans, to promote constructive understanding of African Americans through behavioral-oriented research, and to develop mental health policies and programs for local, state, and national decision-makers.

Impact of HIV/AIDS on the African-American community

1) Through December 1991, the number of AIDS cases among adult/adolescent male/female African Americans was 56,977, and through December 1993, the number increased to 112,002. A difference of 55,025 in only two years. Through 1991, 10,899 female adult/adolescent AIDS cases were reported and through December 1993, the number increased to 23,810. For male adult/adolescents the number increased from 46,078 to 88,192.

2) During this same period the percentage of AIDS cases of male adult/adolescents who have sex with men decreased from 44% to 41% even though the number of cases increased from 20,149 to 36,446 (1993). The percentage of injecting drug use increased from 36% (1991) to 37% (1993) and the number of cases increased from 16,443 to 32,218. Among female adult/adolescents the percentage of injecting drug use decreased from 56% (1991) to 52% (1993) but number of cases increased from 6,050 to 7,613. The percentage of heterosexual contact decreased from 34% to 32%, whereas number of cases rose from 3,684 to 7,613.

3) The data clearly shows a definite increase in the number of AIDS cases among both male and female. In addition, transmission from men who have sex with men 20,149 (1991) to 36,446 (1993) is higher than from men who injected drugs (16,443 to 32,218); and transmission from injecting drugs in women (6,050 to 12,459) is less than heterosexual (3,684 to 7,613).

Prevention Efforts: 1987-1993

Since 1987, the Association has been involved in HIV prevention by training over 70 of its member psychologists who then provided technical assistance and training (TAT) to its 32 affiliates/chapters, hundreds of community-based organizations (CBOs), local health departments, small businesses, social service organizations, churches and other groups that serve African-American adults and adolescents.

Specific prevention services included providing culturally appropriate HIV education and public information; conducting small support/discussion groups for African Americans infected and affected by the HIV virus; organizing and conducting workshops to train local professionals and service providers regarding how to plan and deliver culturally specific/relevant HIV education and services to African Americans; and developing a collaborative network system with local health departments and CBOs to enhance the effectiveness of their services to African Americans.

Those efforts were conducted in cities including Boston, New York, Washington, DC, Jacksonville, Florida, Atlanta, Miami, Houston, New Orleans, Chicago, Denver, Los Angeles, San Diego and San Francisco. And in collaboration with Howard University, the Red Cross, National Urban League, National Organization of Black County Officials, National Association of Negro Women, National Association for Equal Opportunity in Education, Health Watch, BEBASHI, Jackson State University and many other local and regional organizations. We have worked with churches, jails, barber and beauty salons, hospitals, clinics, schools, universities, homeless shelters, etc.

Prevention Efforts: 1993-

In 1993, ABPsi received another five year grant from the CDC to provide technical assistance to community-based organizations and AIDS Services organizations (ASOs). Our technical assistance consultants were trained by subcontractor, Progressive Life Center (PLC) to deliver services in the area of: grant writing/proposal development; board development; team building; cultural competency; networking/collaboration; recruitment and retention of staff and volunteers; program evaluation; program planning and implementation and needs assessment.

The purpose of this TA initiative is to build/strengthen organizations capacity/ability to deliver a comprehensive range of HIV prevention services to African Americans.

Lessons Learned

1. A theoretical framework that includes a cultural element/component for attempting to explain factors that influence behaviors is critical. The Afrocentric framework has been used successfully by ABPsi and PLC since 1987.

2. A community-based needs assessment is another key in attempting to understand communities at risk.

3. Recruiting and training individuals from the target community has been essential. This enhanced our project planning and implementation, and also reduced the reluctance of people to participate in education and training.

4. Networking and interagency collaboration have been decisive in our efforts.

5. Including evaluation personnel in our program planning and design and who then provide program staff with feedback and consultation has been rewarding.

6. A recognition that AIDS prevention is a slow process. The approach must be comprehensive, theoretically sound and needs-driven. The ultimate test over the next 5 years is to see a significant decrease in behaviors that place individuals and communities at risk for the infection that causes AIDS, a decrease in new infections, a decrease in mortality from AIDS and sustained social and economic development of African-American communities.

Mr. TOWNS. Ms. Georges, good to see you again.

STATEMENT OF C. ALICIA GEORGES, R.N., M.A., F.A.A.N., PRESIDENT, NATIONAL BLACK NURSES FOUNDATION, INC.

Ms. GEORGES. Congressman Towns, thank you for inviting me to speak before your committee today.

I am C. Alicia Georges, president of the National Black Nurses Foundation. I am the immediate past president of the National Black Nurses Association and a registered professional nurse with over 25 years of community health experience in New York City. It is in this context that I present testimony to you today about AIDS in communities of persons of African descent.

The dire statistics released periodically about this continuing problem must be viewed critically. We must analyze the variables that have a profound impact on the staggering morbidity and mortality statistics from this disease. We have to attack the root causes of the problem.

The young lady who spoke on the last panel talked about the lack of information, ignorance of young people, some poor self-esteem issues, poor coping skills that may lead to use and abuse of substances, and to have young people engage in early sexual activities.

The fear of not fitting in and downright hopelessness is another issue that must be addressed. Each time we see a pregnant teenager in our community, we should shudder not because of all the data we have available about the potential long-time problems that a beginning family will have, but because three or more lives have been placed at risk for HIV infection and AIDS. Yes, placed at risk because of unprotected sex. We must not confuse the issue of AIDS and HIV with any moral judgment.

At this time in the history of the disease of AIDS, persons of African descent are at great risk. But our greatest risk are the teenagers in our community. You heard a statistic from the AIDS Institute of New York. Let me tease out one statistic for you.

Currently, New York State has the unfortunate distinction of leading the Nation in the number of AIDS-reported cases among adolescents and young adults. For New York, this is more than 10,000 people. Each one of those young people have a name. They have got a face. They are children, they are the children of our neighbors, they are our sons, our daughters, our nieces, our grandchildren. This should cause us to pause and reexamine our priorities in the prevention arena.

On the primary level of prevention, we need to inject more dollars into programs that are about helping young people to build their self-esteem, their interpersonal relations and social skills. Why? Because we must help them see that they have other alternatives besides early sexual activities and/or substance use or abuse.

We have to start someplace. Let's use some of their role models to permeate the market, where young people shop for services. Let's pour money into the appropriate medium which the youth of today utilizes best.

It is with great trepidation that I mention giving money to rappers, but we know this has worked for some intervention strategies. Let's utilize the skills of the advertising and marketing experts and give cogent data that could assist in behavioral changes.

For those persons who are already infected with AIDS, we need to have available community-based services that are culturally sensitive, that will help them to avoid the environments which place them at greater risk for opportunistic infections; decent housing, meals, child care, other ego-enhancing activities, being able to go out and partake in cultural activities, increasing the budget for those community-based research programs.

I want you to address another group that got a lot of money in this government, NIAID or the Institutes of Health. Where is the money for African-American communities?

Brooklyn has a great one, Dr. Larry Brown. He told me he wasn't refunded. You need to give money out of AID to those African-American institutions and practitioners who will expand capacity in our community.

We must have competent and knowledgeable practitioners. Create some additional funding for more collaborative partnerships to create models that will combine what has been learned from the research of community-based trial programs with what practitioners and people living with AIDS know works best. Let groups such as ours, the National Black Nurses get some of the money, too, and take some of the lead in utilizing their connections in the community, not to run it but to connect and work with those groups.

The fight against HIV infection and AIDS requires an open-minded, multiple-pronged approach. Let us not insist on waiting for all the data to show what is truly effective. Let us use models that have caring as the major components. Caring is not mutually exclusive of scientific approaches.

The future health of this Nation is dependent on the health status of its youth. We do have the financial resources within this government. All we need now is the will to make it work.

[The prepared statement of Ms. Georges follows:]

National Black Nurses Foundation, Inc.

C. Alicia Georges, RN, MA, FAAN
President

TESTIMONY OF C. ALICIA GEORGES MA,RN,FAAN
BEFORE THE SUBCOMMITTEE ON
HUMAN RESOURCES AND INTERGOVERNMENTAL RELATIONS
SEPTEMBER, 16, 1994

Congressman Towns, and members of the Subcommittee on Human Resources and Intergovernmental Relations. I am, C. Alicia Georges, President of the National Black Nurses Foundation, Immediate Past President of the National Black Nurses Association, and a registered professional nurse with over twenty five years of community health nursing experience in New York City. It is in this context, that I present testimony to you about AIDS in communities of persons of African descent.

The dire statistics released periodically about this continuing problem must be viewed critically. We must analyze the variables that have a profound impact on the staggering morbidity and mortality statistics from this disease. We must attack the root causes of the problem. Factors such as : ignorance, poor self esteem, poor coping skills, fear of not fitting in and down right hopelessness.

Each time, we see a pregnant teenager, we should shudder. Not because of all the data we have come to know about the potential longtime problems that a beginning family will have, but because three or more lives have been placed at risk for AIDS. Yes placed at risk, because of unprotected sex.

We must not confuse the issue of prevention of AIDS with any moral judgements. At this time in the history of the disease of AIDS, persons , of African descent are at great risk. But at greater risk are the teenagers in our community. Currently, New York State has the unfortunate distinction of leading the nation in the number of AIDS cases reported among adolescents and young adults. For New York this is more than 10,000 persons or 15% of the reported cases of AIDS in NY State.(NYSDOH) This should cause us to pause and reexamine our priorities in the prevention arena.

On the primary prevention level, we need to inject more dollars into programs that are about helping young people to build their self esteem, interpersonal relations and social skills. Why? Because we must assist them in seeing that they have other alternatives besides early sexual activities, and or substance use and abuse. I speak of young people, because we must start someplace. Let's use some of their role models to permeate the markets where young people shop for services. Let's pour money into the appropriate medium which the youth of today utilize best. It is with great trepidation, that I venture to mention giving money to rappers. We know this has worked for some interventive strategies. Let's utilize the skills of the advertising and marketing experts and give cogent data that could assist in behavioral changes.

For those persons already infected with the AIDS virus, we need to have available, community based services that are culturally sensitive that help them to avoid the environments which place them at risk for opportunistic infections. Decent housing, meals, child care and other ego enhancing activities are important. Increasing the budget for those community based research programs funded by NIAID, would help to expand the capacity of African American institutions and practitioners. We must have culturally competent and knowledgeable practitioners.

Create some additional funding streams for more collaborative partnerships, to create some models that would combine what has been learned from the research of community based trial programs with what the community health practitioners know work best. Let groups such as the National Black Nurses take the lead and utilize their connections to communities.

The fight against HIV infection and AIDS requires an open minded multiple prong approach. Let us not insist on waiting for the data to show what is truly effective. Let us use models that have caring as the major component. Caring is not mutually exclusive of scientific approaches. The future health of this nation is dependent on the health status of its youth. We have the financial resources, we need the will to make it work.

Mr. TOWNS. Thank you.

Thank you very much for your testimony, all three of you. You give us a lot of information that can be very helpful in the days ahead.

Let me begin with you, Dr. Braithwaite, in terms of something that you said. It is not clear to me what you meant by it. You said AIDS prevention is a slow process. What do you mean by that?

Dr. BRAITHWAITE. To prevent a disease which is behavioral does not take place overnight. Some examples of this is in the gay community, it took them over 10 years to decrease the infection rate and also to decrease the new infections, and that is what I mean by a slow process. Because you are dealing with the behavior change which might have been acquired, core behaviors which may have to be changed which might have been acquired over 10 or 15 years of a person's life. That is what is meant by a slow process.

If it were a dramatic change, there would be a significant decrease in the infection rate. Since 1981, over almost 30 years, there has not been a significant decrease in new infections outside of one community because of the moral rigid community relationship that exists in that community, that is the gay community.

Mr. TOWNS. Let me raise this then.

Do you think that this has something to do with the thinking that is going on now within the agency as to why funding prevention was not increased?

Dr. BRAITHWAITE. I would not want to draw a correlation between level of funding and a process which is considered slow in terms of behavior change. That is the reason for the thinking. I would suspect that there are a number of things that might be driving the level of prevention dollars.

One might be, in terms of the African-American, might be the level of advocacy within the African-American community itself. And second could be the whole concept of divisibility of care, as against divisibility of prevention, in that hospitals and clinics and treatment facility might be more visible in a congressional district than possibly you have prevention, which may not be as visible. Those might be some of the reasons for the thinking in terms of prevention dollars. I don't draw a correlation between the slow process of change and the level of funding.

Mr. TOWNS. Ms. Georges, do you want to add anything to that?

