

HIV/AIDS: The Disproportionate Impact on Women of Color in the U.S. January 10, 2005

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Celia Maxwell, M.D., FACP: Wonderful afternoon, and welcome. Welcome to this Congressional briefing today. My name is Dr. Celia Maxwell. I'm the assistant vice president of Health Sciences and the director of the Women's Health Institute at Howard University. I'm also an associate professor of medicine and infectious diseases, so this is a very timely topic.

I am here as a representative of the Society for Women's Health Research; I'm a board member. And I would like you to know, if you don't already know, that this Society is perhaps the only non-profit organization in this country whose sole mission is to improve the health of women, through research and education and advocacy. The Society also encourages the study of sex differences between men and women that affect the prevention, diagnosis and treatment of disease. amFAR, represented here by Judy Auerbach, who is the vice president of Public Policy and Program Development, the Foundation for AIDS Research, the Society, and Women's Policy, Inc. are delighted to have the opportunity to host this Congressional briefing on the disproportionate impact of HIV/AIDS on women of color in the United States.

As we all know, this is really a silent epidemic that's happening almost in our very midst, in front of our eyes, and we need to be able to take immediate action. Women of color,

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combined African-American women and Hispanic women, only represent about 24 to 25 percent of all the women in the country, yet they're disproportionately affected by this infection, to the tune of about 70 to 75 percent. Clearly, all women of color, and all women, are impacted or can be impacted by this disease. So we need to understand why this is happening. And we also need to break this vicious cycle.

We're pleased to announce that the Kaiser Family Foundation is web casting the briefing today, and it will be up on their web site, I think, by tomorrow at about three o'clock.

I would now like to turn the briefing over to Judy Auerbach, who will be our moderator for today. And enjoy your lunch. Thank you.

Judith D. Auerbach, Ph.D.: Thank you, Dr. Maxwell, or Celia. Since I know you, I can call you Celia. Welcome, again, to everyone, and we very much appreciate you taking time out of what in everybody's case is always a very busy day to join us for this very important Congressional briefing. On behalf of amFAR, I'd like to add my welcomes and my thanks, especially to our co-sponsoring organizations, Women's Policy, Inc. and the Society for Women's Health Research, and the many organizations you'll see listed in your program as co-sponsors and supporters of this activity.

amFAR, as you probably know, is a foundation dedicated to ending the AIDS epidemic by advancing AIDS research. We do

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that in three key ways: directly supporting research through grants and fellowships; making sure that the findings from that research and others is made available to all publics who need them. So education, translation, dissemination of research results is the second key effort. And thirdly, ensuring that the findings of research are also implemented. So we work a lot in the realm of public policy and making sure that research makes its way to the practitioners and to all publics that need to know about those findings.

We have a cross cutting initiative at amfAR called Women's Sexual Health and HIV. And that initiative has a number of components, one of which is the briefing and symposium series. And our support for this briefing today is part of that initiative, so we're very pleased to be here in that regard as well.

As you may have discovered in your packet, there are materials from all three key sponsoring organizations that will give you more information about what we're all and each doing with respect to addressing women and HIV, and women of color and HIV in particular. And outside the room, there are materials provided by all the co-sponsoring organizations who were able to bring them as well.

I'll be back to moderate in just a minute, so I'm going to take this moment to introduce Cindy Hall, who would like to say, "Welcome" on behalf of Women's Policy, Inc. Cindy Hall is

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the executive director of Women's Policy, Inc.

Cindy Hall: Thank you so much, Judy. And as most of you know, Women's Policy, Inc. is a non-partisan non-profit whose mission is to make sure that policy makers are well informed on key issues, obviously including this one. And we've been very active around HIV/AIDS in women since our founding 11 years ago.

And I just want to take one minute to thank also our partners in this effort, amFAR and the Society for Women's Health Research, as well as the many sponsors and supporting organizations, and also a word of thanks to the many Congressional caucus organizations that are represented as well. Their support, the Congressional Caucus for Women's Issues [inaudible] work on all of our Hill briefings, the Congressional Black Caucus, the Congressional Hispanic Caucus, the Congressional Hispanic Conference and the Congressional Asian-Pacific-American Caucus. So we are really pleased with the very strong support from so many Congressional members and their organizations.

And then, lastly, just a special thanks to the Kaiser Family Foundation for web casting this event, so that a much broader audience will be able to take advantage of this important information. And last but not least, a wonderful thank you to our wonderful speakers, who have come from quite a distance to be here today. So thank you so much.

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Judith D. Auerbach, Ph.D.: One thing we also wanted to mention, as you've already discovered, it's a little difficult to see the slides. We had to make a choice between lunch and excellent slide presentation vehicle. So we opted for lunch, and we hope you appreciate that. The room is a little bit constraining with regard to audio-visual capacities. So, to compensate, you either have or will have copies of all the slide presentations so you can follow along that way. But I think it's even better, because this forces everybody to actually listen to the presentations [laughter] rather than be concentrating on the text on the slides. So we'll have to go back to the old fashioned way of actually listening.

Without further ado, I'd like to begin to introduce our speakers. Of course I want to add my thanks to all of them as well for coming here to participate in this very important activity. We have a wonderful array of presenters. We're all talking very fast because we want to maximize their time. And what we're going to do is have each presentation made, and at the end of all we'll open up, with what time we have remaining, for questions and answers. And at that point, there is a microphone. We'd ask you to come and pose your questions there.

So, without further ado, I would like to introduce our first presenter, who is Dr. Lynn Paxton, who is the leader of the Antiretroviral Prophylaxis and Microbicides Team—if you

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know what that means, you can go home ... [Laughter]

Lynn Paxton, M.D., M.P.H.: You'll know. I'll tell you. [Laughter]

Judith D. Auerbach, Ph.D.: -in the division of HIV/AIDS prevention at the CDC, Centers for Disease Control and Prevention. And she is going to present an overview of the HIV epidemic among women and girls, to help set the stage.

Lynn Paxton, M.D., M.P.H.: Thanks a lot, Judy. Well, you know, I'm here from the CDC because you need somebody to stand up here and show people the numbers, to get them situation with regard to what we're talking about. But I just want to say two things. One, I'm actually in the epidemiology division. What I do—for those of you who've never heard of HIV chemoprophylaxis, let me tell you what it is. It's what we're trying to do, is look to see what—we're looking into innovative ways of trying to prevent HIV, including the use of antiretroviral drugs in people who are not infected, to see if we can prevent infection.

And so while my love is of biomedical means of prevention such as microbicides and possibly chemoprophylaxis, I'm going to talk to you today about really the epidemiology of the disease so you can get sort of a better flavor of how this disease is acting worldwide and in the United States. And I want to thank my colleagues at CDC in the surveillance branch and also epidemiology branch who furnished me with some of

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these slides. So, if you like the slides, then give me all credit. If you don't like them, it was my colleagues.

[Laughter]

Now, I'm just going to start off. I have 15 minutes to try and cover all of the HIV epidemic, so bear with me. I'm going to first start off globally and then bring it back to the United States, and just touch at the very, very end of my presentation, on some of the things that CDC is doing and some of the things that I feel might be next steps in HIV prevention. But I'm going to be dealing mostly with the epidemiology.

This actually projects a little better for you than it does for me. But this is to remind you that HIV, obviously, is a global disease. This is a slide that is as of the end of 2004. At the end of 2005, as you might expect, there are actually more infections. We are hovering at around—well, the estimates are that we are maybe at 42 million people who are infected with HIV worldwide. And to keep it in perspective, this is mainly a disease that's devastating sub-Saharan Africa, you know, with 25, 26 million people infected; South and Southeast Asia, about 7 million people infected; the former Soviet Republic and eastern Europe, about 1.4 million; and even in Latin America, 1.7 million. Here in the United States, you know, we have about 1 million people who are infected with HIV. So this is just to remind you that this is not just a disease

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that affects us. It's affecting the entire world.

And this is a slide that you might have seen before, but I always keep it in, because as we're sitting here eating lunch, there are literally hundreds of people who are getting infected with HIV. And they estimate there are about 14,000 new infections every single day. Most of these are occurring in low-income and low- and middle-income countries. Almost two thousand of these infections every day are in children under the age of 15, and about 12,000 are in young people—well, I'm still in my 40s so I still consider that young—and about 50 percent are women, and about 50 percent of the 15 to 24-year-olds. So I'm putting this in here to emphasize that, number one, every one of these data points I show you is a person, and that this is becoming increasingly a disease of women. It's becoming a woman's disease throughout the world. And I'll show you a little bit more about the United States.

This slide looks at, again, young women. This is the HIV prevalence among 15 to 24-year-old men and women in sub-Saharan Africa between 2001 and 2005. Actually, the incidence of HIV is lower in West Africa. So we're starting from Ghana. You can see that it's low, but it's much more prevalent in woman. And as you go across, you start to see astronomical HIV prevalence for that age group. Getting up toward Zimbabwe, we're heading up to near 20 percent of girls 15 to 24 being infected. And that has not only implications for the infected

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woman herself but for any children she might have, for her family, her husband. It's just devastating the amount of infection that is going on.

And if you look at how this is affecting even life expectancy, this graph here shows—this starts in 1950 and 1955, and it's basically showing in these countries here on this slope, which have got low HIV prevalence, as a good thing you're seeing that basically the estimated life expectancy is going up, which is exactly what we want. Now these other countries—Zimbabwe, South Africa, Botswana, where I do a lot of work—you see that before AIDS hit, life expectancy was high and getting higher, and then boom. It drops. And that's all because of HIV.

Now, to bring it back to the United States, this is sort of our graph. And as you can see, since the beginning of the HIV epidemic, around '80, '81, this is the incidence. Incidence means new infection. Prevalence means sort of ongoing, current infections. And these here are deaths. And as you can see, all of these lows—this is 1993, where there was a slight change in the definition. And then around this time was when we started to get antiretroviral drugs, AZT sort of being the first one coming on board, ddI and all that, and then, in 1996, when we got sort of the cocktail. And as we were happy to see, with the implementation of better drugs treatments we started to see a fall off in death, although it's

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now starting to level off. We saw somewhat of a fall off in incidence of AIDS. Again, let me specify. These are not new HIV infections. I'm sorry. What I meant to say: this is the incidence of actual AIDS. And so we started to see, with the implementation of better antiretroviral therapy, fewer AIDS cases and fewer deaths. And as a consequence, because people weren't dying, you're seeing more and more people living with HIV. So actually, the prevalence of HIV is becoming more and more. But it's not dropping. It's continuing to go up.

And this just shows you sort of what the epidemic looks like here in the United States. It is still MSM—men who have sex with men are still the largest category of people with AIDS in this country, although that has fallen from the very beginning of the epidemic. Nearing 70 percent of people who were affected were MSM, and that has been falling over the years. And at the very beginning of the epidemic, injection drug use accounted for a fair proportion and started to rise, and has been falling, actually, a little bit. Here is the big change: heterosexual contact, the people who are reporting that their risk factor for becoming HIV infected was heterosexual sex.

This is the racial breakdown of the epidemic. If you could say that at the beginning of the epidemic, the stereotypical patient was a gay white male, that's no longer the case. Whites as a group actually represent a smaller

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proportion of AIDS cases at this point in time than they ever have. And as you can see, blacks are—this is the crossing point. Blacks have gone over and they actually represent a larger proportion of people with AIDS, and Hispanics have also been rising as well.

So, all this is coming to say that basically the face of the AIDS epidemic in the United States has changed color and it's changed race. While, as I said, MSM still primarily account for the large proportion of HIV cases in the United States, the face of the AIDS epidemic is becoming increasingly darker, people of color, and increasingly more female. And so heterosexually black and Latino females are disproportionately impacted if you look at what portion of people they make up in the general population. And as I will show you some other slides, there's a geographic disparity, there are more cases in the south; adolescent females are at risk for HIV and STDs; and that there are many women with unidentified risk factors at initial HIV diagnosis. The number of women who report they don't know what their risk factor was is increasing. I'll show you in these slides. Even *Newsweek* jumped on the bandwagon. This is from the December issue in 2004 about the new face of AIDS, asking why is HIV praying on minority women and what can America do about it.

So, this shows you the general population is about 71 percent white and about 13 percent black and about 11 percent

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Latina. Now, when you look at female AIDS cases, that proportion almost flips, with about 67 percent black and about 16 percent white and Latina.

The transmission category, then and now: Back in 1985, about 53 percent of all women with AIDS reported that their risk factor was related to injection drug use. And now that has dropped down to 27 percent. And about 71 percent report that their risk factor is heterosexual sex.