Ms. GEORGES. Congressman, you know that it is the squeaky wheel that gets the most oil. And you need to look at who gets the bulk of money. Our government pays more attention—I don't want to you misunderstand—pays a lot of attention to the cries that it hears from the top researchers in this country.

You look at where the dollars go. How many—who are the people who are clamoring for the prevention dollars? They are not your major, major medical institutions. No, they are community-based organizations. They are your health departments who have been decimated.

The whole infrastructure of public health has been destroyed in this country. They are not the people who have been getting the money. The researchers have gotten money. That is where we shift our dollars.

We need to have a paradigm shift here and begin to allocate the dollars. I don't know if you want to call it not equally, but at least equitably using some criteria to weigh what it is we are looking to accomplish. But the prevention folks have not been screaming loud—only now—and even those of us who have been screaming, nobody has been listening.

If our State health department can't get money through the co-op agreements from the—from CDC, it is because somebody didn't appropriate enough money to CDC to get the moneys to us in the State levels and then down to the local levels. But I bet you NIH moneys haven't been cut.

Mr. TOWNS. And that is the point. I think you make a great point, is—Mr. Hutchings, do you have any ideas as to what we might do in terms of some more targeting, to the kind of targeting that might go on in order to help us address the problem that we find that seems to be much more prevalent in some communities other than others?

Mr. HUTCHINGS. I think the targeting needs to be kind of like from the top down. We need to talk about AIDS more. We need to be more concerned about AIDS more. We have so many problems in our African-American media where we have encountered where they don't want to cover it. Nobody wants to talk about it. When you don't talk about it enough, then it is not regarded as a problem.

You know, when I sit up here and ask today, have you been tested, that is something that people need to know. You are role models. There are other people out here in this community that are role models. If they can stand up and say it rather matter of factly, then maybe that other person will find it a little more easier to take some prevention methods for themselves.

But if people are—sometimes it is just as good to talk about the good things as it is to talk about the bad things. And when you hear about the bad things as far as the tragedies, the number of deaths and this type of thing, and you don't hear about what people are doing to prevent this, what people, you know, how many people are going out here and being tested and know about their status, don't have a problem talking about their status, then it doesn't become such a scary type of issue anymore. And that is why I say the role model aspect is very, very important. It has always worked in our community.

Mr. TOWNS. Well, let me thank all three of you for your testimony. You are very, very informative, Dr. Braithwaite, Ms. Georges and also Mr. Hutchings. Thank you again.

Let me call the next panel up. Catherine Sykes, national president of the National Association of Negro Business and Professional Women's Clubs; Dr. Norma J. Goodwin, founder and president of Health Watch Information and Promotion Service, Christine Williams, HIV/AIDS prevention coordinator, Black Veterans for Social Justice, Martin Ornelas, National Latino a Gay and Lesbian Organization.

Let me welcome you. And before we lose too many people in the room before I call on you, you know, I think that it has been said almost in every panel that we have a lot of work to do. And I agree with the fact that we have a lot of work to do.

What I would like to do is to pass around a sheet of paper and to have you put your names, telephone, addresses, however much information you can give us, so we can begin to have the kind of dialog and the kind of communication and communicating that we should have so we can at least cut down on some of the finger pointing.

There are a lot of folks that are very concerned. However, sometimes they have difficulty expressing their concern. So I would like you to give us that information and we will see what we can do in terms of communicating. Those of you that might not be able to go to the reception, those that might have to go to other places; at least we have that information before you depart. So that is what the list is all about that we are passing around, is not to send back to your workplaces to let them know you showed or didn't show. It is not that. That is not the purpose of it.

Let me thank the panel. And let me begin by asking you, Ms. Sykes, let me first of all welcome you and welcome all of your members here, and to say to you that I find it very heartwarming to know that your organization has taken a special interest in this particular problem. I know that you have members throughout the Nation. To me, that is very, very encouraging. So let me welcome you to Washington, DC, and thank you for the leadership that you are providing.

Ms. Sykes, the president of the National Association of Negro Business and Professional Women's Clubs.

STATEMENT OF CATHERINE SYKES, NATIONAL PRESIDENT, NATIONAL ASSOCIATION OF NEGRO BUSINESS AND PROFESSIONAL WOMEN'S CLUBS, ACCOMPANIED BY DENISE TAYLOR, NATIONAL SECOND VICE PRESIDENT

Ms. SYKES. Thank you, Congressman Towns.

To Congressmen Towns and other Members of the House of Representatives Subcommittee on Human Resources and Intergovernmental Relations, we thank you for providing us the opportunity to appear before you today.

I am Catherine Sykes, as you have stated, I am president of the National Association of Negro Business and Professional Women's Clubs, Inc. Our mission has always been in the 60 years of our existence to seek answers to the critical challenge that is facing the African-American family and not only to face them, but to collaborate and to begin to take action toward resolving some of those problems. Our organization has membership, as you stated, across the country, 350 clubs, including the District of Columbia and Bermuda.

We are very sensitive to this issue because our organization, one of our emphasis is health. This is our third major activity focusing on information and education related to HIV and AIDS. We have had community forums. We have sponsored a seminar here in Washington, DC to educate ourselves, increase the awareness and also the education of our members so that we can go out and join other coalitions in our local communities to do what we can to assist in this dilemma.

In addressing the prevention of HIV and AIDS in African-Americans, I, as an educator for over 30 years, and I have had contact with many young people and know today that it is critically important, as some of the other individuals have said, that we work with these young people and let them know just how serious this is. Because our teenagers of today are not taking it serious. So we have a responsibility to educate them and to see that they do what is necessary.

We have had over the years two programs, walking tall, which is teenage assistance and leadership learning, which since 1980 we have tried to work with young people in increasing their self-confidence and giving them the skills that they need in order to meet the negative forces that they may come in contact with in their daily lives.

Our newest program is program succeed, which means supporting children with the choices to ensure and encourage dignity, determination and discernment. Specifically, targeting young people from ages 8 to 12. And as it relates to education and as an educator, I know that the junior high and the high school is not soon enough. As others have said, we must start when our young people are in elementary school teaching them about self-confidence, health issues and how—that they can relate to, and not get early actively sexually, as many of our young people are.

We have worked this year with Health Watch related to technical assistance with the programs that we already have in existence so that we can mobilize and spread the information. Our focus has been awareness, education and information as a part of what we do as a national organization.

In addition to that, we ask our local clubs to join with other coalitions, medical coalitions, other kinds of organizations so that we can make a difference. And we know that there are many different organizations doing this and we know that it is critical that all of us at all levels, not just those that are directly involved in the health field and those who may be afflicted, that we start at an early age in working with our young people in our communities so that we can help them to make a difference.

And our young person here, younger than I am, who is Denise Taylor, our national second vice president who is responsible for our youth programs. And she will add to the testimony with me.

Denise.

Mr. TOWNS. Move the mike over to her, please.

Ms. TAYLOR. Thank you.

Chairman Towns, I also thank you for this opportunity to appear before you.

In terms of how to prevent HIV in adolescents and young adults, there is a dire need for more intensive educational efforts. Although young people know how serious AIDS is, the data reflecting knowledge in relation to AIDS is not enough. It is about teaching our young—our young people about a behavior change.

As we are well aware, learned behavior is very hard to change without the appropriate supports in place and the opportunity to practice what has been learned in safe and supportive environments. Our organization considers it very important that AIDS education be required in every public school and the teaching should be by culturally sensitive persons and community-based organizations and that monitoring of the effectiveness of these programs be consistently conducted. The monitoring should not only document that the education is taking place but that it is effective, not only increasing knowledge, but also in modifying attitudes and subsequent behavior. The above group should also be involved in the curriculum development for such schools.

In regard to sex education provided in the schools and to youth elsewhere, it must be broader and more realistic, emphasizing the benefits of delaying sexual activity is no longer enough. Teenagers must also be prepared for engaging in safer sex whenever they do choose to become sexually active, especially since they also become sexually active at an unplanned point in time.

Finally, because of our time limitations I would just like to make two additional points. Our teenagers and young adults need to be able to anticipate situations which increase the possibility of their becoming sexually active and to possess the skills to control these situations, and there needs to be more emphasis on the influence of alcohol and drug experimentation and use on sound decision-making.

As national president, Ms. Catherine Sykes has indicated, it is critically important that more funds be made available for minority organizations so that more of us can get actively involved in HIV and sexually transmitted disease prevention in our communities and so that minority organizations already involved can become even more effective in stopping this epidemic.

Again, I thank you.

Mr. TOWNS. Let me thank you for your testimony, as well as Ms. Sykes for hers.

[The prepared statement of Ms. Sykes and Ms. Taylor follows:]

Friday, September 16, 1994
"HIV and AIDS in Minority Populations:
Needs to Reverse the Escalating Trend"
Statements by:
Catherine Sykes, National President
and
Denise Taylor, National 2nd Vice President

Congressman Towns and other members of the House of Representatives Subcommittee on Human Resources and Intergovernmental Relations, thank you for providing the opportunity for me to appear before you today. I am Catherine Sykes, President of the National Association for Negro Business and Professional Women's Clubs, Inc. Our mission is to seek answers to the critical challenges facing the African-American family and to take action towards resolving them. The National Association has been in existence for 60 years. We are a national nonprofit community based social service organization headquartered in Washington, D.C. We have a membership of over 10,000 in 350 chapters throughout the United States, including the District of Columbia and Bermuda.

The scheduling of this hearing reflects your sensitivity and understanding of the state of urgency to develop new strategies and identify additional funding for the prevention of HIV infection and AIDS. The National Association of Negro Business and Professional Women's Clubs, Inc., in collaboration with HEALTH WATCH Information and Promotion Service, decided to make the prevention of HIV and AIDS, especially in teenagers and young adults, a high priority focus of the National Association of Negro Business and Professional Women's Clubs.

I am joined in our organization's testimony by Ms. Denise Taylor, our National Second Vice President for Youth Programs. In addressing the prevention of HIV and AIDS in African-Americans, I also wish to make you aware of my relevant prior experience. I have been an educator for 30 years, and currently teach at Pontiac Northern High School, an urban high school in Pontiac, Michigan whose student body is approximately 60 percent African-American. I am also a member of the Professional Development Team for the Pontiac School District, which develops strategies and programs for youth development and improvement.

Mr. Towns and other members of the Subcommittee, I wish to bring to your attention that the U.S. Centers for Disease Control's cooperative agreement with HEALTH WATCH Information and Promotion Service to provide technical assistance related to the prevention of HIV infection and sexually transmitted diseases to organizations serving minority populations is what has made it possible for the National Association of Negro Business and Professional Women's Clubs to make the presentation of HIV and STD one of our top priorities.

We are aware that there are other national and regional minority organizations (NRMO'S) in addition to HEALTH WATCH which are working in cooperation with CDC toward this same goal. The NRMO's repeatedly demonstrate their skill in reaching out to, collaborating with and providing technical assistance related to HIV and STD prevention to organizations serving minority populations. Given the rapidly increasing rate of HIV infection and AIDS in African-Americans, as well in other communities of color, it is critically important that there be a significant increase in funding to CDC for minority organizations working in HIV prevention because of the critical and unique role which they are able to play in reversing the current escalating rates of HIV and STD in minority populations. Mr. Towns, at this time Ms. Denise Taylor, speaking for the 2,500 youth members of our organization will complete our statement.

(Please turn over)

Ms. Denise Taylor:

Mr. Towns and other committee members, I also thank you for this opportunity to appear before you. In terms of how to prevent HIV in our adolescent and young adults, there is a need for more intensive educational efforts. Although young people know how serious AIDS is, the data reflects that knowing about the disease is not enough; its about behavior change. As we are all well aware, learned behavior is very hard to change without the appropriate supports in place and the opportunity to practice what has been learned in a safe and supportive environment. Our organization considers it very important that AIDS education be required in every public school, preferably by minority and other community-based organizations, and that monitoring of the effectiveness of these programs be consistently conducted. The monitoring should not only document that the education is taking place, but that it is effective in not only increasing knowledge but also in modifying attitudes and subsequent behavior. The above groups should also be involved in curriculum development for schools.

In regard to sex education provided in the schools, and to youth elsewhere, it must be broader and more realistic. Emphasizing the benefits of delaying sexual activity is not enough. Teenagers must also be prepared for engaging in safer sex whenever they do become sexually active, especially since they often become sexually active at an unplanned point in time. Finally because of our time limitation, I wish to make two additional points:

1. Our teenagers and young adults need to be able to anticipate situations which increase the possibility of their becoming sexually active, and to possess the skills to control these situations; and

2. There needs to be more emphasis on the influence of alcohol experimentation and use on sound decision making.

Members of the committee, as our National President, Ms. Catherine Sykes indicated, it is critically important that more funds be made available for minority organizations so that more of us can get actively involved in HIV and STD prevention in our communities, and so that those minority organizations already involved can be even more effective in stopping these epidemics.