So, the parts of the United States that are most affected by HIV: As you can see, where I'm coming from now, it's the south and it's the northeast, New York and this northeast corridor here, where the rates are over eight per 100,000 population. As you might expect, the Midwest has been less affected, and California and Nevada are a little bit more heavily affected [inaudible]. But basically, this is just to show that the south is very disproportionately affected by this.

And HIV amongst females in the south, when we look between 1999 and 2003, only about 29 percent of U.S. women reside in the south, but that's where we're getting 76 percent of our new HIV infection. And what's deeply troubling to me is that 13 to 19-year-old females are more frequently being diagnosed with HIV. So we're seeing rates of eight percent in the south versus only two percent in other areas. And this corresponds to a rate that's two to six times higher than any

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other region. And so part of this is probably related to, there are lots of socioeconomic challenges. This is also the area that's got the highest poverty rates in the United States, the most uninsured population and the fewest high school graduates.

And there have been surveys done about risk in adolescent females. And the Youth Risk Behavior Surveillance in 2003 showed that 45 percent of U.S. high school females had ever had sex, 35 percent were currently sexually active, and 11 percent—this is adolescence—had had more than four lifetime partners. And during roughly that same period, among HIV diagnoses among 13 to 19-year-olds, there were more females than males with newly reported diagnoses. And this just shows the graph, that up until you reach this age, 30 to 39, there are actually more infections among the girls than there are among men. This parallels what we see around other STD rates in the United States, that chlamydia, gonorrhea also is much more prevalent in the south.

So, I've got two seconds, and so I'm just going to run down the list. The CDC, obviously, is active, as are other organizations, in doing many prevention activities. And so some of the things that we're doing that are focusing on women and adolescent females are: comprehensive HIV/AIDS prevention activities with states and local health departments and community-based organizations; there are programs and

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interventions that are working on HIV testing, getting people to know their status; and then linking people to HIV care; addiction and mental health services; and exploring social networks and how those can be exploited to help reduce people's risk. And of course there's a large HIV testing social marketing campaign going on. There are a number of behavioral prevention interventions that have been shown to be effective, such as RAPP, SISTA, VOICES as well, and that we'll work on getting a lot more widely implemented.

What I'm involved in are these clinical trials of biomedical interventions, such as chemoprophylaxis that I talked about, and microbicides, a gel that could possibly be applied to prevent transmission. And then there are upcoming research and intervention activities such as looking at HIV and STD services for young women in rural Georgia, epidemiologic research in black and Latina women in the south and in Puerto Rico, and then there are economic empowerment interventions to reduce the HIV risk among impoverished women.

So the next steps are that we don't want to—even though this is becoming an increasingly female epidemic, men are still affected, and we want to engage male partners. We need to improve testing and risk factor ascertainment, examine what are the prevention needs and barriers in men as well as women, and explore the relationship between risk groups and female HIV rates. And we want to look particularly at men who are

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incarcerated and men who are on the down low, which is men who are engaged in sex with other men but are not necessarily up front about it and do not identify. They may go on to have sex with women as well. We want to enhance the primary HIV prevention for adolescent females and young women. We need to improve HIV education and testing in adolescence. And we need more behavioral assessments to characterize and intervene on risk. And we need to improve program and service integration. HIV and STD prevention and testing should be going hand in hand. We need to find out what are our missed opportunities for testing and preventing sexually transmitted disease and explore what are the local and national feasibility of better integration. And we need to improve our social services for mental health, addiction and poverty.

This is a quote from one of the U.S. Secretaries of Health, Education and Welfare, and he said, "Life is full of golden opportunities carefully disguised as irresolvable problems." We don't feel this is irresolvable. It just needs a concentrated effort on all of our parts. [Applause]

Judith D. Auerbach, Ph.D.: This is how you get to be moderator.

Thank you Lynn, Dr. Paxton, for that very good overview. She was rushing a bit at the end to get all the very important next steps in, I'm sure, but she introduced a number of themes that other speakers will pick up and speak about in a

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little bit more detail.

And so I'd like to now introduce our second speaker, who's Dr. Ada Adimora, who's associate professor of medicine at the School of Medicine and adjunct associate professor of epidemiology at the School of Public Health, both at the University of North Carolina, Chapel Hill. And she is going to discuss some of the biomedical and social factors that contribute to the disproportionate impact and rates of HIV infections, specifically among African-American women in the United States, particularly in the south. Dr. Adimora.

Adaora Adimora, M.D., M.P.H.: Good afternoon, everyone. Thank you for asking me to speak. I really appreciate this opportunity. A substantial part of my remarks will focus on the rural south because of the high infection rates among women in that region, and also because that's where much of my research was done. So I'm going to look first at the distribution of risk factors, and then at aspects of the socioeconomic environment and its contribution to both risk behaviors and also to the risk associated with given behaviors.

So we asked in our research group, "What are some of the factors that contribute to the high rates of heterosexually transmitted HIV infection among black people in the southern United States?" We were especially interested in the role of sexual network characteristics, because sexual networks are what transmit a sexually transmitted disease, including HIV,

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throughout the population. We were also interested in the role of treatable STDs, because they facilitate transmission of HIV infection.

So what we did was a population-based case-control study among black, heterosexual, non-injection drug using men and women in North Carolina to examine risk factors for heterosexually acquired HIV. And the cases were people with recently reported heterosexually transmitted HIV infection, and the controls were frequency matched to cases by gender and five year age group; they were from the general black population of North Carolina. And respondents were interviewed concerning sexual behavior and partnerships, drug use and other risk behaviors. And these slides are, I believe, in the packet.

So the cases, as it turned out, were more likely to have low education, to be poor, toward homelessness, and to express concern about having enough food for themselves and their family in the past month. And they were also more likely to report incarceration. Sorry for talking so fast, but I've got to get this in in 15 minutes. They were much more likely than controls to report behavioral risks, such as increased number of partners, use of crack, or a partner who used drugs. And they also had a much higher likelihood of ever having had a sexually transmitted disease. As you can see, these odds ratios are numbers that demonstrate the increased risk. Independent risk factors for HIV infection were having less

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than a high school education, increased partner number, crack use, having a partner who injected drugs and having a partner who smoked crack. So this is nothing really surprising. So most people had high-risk behaviors and/or high-risk sexual partners. But more than a quarter, 27 percent of the cases and 69 percent of the controls, denied high-risk sexual behaviors or high-risk partners.

And these people, whom we called lower risk partners—again, they were people who had HIV infection despite the absence of high-risk behavior or partners that they knew of—these people denied STD diagnosis in the past year, crack use, binge alcohol consumption, having an injection drug using partner, trading sex, a partner who smoked crack, or having a male partner who had sex with other men. Independent risk factors among this lower risk group for HIV infection were less than high school education, food insecurity—that is, saying that they had concerns about having enough food for themselves or their family in the past 30 days—and having a partner that was not monogamous with them during the course of their relationship, a partner who had concurrent partnerships, which we'll talk about in a moment.

So, what about the sexual network pattern? The one that we were interested in—this is just one, but also highlight this one—is concurrent partnerships. These are sexual relationships that overlap in time. They're important because

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they can spread an STD, including HIV, throughout a population much more rapidly than the same number of partnerships that are held sequentially. So this is a graphic representation of what they look like. Person A here is monogamous, whereas serial monogamy had sex with partner E, then F. Person B and person D start having sex with one person, G, then alternate, go to H, then come back to G, et cetera.

So, in separate studies of a national database, which is the National Survey of Family Growth, we saw that the five-year prevalence of concurrency among black women in the United States, 21 percent, was considerably higher than among the general U.S. female population, in which it was about 12 percent. But an important point was there were major ethnic groups and marital status. Black women were half as likely to be married, at 25 percent, as other ethnic groups. But also of note, there was little difference between the proportion of black women who had five or more partners during their lifetime, 32 percent, and the proportion of white women, 30 percent, who had done so. So it wasn't that actually black women had substantially greater numbers of partners; there's more concurrency.

When we used multi-variable analysis to control for various factors, the difference between black and white women and concurrency markedly decreased, as you can see from the fall on the odds ratio here, to about 1.3, the differences

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between black and white women and concurrency. What we controlled for was age at time of interview, age at first sexual intercourse and marital status. There really was very little difference.

Now, returning to our study in North Carolina, in that same population that I mentioned before we found that the five-year concurrency prevalence among women in the rural south was actually even higher, 31 percent, than the 21 percent observed among the black women in the national survey. Here it is. And it was even higher, 53 percent, among men. And this is in the general population in North Carolina. People who had concurrent partnerships were more likely to be single, who had been incarcerated, or to have a partner who had been incarcerated, and to believe that their partner had other partners during the course of their relationship. We found that concurrency was independently associated with being a man, and used an odds ratio of 3.7, with early age of first sexual intercourse, with being unmarried, which again is probably not that surprising, and with incarceration of any of the respondent's last three partners.

So what's the reason for the concurrency in this population? HIV is a behaviorally acquired infection, but is there something about the socioeconomic environment that increases the likelihood of engaging in high-risk behaviors and also that increases the risk of actually getting infected once

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the individual participates in these behaviors? We did focus groups among black men and women in this same rural region of North Carolina—the people were between the ages of 18 and 59—to try to address this question. And respondents reported extensive economic depression and racial discrimination that restricted educational and employment opportunities and other aspects of their lives. And here are some examples of their comments. “There are no jobs for anybody coming right out of high school.” That’s one person. Another said, “You can have all the schooling in the world, but if you’re black, you can’t get a good job.” A third said, “Most of the temporary agencies like to send the blacks to jobs in factories. Every job here is a dead end with terrible pay.”

Most said community race relations were poor, and described residential segregation. But they really focused their concerns on institutional racism, such as preferential hiring and job advancement of whites, blacks’ inability to get mortgages, and academic tracking of black youth in schools, so said a couple of people. One said, “A lot of things are divided racially. You have a white side of town, and the black side doesn’t usually mix. It’s sort of covert. We don’t have white folks walking around in robes or anything, but in the schools and things you can see it.” Another said, “It’s hard to get a loan to get a house. Banks just don’t give black people loans. You got to know somebody.”

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Some women noted gender inequality and women's perception, especially those who were poor or had lower educational attainment, that they're dependent on men. One person said, "To get to the next semi-urban city, if you don't have a job or a good education, you've got to depend on somebody to get you there. For young black women, it's not a good position to be in, without a good job or a good education." Another said, "The choices in men are very limited around here. I guess the women put up with the men they have because there aren't that many." As you can see from these remarks, they perceive a huge disparity in the ratio of available black men to women because of male attrition due to incarceration, drug addiction or death. One person said, "There's so many black men in prison, strung out on drugs or dead that if a decent black lady finds a decent black man, she's going to do whatever it takes to get him." I should think it was a man who said that. And another said, "It's not that many good men worth anything in this area." And another one just flat out stated, "The ratio of women to men is very high."

They described concurrency as widespread among unmarried men and indicated that the male shortage and the bad socioeconomic plight of both black women and black men profoundly affect partner selection and the types of male behavior women tolerate. Here's an example: "If they aren't

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planning on getting married, they're probably going to have relationships on the side." You can see the other two comments there. So we concluded that contextual features including racism, discrimination, limited employment opportunity and resultant economic and social inequity may promote sexual patterns that transmit HIV.

So a look now at the contextual features and sexual networks from the perspective of at least some social scientists. Focus group respondents actually were correct. The sex ration, which is commonly thought of as the ratio of men to women, is notoriously low among blacks in the United States because of increased black male mortality due to violence and disease, and is further lowered by the disproportionate incarceration of black men.

Sociologic research illuminates the pathways between contextual forces such as poverty, incarceration and segregation and some sexual network patterns. For example, the low sex ratio is one of sociologists' main explanations for decreased marriage rates among blacks, which we saw is an important factor in concurrency. And it may also increase bridging between low risk women and men from higher risk subpopulations. The other major reason for blacks' low marriage rates that many sociologists give, though not all, is poverty, which further decreases the pool of economically viable men and destabilizes marriages.

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Incarceration is also a major contextual factor. Young black men are ten times as likely to be incarcerated as white men. Incarceration directly affects sexual networks by physically removing people from partnerships. The partner entering prison may have sex while there with people whose likelihood of HIV and STDs is high. The partner who is left behind loses the social and other supports of the incarcerated partner and may seek other partners. And we saw, in that previous study, that women whose partners had been incarcerated were more likely to have concurrent partnerships. As inmates return to the community, they may resume old partnerships and/or start new ones, increasing the likelihood of concurrency. While people are in prison, they can join gangs and forge new long-term social connections or renew the long-term links with anti-social networks that can affect sexual networks by connecting previously lower risk people, like the girlfriend back home, with new high-risk subgroups. Incarceration reduces employment prospects, which increases poverty risk and destabilized long-term partnerships. High incarceration rates also affect the community, not just individuals, causing high unemployment rates and shrank not only the absolute number of men but also the proportion of financially viable men.