Thank you.

Mr. TOWNS. At this time, I call Mr. Ornelas.

STATEMENT OF MARTIN ORNELAS, DIRECTOR OF AIDS PROGRAM, NATIONAL LATINO/A GAY AND LESBIAN ORGANIZATION

Mr. ORNELAS. Thank you, Mr. Chairman.

First and foremost, I would like to give thanks for the opportunity to be present here. I am. However, I would like to state on the record that not I, nor anyone on my staff, were informed that the focus had shifted from HIV prevention, communities of color, to HIV prevention in the African-American community. And with all due respect, I hope there I can continue with my brief comments and hope that it may apply some similarities to a subpopulation of the African-American community in the spirit of cooperation, collaboration and future partnerships.

Mr. TOWNS. By all means, anything to do with prevention, we want to hear it.

Mr. ORNELAS. Thank you.

Good afternoon, and thank you for the opportunity to testify on the behalf of gay, lesbian, bisexual and transgenderal Latinos and Latinas in the United States and Puerto Rico. It is important to recognize and affirm the diversity that does exist within the people of color communities. All of those communities must have the opportunity to share their experiences. It is even more important to hear their voices when we are speaking of the HIV and AIDS epidemic within these communities.

One of the greatest problems facing gay and lesbian, bisexual and transgenderal Latinas and Latinos in this country is our lack of visibility. We are one of those communities that falls through the proverbial cracks. Mainstream gay and lesbian and people of color organizations purport to serve these communities, but in reality, few directed services actually exist.

According to the 1993 CDCP statistics, Latino gay men constitute the majority of AIDS cases within the Latino community. In 1993 alone in the Latino community, 15,301 cases were diagnosed with AIDS. Of those, 6,519 were men who have sex with men, 5,872 were through intravenous drug use, and 3,324 were Latino women.

Similar patterns in the African-American community exists; 9,220 African-American women were diagnosed in 1993, 10,961 through intravenous drug use and 10,509 through contact with other men or gay African-Americans. These statistics do not lie and they cannot continue.

Unfortunately, when you look at funding that is allocated for AIDS services, you see that this community does not receive funding commensurate with the numbers infected, as I have demonstrated.

Within the context of the community prevention planning process, Latino gay men, Latina lesbians, bisexuals and transgenderal people hope to finally have their HIV prevention needs recognized and consequently addressed. An examination and possible redistribution of resources to address the real and documented needs of these affected and infected communities would go far in addressing the imbalances experienced by Latino gay men and Latina lesbians.

In year 12 of the epidemic, it is time that the money go where it is supposed to go. We must address the racism and homophobia that exists within and outside the communities of color. The needs of the Latino/a gay and lesbian, bisexual and transgenderal communities are complex and, in like many communities of color, go far beyond the issues of the epidemic.

The needs of Latino/Latinas begin with the development of capacity in our communities. The effects of homophobia, sexism, racism and economic disenfranchisement have taken their toll upon us, both as individuals and as a community. We need resources to build institutions that affirm our experiences and life choices. We need HIV prevention programs that are developed within our communities to address the social, cultural and linguistic needs of our communities. Our communities are filled with ancianos, jovenes, niños, niñas, hombres y mujeres, our elders, our children and our men and women. We need resources to provide comprehensive HIV services to each of these groups.

We need the support of our brothers and sisters of color to make sure that Latino lesbians, Latino gay men and bisexuals and transgenderals are not left out of the loop. Remember that none of us are free until all of us are free. Please join us in the battle against AIDS, racism and homophobia.

I give thanks for your leadership, your courage and your attention.

Mr. TOWNS. Thank you. Thank you very much for your testimony.

[The prepared statement of Mr. Ornelas follows:]

Testimony on

HIV PREVENTION IN PEOPLE OF COLOR

Friday, September 16, 1994

MARTÍN ORNELAS-QUINTERO
Director of AIDS Program

The National Latino/a Lesbian and Gay Organization

LLEGO

Congressman Edolphus Towns
Chairman, Committee on Human Resources and
Intergovernmental Relations
Committee on Government Operations
House of Representatives

GOOD AFTERNOON AND THANK YOU FOR THE OPPORTUNITY TO TESTIFY ON THE BEHALF OF GAY, LESBIAN, BISEXUAL AND TRANSGENDERAL LATINOS AND LATINAS IN THE UNITED STATES AND PUERTO RICO. IT IS IMPORTANT TO RECOGNIZE AND AFFIRM THE DIVERSITY THAT EXISTS WITHIN THE PEOPLE OF COLOR COMMUNITIES. ALL OF THOSE COMMUNITIES MUST HAVE THE OPPORTUNITY TO SHARE THEIR EXPERIENCES. IT IS EVEN MORE IMPORTANT TO HEAR THEIR VOICES WHEN WE ARE SPEAKING OF THE HIV AND AIDS EPIDEMIC WITHIN THESE COMMUNITIES.

ONE OF THE GREATEST PROBLEMS FACING GAY, LESBIAN, BISEXUAL AND TRANSGENDERAL LATINOS AND LATINAS IN THIS COUNTRY IS OUR LACK OF VISIBILITY. WE ARE ONE OF THOSE COMMUNITIES THAT FALL THROUGH THE PROVERBIAL CRACKS. MAINSTREAM GAY AND LESBIAN AND PEOPLE OF COLOR ORGANIZATIONS PURPORT TO SERVE THESE COMMUNITIES BUT IN REALITY, FEW DIRECTED SERVICES ACTUALLY EXIST. ACCORDING TO THE 1993 CDCP STATISTICS, LATINO GAY MEN CONSTITUTE THE MAJORITY OF AIDS CASES WITHIN THE LATINO COMMUNITY. IN 1993 ALONE IN THE LATINO COMMUNITY, 15,301 CASES WERE DIAGNOSED WITH AIDS. OF THOSE, 6,519 WERE MEN WHO HAVE SEX WITH MEN, 5,872 WERE THROUGH INTRAVENOUS DRUG USE, AND 3,324 WERE LATINA WOMEN. SIMILAR PATTERNS IN AFRICAN-AMERICAN COMMUNITY EXISTS. 9,220 AFRICAN-AMERICAN WOMEN WERE DIAGNOSED IN 1993. 10,961 THROUGH INTRAVENOUS DRUG USE AND 10,509 THROUGH CONTAC WITH OTHER MEN OR GAY AFRICAN-AMERICANS. THESE STATISTICS DO NOT LIE AND THEY CANNOT CONTINUE. UNFORTUNATELY, WHEN YOU

LOOK AT FUNDING THAT IS ALLOCATED FOR AIDS SERVICES , YOU SEE THAT THIS COMMUNITY DOES NOT RECEIVE FUNDING COMMENSURATE WITH THE NUMBERS INFECTED. WITHIN THE CONTEXT OF THE COMMUNITY PREVENTION PLANNING PROCESS, LATINO GAY MEN, LATINA LESBIANS, BISEXUALS AND TRANSGENDERAL PEOPLE HOPE TO FINALLY HAVE THEIR HIV PREVENTION NEEDS RECOGNIZED AND CONSEQUENTLY ADDRESSED. AN EXAMINATION AND POSSIBLE REDISTRIBUTION OF RESOURCES TO ADDRESS THE REAL AND DOCUMENTED NEEDS OF THESE AFFECTED AND INFECTED COMMUNITIES WOULD GO FAR IN ADDRESSING THE IMBALANCES EXPERIENCED BY LATINO GAY MEN AND LATINA LESBIANS. IN YEAR TWELVE OF THE EPIDEMIC, IT IS TIME THAT THE MONEY GO WHERE IT IS SUPPOSED TO GO. WE MUST ADDRESS THE RACISM AMD HOMOPHOBIA THAT EXIST WITHIN AND OUTSIDE THE COMMUNITIES OF COLOR. THE NEEDS OF THE LATINO/A GAY, LESBIAN, BISEXUAL AND TRANSGENDERAL COMMUNITIES ARE COMPLEX AND LIKE IN MANY COMMUNITIES OF COLOR, GO FAR BEYOND THE ISSUES OF THE EPIDEMIC.

THE NEEDS OF LATINO/AS BEGIN WITH THE DEVELOPMENT OF CAPACITY WITHIN OUR COMMUNITIES. THE EFFECTS OF HOMOPHOBIA, SEXISM, RACISM AND ECONOMIC DISENFRANCHISEMENT HAVE TAKEN THEIR TOLL UPON US, BOTH AS INDIVIDUALS AND AS A COMMUNITY. WE NEED RESOURCES TO BUILD INSTITUTIONS THAT AFFIRM OUR EXPERIENCES AND LIFE CHOICES. WE NEED HIV PREVENTION PROGRAMS THAT ARE DEVELOPED WITHIN OUR COMMUNITIES TO ADDRESS THE SOCIAL, CULTURAL AND LINGUISTIC NEEDS OF OUR COMMUNITIES. OUR COMMUNITIES ARE FILLED WITH ANCIANOS, JOVENES, NIÑOS, NIÑAS, HOMBRES Y MUJERES. WE NEED RESOURCES TO

PROVIDE COMPREHENSIVE HIV SERVICES TO EACH OF THESE GROUPS. WE NEED THE SUPPORT OF OUR BROTHERS AND SISTERS OF COLOR TO MAKE SURE THAT LATINA LESBIANS, LATINO GAY MEN, BISEXUAL AND TRANSGENDERALS ARE NOT LEFT OUT OF THE LOOP. REMEMBER THAT NONE OF US ARE FREE UNTIL ALL OF US ARE FREE. PLEASE JOIN US IN THE BATTLE AGAINST AIDS, RACISM AND HOMOPHOBIA.

I GIVE THANKS FOR LEADERSHIP, COURAGE AND ATTENTION.

Mr. TOWNS. At this time, I call on Christine Williams of the Black Veterans for Social Justice.

STATEMENT OF CHRISTINE M. WILLIAMS, HIV/AIDS COUNSELOR, BLACK VETERANS FOR SOCIAL JUSTICE, INC.

Ms. WILLIAMS. Good afternoon, Congressman. My name is Christine Williams. I represent Black Veterans for Social Justice in the war against HIV and AIDS.

In some of the areas that we service such as Bedford-Stuyvesant and Fort Greene, Crown Heights and East New York and Flatbush, as of 1993 in December, there were approximately 6,900 cases of people with AIDS. This is far too many people in one borough to have this disease. And as you might not know, it is rising rapidly and it is not—it is not—there is no end in sight. There is no cure or anything.

As of the year of 1995, it is estimated that if nothing is done about this and fast, our statistics will more than double. Black Veterans for Social Justice has a certain strategy to prevent the spread of this debilitating disease. Some of the units' goals are to fulfill—to fill the void in inconsistent, incomplete and inaccurate information, to reduce and eventually eliminate the transmission of HIV and to reach as many people as possible in the previous mentioned areas.

We do this by outreaching on street corners in these neighborhoods. This consists of distributing preventive information, referring people to get anonymous as well as confidentially tested at local hospitals and centers. We explain the importance of abstinence, but we also provide a choice by handing out condoms.

Our job does not stop there. We try to reach homeless veterans and veterans alone at project torch in a VA outreach program every Tuesday in Brooklyn. We go into the New York City shelters and try to reach homeless people with HIV and that are negative and are at risk.

We recently have just been accepted into the New York City correctional facilities to give presentations to inmates. We also operate as a referral center for anyone who is HIV positive in reference to receiving housing, medical treatment, free food and other services that they might be entitled to but may not be aware of.

We don't wait for HIV positive and people who are at risk to come to us. We go to them.

I am pleased to announce that our organization has received funding through Ryan White for case management and housing clients that we receive. Keep in mind this is still not enough. Our coordinator Charles Johnson is invited to Beijing, China to take part in the international symposium on HIV and AIDS in October 1994. But of course, there isn't enough money in our budget, so we have asked for donations to meet the trip's expenses.

Black Veterans for Social Justice is a small community-based organization and we are accomplishing a lot in the fight against AIDS. But this is still not enough.

What I don't understand, Congressman, is why is it so hard for community-based organizations such as ours to receive funding for HIV, preventive and supportive programs? We are the ones that are dealing with these people hand-to-hand, face-to-face every day.

We need to receive funding for substance abuse programs, which everyone knows that those two go hand in hand. We need funding for youth programs because there is also—they are also starting to lead in statistical data as those that are infected with HIV.

Before I end, I would also like to add what about the people that are already HIV infected? We need to concentrate with them more. Why is it that people that are HIV infected have to fall under certain criterias of having AIDS, which by that point there is nothing that can be done before they receive help from the government. I think the need for increase in funding as well as support is evident.

I would like to thank you, Congressman Towns, for the opportunity to present myself on behalf of my organization as a person that deals with these people hand-to-hand every day. I appreciate you recognizing this rapidly growing problem. And I will appreciate it more when some stronger actions have been taking place.

Mr. TOWNS. Thank you. Thank you very much for your testimony, Ms. Williams.

[The prepared statement of Ms. Williams follows:]

Statement of Testimony

To The Subcommittee on Human Resources
and

Intergovernment Relations
Committee on Government Operations

U.S. House of Representatives

On

The Prevention of HIV and AIDS Among People of Color

By:

Christine M. Williams
HIV/AIDS Counselor
Black Veterans For Social Justice, Inc.

The Prevention of HIV and AIDS Among People of Color

Good afternoon Congressman Towns and the other members of the Subcommittee on Human Resource and Intergovenment Relations, I am Christine Williams, the HIV/AIDS Counselor for the Black Veterans for Social Justice, Inc. On behalf of our organizations and the black veterans that we represent, I want to thank you for giving us this opportunity to present to before you today. The scheduling of this hearing is very timely. I know that we have received previous testimony on data relating to the high rate of AIDS among people of color. However, I want to provide you with some specific data on our target population residing in your district in Brooklyn, NY. These veterans and their family members are depending upon the HIV/AIDS Counselors to not only educate them but also to elevate some of the AIDS hysteria that is pandemic in our community, coming from the lack of support services.

Mr. TOWNS. The next person is one who has been involved in the forefront of so many issues, including this one, down through the years, and it is a privilege to have you come testify before this committee, Dr. Norma Goodwin.

STATEMENT OF NORMA J. GOODWIN, M.D., FOUNDER AND PRESIDENT, Health Watch INFORMATION AND PROMOTION SERVICE, INC.

Dr. GOODWIN. Thank you.

Good afternoon, Congressman Towns, and for the other members of the committee, I am Norma J. Goodwin, founder and president of Health Watch Information and Promotion Service.

Health Watch is a national nonprofit organization whose mission is improving the health and longevity of minority populations, and we do so in two ways: One, by providing the information and skills needed to make positive lifestyle choices and, second, by facilitating increased understanding and support for minority health issues, concerns and needs.

First, Congressman Towns, I need to thank you for sharing the concern about the devastating impact of HIV and AIDS on communities of color, which former New York State Senator Anna Jefferson of the National Association of Negro Business and Professional Women's Clubs and I expressed to you when we met with you earlier this year.

As you know, the purpose of that meeting was to request your assistance in facilitating the national association's conduct of a workshop on the prevention of HIV in conjunction with the Congressional Black Caucus weekend. And it was the level of your concern which led to the decision to conduct a congressional hearing. Both our organizations thank you again, as do many others.

I wish to briefly share with you and for the record several pertinent Health Watch experiences, findings and recommendations. One, our conduct of the youth AIDS prevention program or YAPP, as it is called, in five inner-city communities in four States, including the Bedford-Stuyvesant YAPP over a 5-year period with CDC funding. We had more than 52,000 teen contacts and were able during the last year of the YAPP to document the fundamental effectiveness of this multisession, multidimensional intervention.

While Health Watch continues its collaborative work with CDC, and we are providing technical assistance to organizations concerning HIV and STD prevention in communities of color, we no longer have funds to continue the YAPP, which was operated—and I would like all of us to focus on this. I have said, we documented its effectiveness and it was being operated in Bedford-Stuyvesant, Harlem, Newark, Philadelphia, and Baltimore. This is tragic when one considers the following. A, the disproportionate and rapidly increasing incidence of HIV and AIDS in high risk inner-city adolescents and young adults.

Second, the lessons we learned from the YAPP which cried out for adaptation and refinement of the intervention.

And third, the potential which existed for the intervention's replication in other communities after its refinement. In the interest of time, I won't say more about the YAPP, but a summary of it is attached to my testimony.

I do want to just indicate that you raised the question of someone else about how do we stop HIV in African-American youths; and if there is an opportunity, having had 52,000 teen contacts in the question and answer period, that I might give you my view of that.

The second Health Watch experience was the conduct of an 18-month statewide strategy development research project on HIV prevention in African-Americans for the New York State AIDS Institute. Our activities included the conduct of 48 focus groups or small group discussions, 92 indepth interviews, an all-day grassroots workshop and all-day leaders and experts workshop and some other activities.

We gained extensive insight from that tremendous amount of work that was done, and we were able to come up with strategies for action for each of the following groups: adolescents, gay and bisexual, adult and adolescent males, heterosexual males, lesbians, prisoners, current and former prisoners, substance abusers and women of childbearing age. We also developed strategies for the black church.

And I want to emphasize all of this related to HIV prevention, not care. While care, for people with HIV, in the full spectrum is key, our entire focus was on prevention. We also developed strategies for the black church, for other African-American leaders, strategies related to HIV counseling and testing and strategies for public communication for the African-American community.

I also want to mention that while our research focused on the African-American community, many of our findings have implications for other communities of color. The final report is to be released soon by the New York State AIDS Institute, but I have attached an executive summary of key findings from that research and strategies to this testimony.

For your information, Health Watch strongly recommends the adoption of the strategies recommended, and I would also recommend adoption of the strategies which come out in that final report and relate to all seven of those subgroups. I think we—although we learned much from this behavioral research project, probably the most important thing we learned was the extent to which much more behavioral research is essential to reversing the increased incidence of HIV in African-Americans, and as I said before, the implications for other communities of color and therefore the need for more behavioral research for all of those communities of color.

We don't have a cure today. HIV can be prevented by behavioral change. We must have more funding for communities of color to address how to modify behavior.

I want to mention one other thing. I want to stay on the research for one other moment to say the research, the behavioral research should be conducted by organizations of color who can—someone mentioned NIH earlier. The behavioral research needs to be conducted by organizations of color that can document their capability to conduct such research. And for those organizations and for other organizations of color that cannot—that don't have the research skills—and we all don't—they should be involved with the academic institutions that have the skills and the desired conduct and evaluation of that research.

So it is time, given the way the epidemic has gone, that more research and evaluation be done, but it be done by organizations of color or by their involvement with those who have the capacity.

Third and finally, I want to mention our improvisational adolescent theater company for Health Watch players, funded in the past by the New York City, New York State Health Department. It is an adolescent theater company which has had 12,000—more than 12,000 teen contacts and has documented the utility of theater and other creative art forms for reaching and influencing inner-city teenagers. I want to say not only do I think theater works very well with teenagers, but based on the extensive research which Health Watch was done, I believe that theater and other creative art forms would also work very well with adult populations in addition and not necessarily limited to African-Americans.

In spite of the fact that the Health Watch players are effective, we have lost our city health department funding and our State health department funding is in jeopardy to continue the Health Watch players. I want to just, in closing, mention a few elements which we consider we to effective HIV, and STD prevention work: One, the messages and approaches must be culturally appropriate which requires customization for various subgroups. We can't have one message for everybody.

Second, the intervening organizations and messengers must be credible with the targeted audiences, as well as culturally sensitive.

Third, the messages and approaches must be straightforward, repeated and reinforced and repeated and reinforced again.

Fourth, it is very interesting—I don't want to deviate, but Madison Avenue and the TV commercials that we see all the time do a great job of modifying behavior. But those messages are repeated and reinforced over and over again. They don't even consider a campaign message that doesn't run for 12 to 26 weeks.

Fourth, skills development for negotiation of risk-reduction experience is essential.

Fifth, support groups are needed by many individuals.

Finally, Health Watch's bottom-line recommendation is for significantly increased funding, specifically aimed at the prevention of HIV and STD in communities of color. Not only for their benefit, but for the benefit of society as a whole. Without such action, we are convinced at Health Watch that our Nation will pay dearly in many more unnecessarily lost lives, injured families and loved ones and avoidable financial cost.

I would like to leave you with the Health Watch motto: knowledge plus action equals power.

I thank you.

[The prepared statement of Dr. Goodwin follows:]

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Statement

to the

Subcommittee on Human Resources and Intergovernmental Relations
Committee on Governmental Operations
U.S. House of Representatives

on

THE PREVENTION OF HIV AND AIDS AMONG PEOPLE OF COLOR

by

Norma J. Goodwin, M.D.
Founder and President
HEALTH WATCH Information and Promotion Service, Inc.

Friday, September 16, 1994

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THE PREVENTION OF HIV AND AIDS AMONG PEOPLE OF COLOR

Good afternoon. Congressman Towns and other members of the Subcommittee on Human Resources and Intergovernmental Relations, I am Norma J. Goodwin, M.D., Founder and President of HEALTH WATCH Information and Promotion Service. HEALTH WATCH is a national 501(c)3 non-profit corporation which has as its sole mission improving the health and longevity of minority populations by: (1) providing the information and skills needed to make positive life style choices; and (2) facilitating increased understanding and support for minority health issues, concerns and needs.

Other pertinent positions which I hold include Clinical Associate Professor of Preventive Medicine and Community Health at the State University of New York - Health Science Center at Brooklyn and Program Director of HEALTH WATCH's Centers for Disease Control and Prevention (CDC)-funded Technical Assistance and Training (TAT) Program.

First of all, thank you Congressman Towns for sharing the concern about the devastating impact of HIV and AIDS on communities of color expressed to you by Senator Anna Jefferson of the National Association of Negro Business and Professional Women's Clubs and myself when we met with you earlier this year. While the purpose of that meeting was to request your assistance in facilitating the National Association's conduct of a workshop on the prevention of HIV in conjunction with the Congressional Black Caucus Weekend, the level of your concern led to the decision to conduct a Congressional Hearing. Both our organizations thank you again, as do many others.

I also thank you for the opportunity to appear before your subcommittee to share key HEALTH WATCH experiences, findings and recommendations. The following, in this context, are called to your attention:

1. Conduct of the Youth AIDS Prevention Program (YAPP) in 5 inner-city communities in 4 states, including the Bedford Stuyvesant YAPP, over a 5-year period with CDC funding. We had more than 52,000 teen contacts and were able, during the last year of the YAPP, to document the fundamental effectiveness of this multi-session, multi-dimensional intervention. It should be noted that while HEALTH WATCH continues its collaborative work with CDC aimed at the prevention of HIV and STD in communities of color, we no longer have funds to continue the YAPP, which was operated in Bedford Stuyvesant, Harlem, Newark, Philadelphia and Baltimore. This is tragic when one considers: (a) the disproportionate and rapidly increasing incidence of HIV and AIDS in high-risk, inner-city adolescents and young adults; (b) the lessons we learned from the YAPP, which cried out for adaptation and refinement of the intervention; and (c) the potential for the basic intervention's replication in other communities after its refinement.

   A summary of the YAPP which provides additional information is attached.

2. Conduct of an 18-month statewide strategy development research project on HIV prevention in African-Americans for the New York State AIDS Institute. Activities

included conduct of: (a) 48 focus groups; (b) 92 in-depth interviews; (c) an all-day Grassroots Workshop; (d) an all-day Leaders and Experts Workshop; (e) a comprehensive literature review; and (f) analysis of selected television commercials and magazine ads targeting African-Americans.

Extensive insight was gained, and strategies were developed for each of the following population sub-groups:

- adolescents,
- gay and bisexual adult and adolescent males,
- heterosexual males,
- lesbians,
- prisoners (current and former),
- Substance abusers, and
- women of childbearing age.

We also developed strategies related to "The Black Church" and other African-American leaders, HIV counseling and testing, and public communications. The Final Report which includes strategy tables for each of the above, is expected to be released by the New York State AIDS Institute in the near future. The Executive Summary, which includes the overall findings and recommended strategies is attached to this testimony.

Although we learned much from this behavioral research project, what we perhaps learned most of all was: (a) the extent to which much more behavioral research is essential to reversing the increasing incidence of HIV in African-Americans; (b) the implications of many of our findings for both other communities of color, and for other disadvantaged groups such as persons who are economically disadvantaged, women, gay and lesbian individuals and adolescents.

Members of this subcommittee, HEALTH WATCH strongly urges increased and earmarked funding for the conduct of behavioral research in minority populations related to HIV and STD prevention, with minority organizations conducting such research where they possess the capability, and with those and other minority organizations also collaborating with academic and other research organizations in the conduct of such research. I also recommend to the subcommittee the overall strategies in the attached Executive Summary, as well as those in the definitive report, to be released shortly.