Looking at just one other feature, residential segregation by race, the prominent feature of racial

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discrimination in the U.S. that concentrates poverty and other negative influences within the segregated group. For example, youth in these neighborhoods, in segregated neighborhoods, are more likely to be exposed to drugs and therefore to use them. Many people choose sex partners from their neighborhood, so even if they don't use drugs themselves, they're much more likely to encounter a high-risk partner than they would be in the absence of segregation.

The major proximal causes of heterosexual HIV infection among African-Americans then are: a high prevalence of STDs, which I actually didn't talk a lot about, but they facilitate HIV transmission; sexual network patterns, an example of which is concurrency; and mixing among different subpopulations, such as crack smokers and non-crack smokers, et cetera. Distal determinants help shape behavior and the risk associated with behavior, and foremost among these distal determinants are poverty, inequality and discrimination.

So, what do to? Well, some examples are: We know that STDs facilitate HIV transmission; so one thing is to increase funding and enhance STD diagnosis and treatment. We know that STD rates rise when funding falls, so that's an important thing to remember. It is also estimated that about a quarter to a third of HIV positive individuals are unaware of their infection, so it's important to increase HIV diagnoses, but people have to have access to antiretrovirals and to medical

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care. People are not likely to tolerate receiving a bad diagnosis without access to treatment. There are considerable difficulties with lack of access to antiretrovirals. Medicaid and ADAP funding vary widely by state. It's important to increase state funding and liberalize Medicaid and ADAP eligibility.

Our youth also need comprehensive sex education, including information about condoms as well as abstinence. Now, most clinicians and public health practitioners—in fact, I would say essentially all—strongly recommend for very obvious reasons that adolescents completely abstain from sex. The problem is that popular American culture barrages them with messages that promote sexual activity. Record numbers of black and Latino youth are getting HIV, giving it to others, and many of these people are going to go on to die from it. The increased risk for STDs that black and Latino youth face is not due simply to increased sexual risk behavior. In fact, when risk behavior is controlled for in some studies, black and Latino adolescents are still at significantly increased risk of some STDs. Condoms really are critically important weapons in the war against HIV. Youth need to be given the full armamentarium of information to protect themselves.

These interventions, though, will not be enough to adequately address racial disparities in HIV infection rates, because structural inequalities underlie the problem. It's

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increasingly clear that a successful U.S. prevention campaign will also require structural changes and broadening of the public health paradigm beyond its usual individual level behavior approach to one that recognizes the influence of social context on disease in different populations. The fundamental question, I think, is: What are effective and feasible ways of addressing structural inequities to decrease rates of HIV and other diseases in minority populations? Who should come to the table to develop intervention? And because so much of the problem is economic and policy driven, I would say that perhaps economists, sociologists, criminal justice experts, politicians, in addition to public health experts and clinicians, should come.

What should be the nature of the intervention? Well, it's unclear, but we will probably need to give attention and involve educational and job opportunities, attention to incarceration and sentencing inequities, extended healthcare access as well as access to drug and mental health treatment. The usual response to this suggestion is to sort of shrug and say, "Well, we can't do anything. We can't change poverty and racism." As long as we continue to accept the status quo, we need to acknowledge that we're actually just accepting racial disparities and disease rates. Racial disparity and HIV rates in the United States is a major civil rights issue, and it is, in fact, a major human rights issue.

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I'd like to thank all the people who've helped with these studies, especially Vic Schoenbach, who's been a long-term collaborator and friend of mine at UNC School of Public Health, and all the other people you can see on the slide. And I thank you for listening. [Applause]

Judith D. Auerbach, Ph.D.: Thank you, Dr. Adimora. As you can see, all good infectious disease docs are really social scientists. And we're going to continue here. Sorry, my fingers aren't very good at this.

Picking up on some of these themes, our next presenter is Dr. Karina Walters, who is associate professor at the School of Social Work at the University of Washington in Seattle. And she is going to discuss the role of alcohol and other drug use and abuse in the HIV epidemic among women of color. Karina. [Applause]

Karina Walters, M.S.W., Ph.D.: [Speaks in Choctaw language before switching to English] My name is Karina Walters. I'm an enrolled member of the Choctaw Nation of Oklahoma, and I wanted to extend my acknowledgement to the traditional peoples of this land that we're on now today. And I also want to extend my thanks and gratitude for being invited to speak and share some information with you today. And finally I want to also acknowledge the Native women who are living with HIV and AIDS and who have been at the forefront; a number of women have been at the forefront of trying to educate

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our communities and other communities about this, especially Lisa Tiger, Carol O'Faver [ph] and others. So I'm looking forward to sharing with you some information today around substance abuse and HIV risk among women of color. But I'm going to focus primarily on American Indian and Alaska Native women, because I think the issues parallel other women of color issues. And it's a group, frankly, that are—we're invisible in terms of dealing with this issue. So I'd like to be able to increase that visibility today.

First, about women, drugs and sex. Yeah, I get to talk about the fun stuff. [Laughter] Okay. Substance use is a preventable behavior, yet it accounts for more deaths, illnesses and disabilities than any other preventable condition. And many of the behavioral health problems that we see for women, in particular around HIV, are directly connected to women's suppressed status and are associated with environmental and institutional barriers and inequities, as our previous presenters have already addressed. I'm going to talk a little bit more about some of those structural and historical inequities and how that currently affects native women's conditions today.

Women of color are also disproportionately—they suffer the negative social consequences of drug use and HIV-risk behaviors compared to other groups, in particular in terms of incredibly high rates of morbidity and mortality. And drug use

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and HIV prevention among women of color should be a primary focus to decrease race-based health disparities. So I'm going to have to do a little bit of American Indian/Alaska Native 101. [Laughter] I hate this. It takes up a little bit too much time, but I do need to talk about this.

Currently, there are about 4.1 million American Indians in the United States—we include those who identify primarily as American Indian and with another ethnic group—and about 2.9 million of you look at those who only identify as American Indian. But that's about approximately one to one and a half percent of the United States population. This is a critical point, because when you look at HIV data, we cannot wait until we have a significant proportion of AIDS cases. If we accounted for 40 percent of the AIDS cases, we're talking about one in four Native people who have AIDS. So we can't wait until we get up to those significant numbers. So we'll talk a little bit about that.