3. Conduct of an improvisational adolescent theatre company. The HEALTH WATCH Players, with funding from the New York City and New York State Departments of Health. The HEALTH WATCH Players, through more than 12,000 teen contacts have documented the utility of theatre and other creative art forms for reaching and influencing inner-city teenagers. Further, based on HEALTH WATCH'S experience with the theatre company, coupled with findings from the aforementioned research, we are convinced that such approaches, if multi-session, can also be effective in modifying the knowledge,

attitudes and practices of many adult groups in communities of color.

In closing, let me highlight a few elements which we consider key to effective HIV and STD prevention work:

1. Messages and approaches must be culturally appropriate, which requires customization for various sub-groups;
2. Intervening organizations and messengers must be credible with the targeted audiences, as well as culturally sensitive;
3. Messages and approaches must be straight forward, repeated and reinforced;
4. Skills development for negotiation of risk reduction experience is essential; and
5. Support groups are needed by many individuals.

Finally, HEALTH WATCH's <u>bottom line</u> recommendation is for significantly increased funding specifically aimed at the prevention of HIV and STD in communities of color, not only for their benefit, but for the benefit of society as a whole. Without such action, we are convinced that our nation will pay dearly in many more unnecessarily lost lives, injured families and loved ones, and avoidable financial cost.

I would like to leave you with the HEALTH WATCH motto:

Knowledge + Action = POWER!

AIDS AND AFRICAN-AMERICANS:

IT'S TIME FOR ACTION!

A STRATEGY DEVELOPMENT RESEARCH PROJECT AIMED AT
"HIV PREVENTION AND RISK REDUCTION
FOR
AFRICAN-AMERICANS"

Conducted by Health Watch
INFORMATION AND PROMOTION SERVICE

Funded by the AIDS Institute, New York State Department of Health

September, 1993

AIDS AND AFRICAN-AMERICANS: IT'S TIME FOR ACTION

PROJECT OVERVIEW

PROJECT PURPOSE

HEALTH WATCH Information and Promotion Service, Inc. (HEALTH WATCH) is pleased to share the results of an 18-month research project, conducted March 1992 through September 1993, whose purpose was to develop a statewide strategy for HIV prevention and risk reduction among African-Americans (persons of African descent residing in New York State). To the best of our knowledge, this project represents the most comprehensive study in the United States to date of factors contributing to the disproportionate and increasing prevalence of HIV and AIDS in African-Americans, and of actions indicated to reverse this disturbing trend.

Funded by the AIDS Institute of the New York State Department of Health, the plan can be used in other states and localities, with appropriate adaptations. Throughout the report, HIV means the Human Immunodeficiency Virus, which is the infectious agent that has been identified as causing AIDS. AIDS means Acquired Immunodeficiency Syndrome, a disease resulting from severe impairment or damage to the body's immune system which protects humans against usual and unusual bodily infections, some cancers, and other serious diseases. The mortality rate from AIDS is high. According to the U.S. Centers for Disease Control and Prevention (CDC), as of September 1993, 60.2 percent of all persons known to have had AIDS have died since the disease was first defined in the United States in 1981

A strategy for HIV prevention and risk reduction for African-Americans in New York State was very much needed because the state's African-American population is disproportionately affected by the AIDS epidemic. For example, data from the New York State Department of Health indicates that as of June 1993, African-Americans made up 14 percent of the state's total population, but comprised 35 percent of the 60,570 persons in New York State with AIDS. Most African-American males contracted AIDS through intravenous drug use (51.1 percent) and homosexual or bisexual contact (33.6 percent). In females, intravenous drug use (62.5 percent) and heterosexual contact (21.8 percent) were the major methods of infection.

Overall project findings in the Final Report include a discussion of the uniqueness of the African-American experience; the context within which HIV/AIDS develops in African-Americans; the layers of discrimination which affect various at-risk African-American sub-groups; and the necessity for cultural appropriateness. Prevalent findings related to knowledge, attitudes, and beliefs; factors contributing to risky behavior; the influence of racism; and concerns about genocide are presented, as well as strategies to address them.

In addressing HIV prevention and risk reduction in New York State's African-American population, HEALTH WATCH's research design involved dividing that population, for study purposes, into the following seven sub-groups:

Adolescents
Gay and bisexual adult and adolescent males
Heterosexual men
Lesbians
Prisoners (current and former)
Substance abusers
Women of childbearing age

In reference to the above sub-groups, it is recognized that a given individual might fall into more than one of the above categories. Further, while not excluded from the study, older African-Americans were not specifically studied because the prevalence of AIDS in this group is relatively low.

The Final Report, in addition to addressing the seven population segments listed above, gives special attention to the role of "The Black Church" regarding HIV prevention and to the role of African-American leaders. For each of the seven population sub-groups, The Black Church, and African-American leaders, a strategy table suggesting overall and specific strategies and activities to increase HIV prevention and risk reduction behavior is presented. For each specific strategy, activities are suggested for governmental agencies, and for communities and organizations. The tables are included in the Final Report to facilitate adoption and implementation of the strategies.

The Final Report discusses the special needs of community organizations which must be addressed in order to maximize their effectiveness in fighting HIV and AIDS. Special considerations related to HIV counseling and testing in African-Americans are also addressed. Further recognizing that public communication is essential to health promotion and disease prevention, a section of the report is devoted to a comprehensive discussion of communication messages, messengers, and approaches which are likely to be effective. Perspectives and experiences of various governmental representatives in high prevalence areas are also summarized.

Although African-Americans were the focus of this research, HEALTH WATCH considers many project findings and recommendations pertinent to other racial and ethnic populations, given the fact that they share numerous experiences and perspectives in spite of their diversity. Similarly, many project findings and recommendations have relevance to economically disadvantaged non-minority populations. This is so because health status and practices are more closely correlated with economic status than with race or ethnicity.

The increasing threat of HIV and AIDS to the future health and well being of African-Americans has serious and multiple potential negative consequences, not only for this population, but for New York State, the epicenter of the AIDS epidemic and the nation as a whole. Given the scope and intensity of the research on which these strategies are based, their implementation should substantially decrease the spread of HIV/AIDS among African-Americans in New York State and thus, its devastating consequences, not only for those directly affected, but for all New Yorkers.

KEY PROJECT ACTIVITIES

Project activities included: (a) conduct of a comprehensive literature review; (b) conduct of 48 focus groups, including 24 baseline focus groups, and 10 pilot testing focus groups; (c) conduct of 92 in-depth interviews; (d) analysis of the content of 19 broadcast commercials and magazine advertisements targeted to African-Americans; (e) conduct of an all-day Grassroots Workshop; and (f) conduct of an all-day Leaders and Experts Workshop. These activities, performed in conducting the project, can be divided into four stages, namely: 1) conduct of the baseline research; 2) analysis and synthesis of baseline research findings and development of preliminary strategies; 3) testing and refining the preliminary strategies; and 4) development of the definitive or final strategies. Following is a brief description of each of these stages.

Stage 1 - Conduct of the Baseline Research

Stage 1 involved conduct of the following research activities:

- a comprehensive literature review;

- twenty-four baseline focus group discussions involving seven population sub-groups, numerous community-based organizations, and a group of church leaders;

- in-depth interviews of 92 researchers, representatives of community-based organizations, governmental representatives, African-American leaders, public health and behavioral specialists and other relevant experts; and

- analysis of 19 selected print advertisements and broadcast commercials targeting African-Americans.

Stage 2 - Analysis, Synthesis and Preliminary Strategy Development

Stage 2 of project activities involved HEALTH WATCH's analysis and synthesis of findings from the literature review, baseline focus groups, and in-depth interviews in order to develop preliminary strategies for HIV prevention and risk reduction among African-Americans.

Stage 3 - Testing and Refining Strategies

To obtain advice concerning the proposed strategies; ensure that the final strategies developed were considered acceptable and feasible by African-Americans; and obtain reactions to preliminary findings, two all-day workshops were conducted:

- a Grassroots Workshop which had 45 participants representing older adolescents, gay and bisexual men, heterosexual men, lesbians, parolees, substance abusers and women of childbearing age. Activities included the conduct of seven sub-group specific focus groups.

- a Leaders and Experts Workshop which had 40 participants, representing the following groups: elected officials, religious, civic, corporate and community leaders as well as public health, medical, and behavioral experts, and criminal justice and substance abuse specialists. Seven focus groups were conducted among participants during the workshop.

After the two workshops, the preliminary strategies were revised, and tested in:

- ten final pilot testing focus group discussions.

Stage 4 - Development of Final Strategies

The Final Report, which represents the culmination and centerpiece of the research, provides key findings as well as strategy tables for each of the seven previously mentioned population sub-groups, for The Black Church, and for African-American leadership. Findings and recommendations related to HIV counseling and testing, and public communication are also provided.

FINDINGS

- Although African-Americans know the two most common ways HIV is transmitted, (through participation in unprotected sex without use of a barrier method and sharing of needles and other materials while using intravenous drugs) knowledge of other modes of transmission is limited.
- While many African-Americans associate having AIDS with death and with being stigmatized, relatively few are aware of the wide range of physical, psychological, social and economic consequences often encountered by people.
- Even though African-Americans are aware that, theoretically, they can develop AIDS as a result of prior or current practices—and many have friends, relatives or acquaintances who are infected with HIV or have died of AIDS—they tend to disassociate this knowledge from a feeling of personal vulnerability.
- Although most African-Americans who are economically disadvantaged are aware that they may be engaging in practices which put them at risk of contracting HIV/AIDS, feelings of helplessness and hopelessness and low self-esteem prevent them from acting in their own best behalf. In other words, there is a very strong link between poverty and attitudes which contribute to the disproportionate prevalence of AIDS in African-Americans.
- Many African-Americans consider institutional racism to be a major contributing factor to the disproportionately high rate of HIV/AIDS in the African-American population, some also consider AIDS a form of genocide.
- Although many African-Americans state they would want to know if they were infected with HIV, most have not received HIV counseling and testing because, among other reasons given, they distrust government and fear they would lose family, social and/or community relationships if they were found to be infected and their HIV status became known.

- Most African-Americans feel that The Black Church can, and must, play a much greater role in preventing AIDS in their communities.

- Many African-Americans feel that African-American leaders and organizations should be much more active in trying to prevent AIDS in their communities.

STRATEGIES FOR ACTION

- Provide culturally appropriate information, messages and approaches, delivered by organizations and individuals which have credibility among African-Americans.

- Provide explicit information and education in non-threatening and familiar environments, using multi-media materials and approaches which have been designed according to educational level and other significant variables such as population and sub-group culture.

- Use peer educators and facilitators for intervention efforts at all levels, including those with African-American church leaders and other African-American leaders.

- Incorporate HIV related information and discussion in non-AIDS related health and other materials and packages for African-Americans in order to: (a) facilitate the removal of the stigma from HIV disease; and (b) promote the holistic approach to preventive health.

- Increase the active involvement of African-American leaders in HIV prevention efforts, with emphasis on the need for their increased financial support, increased community awareness of the severity of the problem, and increased community mobilization and action.

- Increase the active involvement of The Black Church in HIV prevention efforts, in spite of the challenges and complexities involved in achieving this.

- Target to African-Americans an intensive and ongoing culturally appropriate public communication effort.

- Develop and implement an approach to promoting and providing HIV counseling and testing for African-Americans which: (a) recognizes that many African-Americans distrust governmental agencies, and programs believed to be operated or sponsored by them; and (b) uses culturally sensitive messages, and culturally sensitive <u>and</u> credible individual and organizational messengers and providers of the service.

POSSIBLE USES FOR THE REPORT

The information gathered in conducting this research project, and the related strategies for action reported herein have many possible uses. **Although this project is aimed at HIV prevention and risk reduction among African-Americans living in New York State, most of the strategies are appropriate for or easily adaptable for other United States racial and ethnic populations, as well as for economically disadvantaged non-minority populations and for other states and localities.** This is so for several reasons:

- New York State's African-American population is heterogenous, incorporating a variety of income and sociodemographic groups, lifestyles, and ethnicities and state and countries of origin.

- The research covered a broad geographic area including 12 cities and counties in the state.

- A broad range of African-American sub-groups—including male and female adolescents, gay and bisexual men, low and middle-income heterosexual men, lesbians, male and female parolees, male and female substance abusers, women partners of injection drug users, and women of childbearing age of various African-American ethnicities and language groups—were studied.

- Health status and practices are more closely correlated with economic status than with race or ethnicity.

Some of the uses of the findings and related strategies for action follow.

- Governmental agencies as well as other public and private institutions and community organizations serving African-Americans can use information in this report to plan and develop programs that address the general HIV prevention related needs of African-Americans or those of one or more African-American sub-groups.

- HIV/AIDS and other health advocates, advocates for African-Americans, African-American leaders, and legislators can use the information and suggested strategies to formulate and ensure adoption of policies and laws that promote appropriate and culturally relevant HIV prevention strategies for African-American sub-groups.

- Governmental agencies, legislators and private foundations can use the information in this report to estimate needed funding and other resources for implementing certain strategies and/or programs, and ensure that the necessary resources are available.

- Broadcast and print media, health educators and other information specialists can use the public communication analysis in this report as a base to develop appropriate HIV prevention messages and public communication campaigns that will effectively motivate African-Americans to increase their HIV prevention and risk reduction behavior.

Finally, although the analysis for the Final Report was comprehensive, there exist a mass of information collected which, given the necessary resources, offers the opportunity or further analysis and reporting of project findings.

AIDS AND AFRICAN-AMERICANS: IT'S TIME FOR ACTION!

Norma J. Goodwin, M.D.
Founder and President

Health Watch
INFORMATION AND PROMOTION SERVICE

EVALUATION OF AN HIV PREVENTION PROGRAM FOR INNER-CITY ADOLESCENTS IN FIVE URBAN COMMUNITIES

Goodwin, Norma J., M.D., President and Carter, Anjean B., Senior Associate
HEALTH WATCH Information and Promotion Service

Objectives

HEALTH WATCH Information and Promotion Service, with CDC funding, conducted a six-year, multi-dimensional, Youth AIDS Prevention Program in Bedford Stuyvesant, Baltimore, Harlem, Newark and Philadelphia, totalling more than 50,000 teen contacts, which evolved into a standardized three-session intervention, each with specified objectives and curriculum content. Activities included discussion, video viewing, games, contests, role play and skits. The following evaluation objectives were established:

1. To initially and periodically assess the baseline knowledge, attitudes and practices of participating adolescents in order to customize and adapt the intervention.

2. To assess and document the impact of the intervention on teen knowledge, attitudes and projected HIV risk-related practices by comparing pre- and post-intervention results.

Methodology

HEALTH WATCH developed a questionnaire to gather participant demographic data as well as information about their knowledge, attitudes and projected practices. Regarding knowledge, the relative risk of various practices was included in the assessment, such as participation in vaginal versus anal sex.

The "pre-test" was administered at the beginning of the first session and an identical "post-test" at the end of the third session. During the developmental process, the instrument documented the distinct advantages of multiple over single-session interactions. Logistical, cost constraints and the difficulty of retaining the teenagers through multiple sessions were also considered in determining the number of sessions.

(Please turn over)

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The tests were administered orally by an older adolescent or adult to mitigate problems related to reading ability among the teens. During the sixth year of the program, the post-test was readministered to a sample of participants three and six months following the intervention to assess intervention impact over time.

Results

Based on 400 pre-test and 385 post-tests, with 85 percent of the teens participating in all three sessions, the results document the overall effectiveness of the intervention. The greatest effects were in increasing teen knowledge (19 percent increase). Although there was a substantial improvement (nearly a 11 percent increase) in teen HIV-related attitudes and beliefs, the scores were very suboptimal before and after the intervention (50 percent and 56 percent desired responses, respectively). Teens' understanding of the relative risk of various HIV-related practices and projected HIV-related practices improved slightly, by 5 percent and 4 percent, respectively (see attached table). Post-tests administered three and six months after the intervention were gratifying: overall, the increases were maintained in all categories and in some instances the scores had actually improved.

Key logistical and administrative problems encountered in conducting the evaluation were: (a) the program's inability to ensure that a given cohort of teenagers would participate in all three sessions in spite of an incentive component; and (b) difficulty in achieving test giver consistency in administering the test, including ensuring participant attentiveness throughout.

Conclusions

While the evaluation showed the best results for general knowledge, they document major areas of inadequate information or misinformation, especially regarding the relative risk of various practices. In addition, the HIV related attitudes and beliefs of inner city teens are very suboptimal, and require intensive and customized approaches to achieve change. Further, for a majority of these teens, delayed sexual activity is highly improbable, making it all the more necessary for intervention to focus on decision making, skill development to negotiate safer sex, esteem building and mutual support. Finally, the HEALTH WATCH experience documents the need for long term intervention studies with a structured evaluation component.

HEALTH WATCH Youth AIDS Prevention Program (YAPP)

SUMMARY OF PRE- AND POST-INTERVENTION RESULTS

AREA	PRE-TEST RESULTS	POST-TEST RESULTS	DIFFERENCE	
			AMOUNT	PERCENT
Knowledge	60.95	72.68	12.49	19.2
Risky behaviors	64.00	67.43	3.43	5.3
Personal beliefs	50.34	55.78	5.44	10.8
Future behaviors	56.45	58.91	2.46	4.4

Mr. TOWNS. Thank you very much.

Let me say to all of you that we certainly appreciate your coming and testifying before the committee.

Let me begin by, I guess, sort of following up on—with you, Ms. Williams, which I think was a very excellent question that you raised, why is it so difficult for community-based programs to get funds? I think that was the question.

I think that in the earlier statement that was made, and I think by Ms. Georges, I think the indicated fact that sometimes when we are not organized and to make the kind of noise that we should make, that sometimes things do not happen.

The other thing I think that—which Dr. Goodwin raised in her testimony, is that in terms of research, research is important and we should stress it. I mean, we know that it is important. We want it to move forward. But also, we cannot ignore the fact that prevention is also important, as well. And we know that prevention works.

Research, we are still trying to work on something. So I think that it is important that we sort of get that message across.

And it is not just on this area that it is happening. It is happening in other areas. So I think community-based organizations are either going to have to become much more vocal and get more involved in the process and begin to push those of us who are in government to begin to respond. Because I think you are right. I think that the community-based organizations can do a whole lot if they have the kind of support that they need.

I think it was mentioned by Ms. Hughes earlier, I think it was, that—about models. That if we have a model and it is there and it is just over there and nobody is doing anything about transferring that information to other locations, or then there is not too much that we will do in terms of our—too much information that we will gain from it. So I think that these are issues that really have to be sort of talked about and put out there.

And I give it to you in terms of cancer, you know. We know some basic things about cancer, that we know that diet has a lot to do with cancer in terms of people getting cancer. We know that. But very little of the total budget is spent in terms of education prevention, making people aware of the fact that if you eat properly, certain things will not happen. That is not, you know, it is not the kind of thing that people want to deal with. They want to deal with all the money in certain areas and research.

And I think the other question is that the powerful folks are involved in research and the not so powerful are involved in terms of community-based organizations. I think that is the bottom line. I can't say it I think any clearer. So I think somewhere along the line that our community-based organizations will have to get more involved and—in order to bring about this change.

So I think that was an excellent question and I am happy that you raised it. And I am certain that as my colleagues in the Congress will read the record, they will see in terms of that information that you were—brought forth. And I think that is very important.

The other thing that I think, Dr. Goodwin, I would like to get to you on, is you mentioned in terms of how to stop HIV in the African-American—among the African-American youth. I would like to hear more about that. And also, if you would just tell me what YAPP is all about.

Dr. GOODWIN. The YAPP means youth AIDS prevention program. Youth AIDS prevention program. That was the program that was funded by CDC for 5 years and, as I said, and attached to your testimony is even some evaluation result. The question came up how do we know these programs work?

We designed and tested a pre/post test so that we could tell—we look at four things—knowledge, understanding—these are teenagers—understanding of the relative risk of different practices, their attitudes and beliefs, and what they say they will do in the next 12-month period, which is important, attitudes and practices are more important than knowledge. But we look at all four.

And we did it as a pretest before the intervention. We did it as a post-test immediately after the intervention. And more in the past—in the last year, we also looked 3 months after the intervention and 6 months after the intervention to see if they had lost the benefit that they gained from the intervention. Because right at the end, people can remember a lot of things and their attitudes may be different.

But I think the real question is what happens 3 months from now? What happens 6 months from now and 1 year from now?

So there is some information about that attached to your testimony. Of course, we have a lot more.

On the issue of how to decrease HIV in African-American teenagers, one thing clearly is that more money has to be provided to refine, replicate and extend programs that can be shown to be effective. There is just something wrong if we know how to prevent HIV or to decrease its incidence and then we shift gears and then everybody stops funding it. This was in 5 inner-city communities and it should have been in 50, in my judgment.

Now, on—more specifically, what do we need to do? With inner-city adolescents and with minority populations, I think a major problem related to prevention is inadequate self-esteem. So—and you notice, I didn't say condom. So therefore, to me, the most important thing that can be done if we are serious about HIV prevention and violence prevention and teenage pregnancy and some other things is to first focus on building and increasing self-esteem. It is a major problem in our communities.

A second thing which relates to building self-esteem is to build the sense of culture and heritage and history of one's people so that one understands the relationship between what one is doing and the future of the race, the future of the culture. It is an important requirement. Again, I haven't mentioned the condom yet, which we should know this.

The third thing is to provide culturally sensitive education, and any intervention which is done with teenagers, in my judgment, must be multisession. Teenagers have—I think it is for adults, too, by the way—but teenagers have a short attention span. So there is no way in one—if anything that lasts more than an hour for teenagers, probably you have lost—you have lost your ability to communicate with them, anyway. And so therefore, if we are serious, we have to have interventions which are multisession so that one can spend enough time.

And they need to be nondidactic. We can't stand up in the front of rooms and talk down to teenagers, they must be multidimensional. They must involve them in small group discussions and circles and not standing up, talking down at them. And they must again repeat and reinforce messages.

We must provide skills, skills development, role playing needs to be done, so that they know how to negotiate, how to say no if they decide to say no. And if they decide that they want to engage in safer sex, how to negotiate a situation so as to be able to do so.

And finally—and this is not all inclusive but these are key points, they need support groups. If one thinks about all the messages out there that encourage unsafe sex and that glamorize sex and that focus on self and not others and not one's community or one's people, then we have got to have support groups for them so that they can have any chance of doing what is desirable in the face of all those negative messages and pressures, including negative environmental forces.

Mr. TOWNS. Let me thank you. And as I listen to you, you know, not being an accountant—and I thought about it. You know, if we did it, we probably would save money. If we put the resources there, and within 2, 3, 5 years down the road, I think that we would save a lot of dollars. And I know for a fact that we would save a lot of lives. That I know.

So let me sort of ask any—either one of you, sort of switch roles a minute and put you in the Congress. What would you do as a Member of the U.S. Congress? And I am asking for advice now from you, anybody, switch roles. Put me to the table and you sit up here.

Dr. GOODWIN. Yes. I will wait until someone else speaks.

Ms. SYKES. As a Member of Congress, I would, No. 1, introduce legislation that I think would help the AIDS situation, starting from prevention in the schools as related to education, related to care, health care. I would also, whatever issues come up that—bills that come up that your vote is wanted on, you might want to add to it, as I have watched on TV, CNN, to—an attachment of HIV and AIDS always in the forefront, always, all the time, in addition to the many issues that are there or that come up before the Congress. I would make it an important issue that is always on the table. And it needs to be, because it will save all of us.

I would not only present it from a standpoint of those who have AIDS but the fact that our children, our future, is important and that if we don't do something, then we are not going to have the kind of future, the kind of leadership that we need in this country because of the negative forces, HIV being one of the health issues that we need to consider.

Mr. TOWNS. Thank you.

Dr. Goodwin, you wanted to add something to that?

Dr. GOODWIN. Yes. I think it is—well, first of all, not only do we have a Congressional Black Caucus but a Hispanic or Latino Caucus. And I think we have to all be aware here that HIV and AIDS is increasing so very disproportionately in African-American and Latino populations, as compared to everybody else, that someone—

and I think it is our caucus. Those two caucuses together, I think, really need to look at the changing face, the changing color of the epidemic, the difference in prevalence in incidence figures and to really begin to organize themselves.

And I certainly know that there are other organizations in addition to Health Watch that are prepared to come and bring the information and the expertise to those caucuses so that they can come up with an agenda to see to it that both—I don't think all of the issue is reallocation. But some of it is reallocation and some of it is increased resources. And I just know that the argument can be made in a way to significantly increase the level of funding available for the kinds of things that we know will work for African-American and Latino communities. And I also want to include Asian-Pacific Islander and Native American communities that don't have caucuses, because those communities don't have as much—haven't had as much attention and support.

But for communities of color collectively, I think there needs to be a special agenda developed through those caucuses. And I know that their colleagues, among other national and regional minority organizations that would be glad to work with me, with Health Watch, to help make that an issue that you could take to the Congress. To you to you let me—yes.

Mr. ORNELAS. If I may add one thing; that if I was a Congressperson and there was an increased funding for HIV prevention, I would want to make sure that if—I meant HIV prevention, for resources to get to community-based organizations, that I think that needs to be very explicit. Because whether there is an increase in funding, the trickle down, it never trickles down. And I think the times when it has trickled down, we also need to ensure that if we want to have resources devoted to the African-American community, the resources need to go to an African-American rooted agency.