We're an incredibly diverse population. There are over 562 federally recognized tribes, over 200 state-recognized tribes, and well over 200 languages that are still spoken in the United States. I represent some of that diversity. I was born and raised in Los Angeles, California. I'm an urban Indian. Over 65 percent now live in urban environments. I was actually raised in Hollywood, so I guess you could say I'm a real Hollywood Indian. [Laughter] But also, we range in terms

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of how we phenotypically look and also in how much we engage in our cultural practices.

We are a young population. Thirty nine percent of our population is under the age of 20. We have lower high school graduation rates compared to non-Natives. We are more impoverished compared to non-Natives. And Native women make up about half of our population, with the majority being female-headed households and living in poverty. The mean age of Native women is almost 30 years old, and the life expectancy for Native women is less than Native men. I've already acknowledged that we live primarily in urban settings.

I'm going to have to speak quickly, which is not traditionally how we do things in our ways, but this is D.C., so I figure you guys can keep up with me. If I'm going to fast, just wave your hand and I'll slow it down. I've also had lots of coffee. [Laughter]

We also have the highest rates of most communicable disease than any other ethnic group, and I'll talk a little bit about that. And 27 percent of our population lacks health insurance coverage, which is the second highest compared to any other ethnic group. Our poverty rate is three times that of other ethnic racial groups. And as already has been highlighted, poverty is one of the major cofactors in the advance of the AIDS pandemic. Relative to rural Natives, actually our urban brothers and sisters are doing worse than

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our rural and reservation-based folks. And the reason is that we have, for example, higher infant mortality, primary mortality rates due to alcohol and injury, high or low birth weights. And the reason why we have poorer health in some of our urban centers is because most of our healthcare that's provided through Indian Health Service is not provided in urban centers. Less than two percent of Indian Health Service funding goes to urban locations. So a lot of folks wait until they get really sick before they try to go home and get assistance. So, this economic vulnerability makes women of color in general, Native women in particular, more vulnerable to poor health, poor diet, which then also can lead to weakening of the immune systems for those who are living with HIV, and hastens the progression to AIDS at a faster rate than others.

Now, as researchers, we've proposed various ways to understand this. How do we understand the link between drug use and HIV risk among women of color? And most of the research really hasn't done a great job of delineating the cultural factors that are part of that process, the social and cultural context that are part of that process. So we've developed a model that delineates social experiences and substance use and health behaviors to provide a coherent means of integrating social, psychological and cultural reasoning about discrimination and other forms of traumatic stressors as

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determinants of substance use and other health outcomes, in particular HIV risk behaviors. This is the model that we're using. I'm going to simplify it today.

Let's talk about the triangle of risk. Trauma and violence, and poverty behind that—we think about that as the backdrop—alcohol and drug use, and HIV sexual risk behaviors. If we walk away with anything today, think about the triangle of risk that women of color, especially Native women in particular, have to deal with.

So, let's talk about HIV/AIDS and Indian country. You saw the flat line on the slide earlier. Okay, I'm going to illustrate something about that in a minute. Okay. We actually have the second highest STI rates of any of the ethnic groups in the country. We have the second highest gonorrhea rate, chlamydia rate, syphilis rate. So, that means we are having unprotected sex. This not only signifies high-risk behavior but also vulnerability to the transmission of HIV, because women who are infected with an STI are two to five times more likely to become infected with HIV. So there's a little bit of background on that.

Now, here's a typical slide that you might see. If you look at our total numbers of American Indians that are currently infected with AIDS, we look like we're not in trouble. We're last on that slide. But if you look at us in proportion to our population, we are now third. And you never

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hear that in the media, do you? Right? So again, this is part of the institutional discrimination that Native people face, that we are rendered invisible in the data. You have to look at us in proportion to our population. As I told you earlier, if we do it in proportion to the number of AIDS cases, then we're talking about an incredibly devastating disease wiping out a quarter of our population, potentially. So we can't wait for those numbers, since we're so few.

But if you look at our cumulative growth in AIDS cases through 2003, we've had a dramatic growth. As a matter of fact, the number of cases has grown more rapidly than any other ethnic group, increasing almost 800 percent between 1990 and 1999. And General Satcher had noted that although we make up just under one percent of the population, there was an estimate that we may be accounting for as much as six percent of the newly diagnosed HIV cases. And looking at the prevalence data in our current research, we found prevalence ranging from two percent in a Pow Wow sample, which is not a representative sample, to six percent and 16 percent in respondent-driven sampling that we've done in New York City and nationwide. The 16 percent, by the way, is among primarily Native men who have sex with men. Okay? But the six percent was a community-based sample. It wasn't clinic based. It was a community-based sample in New York City, where we randomly selected people within people's networks, and that's the numbers we got. And

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we were very disturbed by that, actually.

In terms of Native women, unlike the injection drug use going down for other populations, for Native women it is still the primary factor in terms of exposure to HIV. Nearly 59 percent, if you include sex with an injection drug user, of the cases are related to injection drug use, where drug use is a major factor. In terms of looking at survival of Native women and men, we actually have low survival rates once we are diagnosed with AIDS, which is not inconsistent with women of color in general as well.

Now, let me just highlight a couple of the challenges to the HIV/AIDS surveillance data, which I think we've already noted. But one of the big issues is we really don't know, we don't have accurate numbers to the extent of this disease in our community. In part, that's because there are incredibly high amounts of underreporting and racial misclassification of Native people in the data. A review of 6500 records of community-based organizations of persons living with AIDS found that 70 percent of American Indian/Alaska Native clients were incorrectly classified as other races. That's a major factor. We don't have a national standard for reporting for American Indians Alaska Natives by state and local health departments. And a review of national studies of seroprevalence, HIV counseling and testing and national measures of risk behavior revealed that none categorized by American Indian/Alaska

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Native. And when we do get categorized, we are so few in number we get thrown into—poor Asian/Pacific Islanders—we get combined together and we're called "Other." So we really don't have a way of really understanding. So I actually think this is probably a serious underestimate of the extent of the disease in our community. If we look at something that gives us another idea about this, we can look at our linked serostudy in New York City, a voluntary testing which showed that the percentage of Natives testing positive over four years was comparable to that of African-Americans for this disease, may be more [inaudible]. Okay. Cool.

Alcohol and drug use. We have high rates of alcohol and drug use. You can read about that. [Laughter] The point about gender and drug use is that, the one piece I wanted to mention about that, is that although women progress as rapidly to AIDS as men, they have approximately half the viral load in their bloodstreams when they developed AIDS. So that suggests biological vulnerability there.

One piece I wanted to end with for the next few minutes is: How do we understand this high rate of alcohol use, HIV sexual risk, poverty as the background—how do we understand that? And one of the major discourses in our community is talking about the social and historical context in which these behaviors occur. Native people, as well as other women of color groups in this country, have endured tremendous

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historical challenges around racism, colonization and oppression. And our communities talk about that a lot in terms of historical trauma. And I just want to highlight something about that, because some of our preliminary HIV data shows that there is a relationship between intergenerational trauma and HIV sexual risk taking among Native people. But when I talk about historical trauma, it has to do with collective or cumulative events that target a particular group. And this trauma is transmitted over generations sometimes. There's been some research on the Nazi Holocaust literature to illustrate some of that phenomenon.

For Native people, I'm going to use as an example the boarding school period. And the reason why I'm talking about boarding school--no, I'm not talking about Andover or prep school. [Laughter] I actually had someone ask me that once. [Laughter] I'm talking about the systematic removal of Native children, starting in the 1880s, well into the '30s and still all the way up into the '70s, of Native children being removed from homes and placed into American Indian/Alaska Native boarding schools primarily run by missionaries. This was an attempt by the federal government to actually assimilate Native people and get them to not speak their languages any more and to become part of the mainstream culture. The reason why I'm raising boarding school as a critical period is because that is not long ago. We're talking about people's parents and

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grandparents and great-grandparents who have gone through this. One of the key elements of boarding school experience is it strips Native people—because they weren't parented—it stripped them of their traditional understandings about learning, about sexuality, sexual expression, gender identity, gender expression and all of those issues. The other reason is because they endured incredibly high rates of sexual abuse and sexual trauma in those schools. In some residential schools up in Canada, the rates are as high as 90 percent.

All right. So here's an example of the boarding school experience. This is a young Navajo man who arrived at Carlisle day one. This was him three months later. I'm not sure if they lightened that second picture up. This gives you an example of the militarism that the schools had for these children, dormitory living. Okay.

Part, also, of the historical trauma are different kinds of discrimination. Fisher and colleagues found that white men that had sex with both white and Alaska Native women were significantly less likely to use condoms with the Alaska Native women. So the role of partnering and interracial partnering is a major factor.

Contemporary discrimination is also a major factor. I don't have time to talk about it too much, but this is an example of the invisibility that Native people experience, because people carry stereotypes in their head. And this slide

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says, "Really? You don't look like an Indian," because he had Pocahontas in his head to this young girl. And we do know from their other research that among women of color, discrimination is related to different kinds of poor health outcomes. And our recent research coming out of Native Wellness Center shows that discrimination is related to drug use and sexual risk behaviors.

Violent assaults is another major factor here. The rate for Native women is almost 50 percent higher than that reported by African-American males, and that's according to the Department of Justice. Then we've got child abuse, sexual assault, lifetime trauma, cumulative historical trauma. These are major factors that we need to have in the backdrop for that triangle of risk.

Our recent studies basically show—and I'm cutting to the chase—that violence and sexual risk are connected; that people with histories primarily of child sexual assault in particular are at much greater risk for sexual risk behavior, and that drug use and alcohol use is quite often used to cope or deal with that. So in an example, you get into a sexual situation, you might use alcohol and drugs to calm yourself down to be able to initiate sexual activity. That puts you at greater risk for sexual HIV exposure.

And then finally, I just wanted to end with one of the pieces that we're looking at. Who are some of the most

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vulnerable groups? Of course, women who trade sex for shelter, housing, things like that, but also we looked at lesbian and bisexual women in another study we have in our community. And what we found is that Native lesbian and bisexual women have incredibly high rates of abuse compared to Native women in general, who already have high rates of abuse. But there are some subpopulations that we may need to pay attention to.

Finally, recommendations. Please improve the surveillance system. We need to be counted. That's a critical piece. [Applause] Thank you. We actually need to have a mandate to require national studies of seroprevalence, HIV counseling and testing, and national measures of risk behavior to categorize by American Indian/Alaska Native. I want to give it up for my Asian/Pacific Islander relatives as well. They also get left out of this conversation quite often. We need longitudinal research to examine the structural, social and cultural determinant of HIV risk behaviors among women of color, in particular, mechanisms that perpetuate race-based disparity.

And then finally, in terms of treatment and intervention, I think we need to develop culturally-based interventions that provide more holistic ways of integrating trauma, drug use and sexual risk behaviors, and most importantly, identifying culturally protective mechanisms by which we can develop those interventions. Issues of

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spirituality are critical to our community, and I know it is for woman of color in general. And we haven't really looked at the role of spirituality, the role of social support, and those factors that really play a role in buffering the impact of those traumatic stressors on HIV risk behavior. Not everybody who is exposed to trauma develops HIV risk behaviors, but we need to know who's doing well and why, and build interventions around the strength of our community.

And that's it. Thank you. [Applause]

Judith D. Auerbach, Ph.D.: Thank you, Dr. Walters. And we all apologize for having to hurry a little bit through these presentations. Everybody has much more they'd like to say than we've allowed time for, which is always the case.

Our next speaker will pick up again on some of the themes that I think we're seeing carried through all presentations. Dr. Cynthia Gomez, who is co-director of the Center for AIDS Prevention Studies and associate professor in the department of medicine at the University of California at San Francisco. And she's going to discuss some of the social and cultural barriers to HIV prevention, care and treatment services for women of color. Dr. Gomez.

Cynthia A. Gomez, Ph.D.: My height assistant. I wanted to be as tall as Karina, [laughter] so I thought I'd get ...

Good afternoon. Well, I want to thank the sponsors for

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this great invitation and the privilege to be here with you today to speak to you about a very, very important issue. As you've heard from my colleagues, HIV is a devastating disease in this country, and particularly for women of color. It has affected many women and their families. And although we have made much progress, there is still much more that is needed.

In the U.S., the patterns of HIV transmission are very similar to what Dr. Paxton showed you around the world now. That is, that women are becoming infected primarily through sex with male partners. And this is really something that was not true at the beginning of the epidemic here in the United States but is definitely true today.

Our focus on the needs of women has been slow in coming, from the beginning of the epidemic. In the first decade, we really only referred to women as vectors of disease. They were either drug addicts infecting their male partners, prostitutes infecting their johns, or mothers infecting their children. There was very little discussion about the women themselves and how it is that they had become infected to begin with.