How we are in our mandate as national regional minority organizations, there is a restriction that in order for us to receive "minority money" our governing bodies or our boards of directors must be from the ethnic or racial population we are to serve, that is, if I am to receive dollars to provide services to African-Americans, my board, my staff must reflect the community it has targeted. And it grows across the board for ethnic populations.

What we tend to find is nonminority organizations receiving funding. And if we find ourselves in a situation—if we find ourselves in a situation where we are really talking about the totality of individuals, whether we be Latinos, whether we be African-Americans, whether we be gay Latinos or gay African-Americans, we are really talking about economic disenfranchisement and we truly need to create and sustain our institutions. Our institutions, whether they be the churches or whether they be the social service agencies, are the backbone of our communities and we need to invest in those communities and in those institutions for our survival.

Mr. TOWNS. Let me close by saying, this Member of Congress, I hear you. I think that you have given us a lot of information and I think that if we follow it that we probably will be much better off in days and months to come. We will need your help in terms of continuing to speak out on this issue. You can be assured that I will do so. I think that if we can convince others, then we can begin to move it in the right direction.

We have heard from the agencies today and, of course, they will also—those that left will probably read in terms of the statements that you made. And if not, we will definitely make certain they get it so they will know in terms of what you said.

I view this as being very serious. I think that we cannot do enough and we can't do it fast enough. People are dying every day, and I am certain that we can do a lot better than what we are doing. We just have to focus on it, commit ourselves.

But at the same time, I must admit that I am encouraged when I hear national organizations that have taken the time and the energy to evolve in terms of their organization, and I think that is very, very important. We just need now to get others to sort of come aboard and to make this a priority.

For too long that we have sort of ignored this. We have sort of put our heads in the sand or sort of closed our eyes and said that, you know, when we open our eyes, it will go away. But that is not going to happen. The only way that we can get it to go away is by addressing it and doing the kind of things that we know that need to be done, those of us that know it.

Now, I recognize that some people who don't learn as fast as others and won't come aboard as fast as others, but I think that we have to continue to work to get them aboard. As my son always says to me, he says, dad, sometimes it takes people 2½ hours to watch "60 Minutes." He said that doesn't mean they can't watch it. It just takes them a little longer. So we have to recognize that some people might not be where we are. It might take them a little longer to get to where we are. But I think we have to work to make certain that they do arrive. I think that all of us have that obligation, responsibility to do that.

So I would like to thank all the witnesses today for their testimony and to say to you that we will leave the record open for 10 days for any additional statements or comments that you feel that you would like to make. That goes for the witnesses or anybody else that would like to add.

This hearing is now adjourned.

[Whereupon, at 5 p.m., the subcommittee adjourned, to reconvene subject to the call of the Chair.]

APPENDIX

Material Submitted for the Hearing Record

TESTIMONY OF RONALD JOHNSON,
CITYWIDE COORDINATOR FOR AIDS POLICY
OFFICE OF THE MAYOR, CITY OF NEW YORK
BEFORE THE SUBCOMMITTEE ON
HUMAN RESOURCES AND INTERGOVERNMENTAL RELATIONS
OF THE
COMMITTEE ON GOVERNMENT RELATIONS

September 16, 1994
Rayburn House Office Building

AIDS AND HIV INFECTION IN THE AFRICAN AMERICAN COMMUNITY

Good afternoon. My name is Ronald S. Johnson and I serve as Citywide Coordinator for AIDS Policy in the Office of the Mayor of the City of New York. I also serve as Chair of the New York HIV Health and Human Services Planning Council, which is the planning mechanism mandated under Title I of the Ryan White CARE Act.

I would like to express my appreciation to Representative Edolphus Towns, Chairmen of the Subcommittee on Human Resources and Intergovernmental Relations of the Committee on Government Operations, the members of the Subcommittee, and the staff of the Subcommittee for organizing and conducting today's hearing, which focuses attention on AIDS and HIV infection in African American communities. I also appreciate the opportunity for me to present my own perspective on this issue. This hearing recognizes that AIDS and HIV infection have and are continuing to have a disproportionate impact on communities of color, and in particular, our African American communities. From Boston, New York City, Washington, D.C., Miami, Chicago, Kansas City, Oakland, and Los Angeles, AIDS and HIV infection are devastating our communities and disrupting and all too often destroying our neighborhoods and the lives of our people. I commend Rep. Towns and the subcommittee members for organizing this hearing and for showing your determination to face the challenges of the HIV/AIDS epidemic.

The overall topic of my testimony this afternoon is AIDS and HIV infection in African American communities. My particular focus will be the need for a government and community partnership in the fight against AIDS and HIV infection. More specifically, I would state that a functioning partnership between government and community is imperative to fighting the HIV/AIDS epidemic, especially given that AIDS disproportionally impacts communities of color. My views on the need for a functioning partnership between government and community are based on my current experience as a City government official and on my previous experience as the Executive Director of a community-based organization in New York City that primarily serves people and communities of color. The need for a government-community partnership is also based on the reality that the HIV/AIDS epidemic is still raging virtually out of control. The effect of the failure to control the epidemic is most evident, in my opinion, in the impact of the epidemic on communities of color, and in particular, African American communities. The control of AIDS and HIV infection in communities of color will only be achieved when the fight against AIDS involves a fully engaged community <u>and</u> a fully engaged government working in partnership with each other. Neither the government

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nor community groups and community-based organizations can effect control of the HIV/AIDS epidemic by themselves.

There are ample statistics and data that document the continuing growth and impact of AIDS and HIV infection in African American communities.

- As of December 31, 1993, there have been 355,936 adult AIDS cases reported in the United States by the Federal Centers for Disease Control and Prevention. The United States has more reported AIDS cases than any other single nation in the world.

- Of the total number of reported adult AIDS cases in the U.S., 112,002 are people of African descent. This represents 31.5% of the total adult cases.

- Black males make up 28.3% of the total number of reported adult male AIDS cases. Black females make up 53.7% of reported AIDS cases among adult females.

- Nationwide, 5,228 pediatric AIDS cases have been reported as of Dec. 31, 1993. More than half of the reported pediatric AIDS cases, 55%, children of African descént.

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- Black males make up 19% of reported AIDS cases among men who have sex with men. Black males make up nearly 50% of reported AIDS cases among male injecting drug users. Black males account for nearly one-third of the reported AIDS cases in which the risk factor is both homosexual activity and injecting drug use.

- Black females make up 57% of reported AIDS cases among female injecting drug users.

- Among reported adult AIDS cases in black men nationwide, 41.3% are men who have sex with men and 36.5% are injecting drug users.

- Among reported adult AIDS cases in black females, 52.3% are injecting drug users and 32% contracted AIDS through unprotected heterosexual activity.

- New York City continues to be the epicenter of the HIV/AIDS epidemic in the United States. As of July, 1994, the New York City Department of Health reported a cumulative total of 67,023 adult AIDS cases and 1,386 pediatric AIDS cases. New York City's AIDS cases represent 16% of the total adult cases in the United States and nearly one-fourth of the total pediatric AIDS cases in the country. New York City has more AIDS cases then the next three cities combined.

- As of July, 1994, there were 21,158 reported adults alive with AIDS in New York City. With the exception of Los Angeles, the number of adults alive with AIDS in New York City is greater than every other city's cumulative total of AIDS cases.

- People of color make up 70% of the cumulative adult AIDS cases reported in New York City. African Americans make up 39% of the total number of cases.

As a result of the Federal Centers for Disease Control's expanded case definition of AIDS, which went into effect on Jan. 1, 1993, there has been a dramatic increase in the number of reported AIDS cases. From December, 1992 to December, 1993, the cumulative total of adult AIDs cases increased 43% nationwide. There was a 126.5% increase in the number of new AIDS cases reported in 1993 compared to 1992. In New York City, the Department of Health projects 15,000-16,000 new AIDS cases in 1994. These numbers exceed most other cities cumulative total of AIDS cases. In the first seven months of this year, 7,920 new adult AIDS cases were reported. Of the number, well over 50% were as a result of the expanded case definition of AIDS.

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As the numbers of AIDS cases grows, the profile of the epidemic has also changed, at points dramatically.

- For the past few years, the most rapid rate of growth in reported AIDS cases is among adult women. Nationwide, between December, 1992 and December, 1993 the number of newly reported AIDs cases among females increased 167%, compared with a 120% increase among adult men. The proportion of cumulative reported AIDS cases accounted for by adult women is also increasing. In December, 1992, adult women made up 11% of total adult AIDS cases. One year later, adult women made up 12.5% of total adult AIDS cases. In New York City, adult women make up nearly 20% of the total adult AIDS cases. Between April and June of 1994, adult women made up 24% of newly reported adult AIDS cases in New York City. In both New York City and nationally, the majority of women with AIDS are women of African descent.

- The proportion of cumulative reported AIDS cases accounted for by gay and bisexual men is decreasing, as AIDS cases grows fastest among injecting drug users. In 1993, for the first time, injecting drug users made up a clear majority of new reported adult AIDS cases in New York City. Between 1992 and 1993, the total number of adult AIDS cases among injecting drug users increased by 52%, compared with a 36% increase in AIDS cases among gay and bisexual men.

- While still representing a small proportion of total cases, AIDS cases attributed to heterosexual transmission has increased rapidly, especially among African Americans and especially among women. Between 1992 and 1993, the total number of adult AIDS cases attributed to unprotected heterosexual activity increased 42.5%. African American men and women make up 51% of the total adult AIDs cases that are attributed to unprotected heterosexual activity. Keep in mind the continued myth, especially among African American males, that men cannot get become infected from having unprotected sex with a woman. Unprotected heterosexual contact is rapidly becoming a major risk factor for AIDS in the United States, especially among African Americans.

A more ominous indicator of the epidemic is posed by the number of people projected to be HIV infected. In New York City, the Department of Health estimates that 125,000 - 235,000 New Yorkers are already HIV infected, representing 3% of the population. A recent study projected that up to 8% of the adult population in Central Harlem between 18-64 years of age may already be HIV infected. The overwhelming majority of the people estimated to be HIV positive do not know their HIV status.

Without such knowledge, they may well be engaging in behaviors that are of high risk for the further transmission of the infection. As many as 5,000 New Yorkers are newly infected each year, 14 a day.

One of the hallmarks in the fight against AIDS and HIV infection has been the role of community-based organizations. Nearly all of the program models for the non-medical care and treatment of people living with and affected by AIDS were developed by volunteers and staff of community-based organizations, especially those within gay communities. Many times both the quality and level of medical care was influenced by the advocacy of community-based organizations, either organizationally or through the efforts of an individual Buddy or Crisis Intervention Worker who yelled and screamed until someone in the hospital emptied a bed pan or brought in a food tray that had been left on the floor outside of the room of a Person With AIDS. Long before many government officials would even whisper the word "AIDS", community-based organizations were on the frontlines providing needed care and comfort to People With AIDS.

Community groups and community-based AIDS services providers remain on the frontlines in providing needed services and advocacy for people living with or affected by AIDS and HIV infection. However, the ability of community-based groups and organizations to remain highly effective is being limited, at times sharply, by the changing nature and increasing complexity of the HIV/AIDS epidemic, primarily driven by substance abuse. The growing and changing epidemic is overwhelming the community-based fight against AIDS. This is especially true in communities of color. I will highlight a few factors that contribute to this situation.

First, community-based groups and organizations are finding it difficult, if not impossible, to cope with rising caseloads. The rate of increases in reported AIDS cases and HIV infection is outstripping the community's ability to respond. In addition, the numbers of people affected by AIDS or HIV infection, for example non-infected family members, close friends, lovers, and care partners, who need HIV-related services is also increasing at a rapid rate. As a result of the expanded case definition of AIDS, which went into effect on Jan. 1 of 1993, the number of reported new AIDS cases is increasing up to and beyond 100%. In New York City, we had been experiencing 6,000 - 7,000 reported new AIDS cases each year for the past 2-3 years. As I previously mentioned, our Department of Health projects reported new AIDS cases in 1994 to increase to 15,000 - 16,000 cases and to remain at that level for 2-3 years. In New York City and in other large metropolitan areas, an increasing percentage of the new reported AIDS cases are substance users and a majority of the new cases are African Americans. By themselves, community-based groups and organizations serving substance users and communities of color cannot keep up with this flood of new cases.

A second factor that is limiting the ability of communities to respond to AIDS and HIV infection is the increasing complexity of the increasing caseloads. We continue to see, especially in metropolitan areas, growing percentages of people who have special needs beyond their AIDS or HIV diagnosis or who have multiple problems that need to be addressed. We are seeing more low income people who have limited or no health insurance, more homeless people, more people who have past or current histories of alcoholism and substance abuse, including gay men who also have substance use as a risk factor, more mentally ill people, including mentally ill chemical abusers, and more people who are infected with both HIV and tuberculosis. We are seeing families that have two or more members who have AIDS or HIV infection or who have died as a result of HIV disease. We are seeing more "AIDS orphans" who have lost one or both parents as a result of HIV disease. By the year 2000, it is estimated that there will be 80,000 children and teenagers whose parents have died as a result of AIDS; 30,000 in New York City alone. The level and quality of services and care required by these individuals and families are very high. Again, by themselves, community-based groups and organizations cannot achieve and sustain such high levels and quality of services.

A third factor that I would highlight is the advances that have been made in the medical treatment and management of AIDS and HIV infection. This includes advances in the early intervention of HIV infection. Yes, we are still a long way from either a cure or a vaccine to prevent AIDS, as this year's international conference in Yokohama reminded us. However, significant, incremental advances in treatment have been made. These advances require a functioning health care delivery system to which people with AIDS and HIV infection have access. All too often, however, this requirement is not met in communities of color and low-income communities. Health care has been a crisis in African American communities long before the HIV/AIDS epidemic. AIDS has made a bad situation worse. African American communities are not going to create a functioning health care delivery system by themselves. There needs to be government involvement with the community to address the total health care needs of individuals and families. Resources must be specifically targeted to high need areas, many of which are African American communities. National health care, which is now struggling to survive in Congress, is only the first step. National health care reform will need to be refined by State and local governments if our communities are to realize real benefits in health care delivery.

In calling for a functioning partnership between government and the community in the fight against AIDS and HIV infection I am very mindful of the overall weak response of government to AIDS, especially to AIDS in communities of color. The Final Report of the National Commission on AIDS eloquently and painfully noted the overall failure of government at all levels to respond to this epidemic. The governmental response to the HIV/AIDS epidemic has been limited by racism, sexism, homophobia, and prejudicial attitudes towards substance users. While I am very proud of the efforts of the New York City government all of us need to do more. We need more cities providing the array of services and funding to community-based organizations that New York is struggling to provide. We need mayors who are knowledgeable about and who care about this epidemic. We need states to provide more assistance and to stop viewing AIDS as a local problem. We need a Federal government, led by the President and Congress to recognize AIDS and HIV infection as an international pandemic that is a national crisis here in the United States. We need a national plan of action. We need a strong Federal AIDS coordinator who has the authority to coordinate Federal resources. We need quick reauthorization of the Ryan White C.A.R.E. Act with authorized funding of $500 million in the first year. We need to increased Federal funding for prevention. We need a stronger and more diversified research effort.

Our people and our communities have paid the price of 13 years of virtual neglect from the national leadership that has trickled down to state and local governments. We cannot afford any further neglect. All levels of government must be involved rather than on the sidelines. African American elected officials, including legislators, must be engaged fully in providing leadership to and involvement in the fight against AIDS.

In calling for a full partnership between government and community in the fight against AIDS, I am also mindful that communities of color must strengthen their resolve and commitment to fight AIDS. We have to work harder to reduce the misinformation, fear, and denial that work to stigmatize people living with AIDS, which still occurs all too often in African American communities. We need to confront and change attitudes regarding sexuality, including homosexuality and bisexuality, and substance use. Some of the strongest resistance to making condoms widely available, including in public high schools, and to implementing needle exchange and other harm reduction programs for substance users, comes from within African American communities. We have to view sexual issues and substance abuse issues not from a conservative, moral stance but from a public health stance. We cannot let our moral views serve as a barrier to doing what is needed to fight and prevent AIDS.

The National Commission on AIDS, in its Final Report, stated that the clock is ticking. At this year's international AIDS conference, Dr. Peter Piot, president of the International AIDS Society, said that "AIDS will be an integral part of the human condition for a very long time." We still, however, have an opportunity to change the course of our response to AIDS. But time is running out. Our community-based organizations may well collapse without strong assistance and support from the three levels of government. Those of us who have AIDS or are HIV positive can live longer with AIDS and HIV infection. We can be productive and live our lives with dignity. HIV infection can be prevented with education and help in changing high risk behaviors. But it is not going to happen by itself or by either the community or government acting by itself. We need a working partnership.

As an "AIDS professional" and a person living with HIV infection, I often get asked as to how I keep going on. The real question being asked is how I avoid becoming overwhelmed with despair. My answer is simple and is based on my religious background. I am sustained by hope. Hope is the certainty that what you desire will be realized. We all desire an end to this plague. Hope is the certainty that there will be an end to AIDS. I know that I personally may not see the end of AIDS. But I know that my people and my community will see it. I am full of hope. I am hopeful that we will effect a genuine partnership between government and community. I am hopeful that this hearing will make a difference in helping to galvanize the needed Federal response. I am hopeful that we will conquer AIDS before AIDS conquers us. Thank you.

SERVICES, PREVENTION AND EDUCATION ARE ESSENTIAL FOR FAMILIES AND PRIMARY CAREGIVERS (PERSONAL TESTIMONY)

BY JACQUELINE R. MITCHELL

The rapid growing rate of HIV/AIDS has demished the quality of life for many families in the United States and the world. Well, in 1992 HIV moved into our home, through a 9 year old African American Doll.

In March of 1992, my 37 year old cousin of Central Islip, N.Y., died of an AIDS related illness. She had six children, ages 7, 9, 10, 19, 21, and 23. I guess she felt that the 19, 21, and 23 year olds were not quiet ready to care for the 7 and 9 year olds. My husband and I agreed to care for the 7 and 9 year olds. The 10 year old was placed in a home with a family friend. One month and a half after we agreed to cake for the two younger children my 37 year old cousin died.

I guess, because she had experienced the many ugly prejudices against persons with HIV/AIDS, she elected not to share with us that one of the children was HIV infected. I can really understand why she didn't share this information of HIV positive status. We enrolled the two children in school. Our 9 year old constantly ran temperatures. The children's maternal grandmother, who lives in New York, said the children just had their physicals and were very healthy kids. I figured that our baby was adjusting to the new environment. So, I gave her Tylenol the first time she ran the temperature. The second time which was about three days after she returned to school. We took her to the hospital emergency room. During the visit to the hospital, I shared with the doctor that our daughter's biological mother died with an AIDS-related illness.

The doctor tested our daughter and the test came back HIV positive. Our first nightmare began. We made many visits to the hospital clinics during the first six months to a year. We changed hospitals 3 times. At no time were we offered prevention information or education about HIV/AIDS. I wasn't even given reading materials at any of the three hospitals and was treated very inhuman. As a matter of fact, the doctor at Georgetown Hospital said she was going to die anyway, so he did not think it was fair that he and his colleague didn't get to do a study on our daughter. I gathered reading materials from various HIV/AIDS organizations. However, because of the many doctors appointments and the other stress, related task that accompanied taking care of a HIV infected child, plus caring for the family and working a job. I was unable to read most of the materials. Some of the materials that I gathered from many sources was conflicting and confusing. The message the media relayed was also sometimes conflicting, which was often frightening and confusing.

Therefore, I had no reliable knowledge and understanding of the disease. This posed a great handicap for the care of our HIV infected daughter as well as my family and me. We had no ideal what the signs and symptoms of HIV/AIDS or complaints that warned immediate medical care. For example, exposure to chickenpox, which could be deadly to an immune compromised person. Also, animals could carry germs or diseases that could cause additional health problems. Such as cats which can carry a bacteria agent that could cause a cat scratch disease, that could cause additional infection for immune compromised persons. Other liquids that contain blood, such as clear fluids from sores.

About two months later, out of fear and frustration, I got on the telephone and called the D.C. Health Commissioner's office. After, being transferred a few times, I talked to a wonderful person who recommended me to a class that would give me the knowledge and education that I needed to care for our family and infected child.

When I called the organization that the wonderful person referred me to, I was told that the class was full. After I called back to the person who referred me to the class. She called the organization, I was then given the opportunity to compete for the class. I was told that there were 30 slots and about 300 hundred persons had applied and I would need to be interviewed for a slot. During the interview it was explained that the class would have a lot of gay people. I was asked how I felt about gay people. Because I love people, regardless of what kind of people, my answer was I didn't have a problem with gay I should not have had to compete for prevention training and/or education as a caregiver of an HIV infected person.

Well, all of this happened in June or July or 1992. By the time the class started, I had just received a promotion on my job. In this position I was working with children and parents from low income housing developments. During my interview with my boss and another manager, I told them that I had been accepted for HIV/AIDS training classes that would be coming up in the near future. Both of them seemed very excited. I did not make them aware of my child's illness, because I was not comfortable with sharing that information. Besides, it was a job where my children were allow to join me.

Time came when class was going to begin. I was working extra time, which included my days off sometime. This was not because I was going to the class, but because I enjoyed what I was doing and I wanted to do a good job. During that time the class was being held, the space in which I was working was occupied and there was no assignment for me. I had enough leave for the class he said "no." I made several requests. This was at a time when this country was officially put on notice that HIV/AIDS was growing at a very rapid rate among our youth. It appeared that my boss simply didn't care about AIDS or young people. Besides, my problem was bigger than the youth on the job. I had a child that was HIV positive and I needed help. I was virtually ignorant about HIV/AIDS. This was a class that would enhance my knowledge and my ability to improve the quality of life for our daughter and family. As well as relieve my family and myself of some our fears. I practically begged my boss to grant me leave for the classes. Although I had not shared my daughters HIV status with him and I didn't feel comfortable doing so. He informed me that he was aware of my daughters illness but his answer was still no. I was really confused and hurt and I felt that my daughter as well as our family life depended on that class. So, I had a choice, to go to the class that I had to seek out and then compete to get into. Although I had plenty of leave and there was no assignment for me at that time, my boss fired me. He didn't realize the importance of me attending the class.

The gay community is the most wonderful and loving group of people that I have ever met. But I must admit that this was a true cultural shock for me. I am a person who feel that sex should stay in the bedroom. I would have never talked about sex publicly until after the experience with my daughter. Talking about the many different types of sex was very difficult for me. Herein person discuss their sexual preference was not what I was use to. The class was a great adjustment that indeed took a lot of praying and courage for me. But this was all the hope I had at this time. Many caregivers or family members may have not been able to withstand this adjustment. As a result of me attending that class I was able to obtain knowledge that has consequently improved the quality of life for our daughter. This training gave me the educational skills that are necessary to properly care for our daughter and family. I can now openly talk in detail to the family about the HIV/AIDS and the modes of transmission. I have become very comfortable talking about HIV/AIDS with anyone. It has enabled me to be an effective educator and peer counselor for my family and friends. Our daughter has gained 45 pounds because of my interactions with other PLWA's, and persons that were experienced and informed about the different treatments that was being used among persons in the PLWA community. This class meant so much to me, I believe without the classes, we would not have been able to enjoy our daughter health for as long as we have.

Another training class that I attended was 99% non minority and no HIV/AIDS primary caregivers were in the class. One person in the class said, they were going to try and get all of those children out public schools. Referring to HIV infected children. She was not aware that I had a child that was HIV positive. Therefore, a setting of this nature was not caregiver friendly. This class was also one that I had to compete to get into as well as pay $40.00. Along with many biases, predjuices and the cultural shocks that a caretaker will experience in the attempts to get education. We may some times loose our jobs as I have.

On the other hand services are very poor. I was hospitalized in August of 1994 for back surgery. I was only able to get respite care for 3 hours a day for two weeks. I had to fight to get the services for that short period of time. I requested a case manager. Well, I had to prove that I needed one. After making many telephone calls, our daughter still does not have a case manager who is productive. This disease is not only tragedy to the family. But there is a lot of punishment that comes to those on the front line trying to help, those we love.

Sometimes I think I am alone in this struggle, but as I speak to other persons across the nation I hear the same problems. We are not given the same financial assistance nor are we given the same social support as a family who give their children up to the government for care. We love our families very much but, the struggles are very hard. Loving and caring for people with HIV/AIDS is very punitive, for many family members and caregivers. Some people may have to stop caring and sharing because of the punishments.

We feel that programs for strong family centered care for the family members and caregivers are very necessary. Also, since it seems to be a problem of service delivery to HIV/AIDS persons and family members and caregivers, independent monitoring of the service providers could be helpful. We need monitors who are not attached to the agencies that are distributing the grants.

My experiences have demonstrated only a few reasons why education, prevention and service monitoring are absolutely necessary to ensure quality services for HIV/AIDS persons and their families. Universal service models are urgently needed.

Thanks for allowing me to share.

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ISBN 0-16-046750-0

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