Although no one really wants to be considered a victim, however, there are many ways in which women have been blind to their risk of HIV. They have not known that they were at risk for HIV, and therefore, ultimately, become victims of a disease that they did not think was one that pertained to them. Many

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of these women had no choice in the decisions that they've made, and you've heard some of my colleagues discuss some of that, and I'll say a little bit more about that in a moment. But it is certainly our responsibility as citizens of a great and resourceful nation to make sure that all women in the United States have the insight, the vision, and the resources to protect themselves against the dreadful and preventable disease.

Certainly, women who are living with HIV should have the best care and treatment our modern society can provide. After all, I believe that we agree that healthcare is a right and not a privilege. And so why is this straightforward, attainable goal, we ask ourselves, why is it not there? Why are women of color so disproportionately affected by HIV? Well, I will tell you for certain, race is not the cause. In black, in Latina, in Native, in Asian/Pacific Islander, those are not the causes for women becoming infected with HIV. Nor is being white protective of becoming infected with HIV. So we again ask ourselves, what is it. What is it that's going on?

Well, we are complex beings, and some of us are grateful for that. We're not robots; we're not cloned very easily. Yet. [Laughter] And therefore, in that complexity, there's complexity of solution. But there are solutions. There are many things that influence us and our health. A woman is constantly being impacted by that, constantly, from

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birth throughout her livelihood. And so if you hear one thing from me today, please understand that there is not a single solution. We are not going to hand you a tool kit and say, "We solved the problem. This is the solution. We have found it," because it's not going to be there. That is not how it's going [inaudible - off microphone].

The solutions really lie in small interventions that occur. They lie in broad systemic changes that we make that are constantly moving, as you can see. [Laughter] And we are constantly impacted by those changes. And so any solution we have today is not relevant tomorrow. And so if you're funding programs today for HIV prevention, do you think you're done? I mean, I'm sure your corporate marketing folks have explained this to you, about why they change commercials every week. It is no different in promoting behavior changes among individuals in this country, the need for rapid and constant change in our strategy.

And so, the solutions are in the small interventions and in the broad, systemic structural changes in our society. They lie in changes in the way we treat ourselves, in the way we treat each other, in the way we teach our children. These are all the ways in which we reach for solutions.

Now, I don't think I'm being idealistic. I really want to be optimistic, and I want to say to you that we can make major changes. And I also want you to understand that every

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single decision that policy makers are making here affects the health of America, and affects the lives and the livelihood of individuals. It will determine whether people live or die. And I just can't emphasize that more, because sometimes we don't recognize that every single decision we're making has that kind of an impact. And it really, really does. It really has that type of impact.

In the meantime, people living with HIV, practitioners, advocates, we continue to address as many factors as possible; factors that converge and create the "perfect storm" for HIV transmission; many, many different things that are just a list of them, but not a complete list, which is here. So let's discuss some of these clinical factors a little bit more.

Perceived vulnerability. So is it really possible, you ask, that women do not know that they're at risk for getting HIV. Is that really possible today, with 2006 already here? Is that really possible? Well, I assure you that all uninfected women in this room probably do know that they could get HIV. But I'm also probably certain that 90 percent of you would state that you don't think you're at risk for getting it. I'm not going to ask you. [Laughter] I'm going to say that I assume that. You don't see yourselves there. You don't see yourselves as the person. And this is typical around the country. Approximately 30 percent of women who become infected each year don't know how they got infected. They have no sense

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of risk.

And that proportion of women who don't know is increasing year after year. More and more women say, "I have no idea. I don't have a risky partner. I don't have a partner who injects drugs. I don't have a partner who has sex with men. I have no idea how I got it." We see this certainly, in asking in the middle of doing a large study of African-American and Latina women, "Why didn't you protect yourself last time you had sex?" And they'll say, "Well, he seemed like a nice guy, so I didn't worry that he would have diseases," or, "I knew he had a wife in Mexico so I figured he was careful." There's no logic to some of these quotes. Or, "He was well educated and we were in love, so I figured, why worry?"

Well, there are other vulnerable women, such as immigrants. Studies, such as those in China, where nine out of ten women in China really believe it's impossible for them to get HIV. Many of those women are migrating to the United States and have that same notion, that it's impossible for them to be infected with HIV. Eastern European women, which we are seeing a large number of them coming into the United States. They also perceive HIV as we did in the beginning - a drug user and gay men disease. It doesn't apply to them. And they're coming into this country, again with these notions. They're very problematic, these erroneous [inaudible - off microphone].

Helping women understand requires frank information

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about what's really going on. Unfortunately, we have to take a stance of guilty until proven innocent in this particular realm, with our sexual partners. And unfortunately I have to take that stance, and I apologize to the men in the room, because it really leads to mistrust. But what I would say to you is, I suggest the same thing for you with any new sexual partner, whether it be male or female - guilty until proven innocent. You must ascertain with your partners that you do not HIV [inaudible - off microphone]. And this is something that really is critical. We can no longer make assumptions, even if we're in love, even if they look fabulous, wonderful, and they're just so darned cute. [Laughter] How could it be possible?

So why are women so vulnerable? There are other very basic reasons why. And, quickly, physiology. And I will go through [inaudible - off microphone] a little more in depth. Lack of information and skills. Control over sexual relationships, violence, things we've heard about. Competing priorities. Cultural and gender expectations. Economics. We've touched upon this as well. And structural patterns. Again, we've touched upon it.

What is it about the physiology? Well, the female body. Now, we happen to be the internals rather than the externals. You know, that makes for more vulnerability in becoming infected with HIV, and that's a reality of who we are

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as women. Age. Very young women have underdeveloped cervixes, and this causes increases in transmission. So yes, we all want young women to delay the age by which they have sexual intercourse. We all want that. There's no one that is saying, "We want eight year olds to be having sex." We want to delay it as long as possible. There are physical reasons why that's true. So let's educate our young women about that. Let's give them the reasons, not just because we don't think you should. Right? I went through adolescence with my daughter. Even with the work I do, she didn't want to hear about it. She knew it all. She knew it all. "Don't tell me. I know how this works." Fine. But let me tell you some more details about how it works [laughter], so that you really get motivated. And they hear things like, "Your cervix hasn't grown up enough yet, and there's some other information. It's not because you're immature." [Clears throat] [Laughter] But you give them real reasons, and young women will find real motivation to actually delay. We need to continue to give them real information so they can make the decision you want them to make, even if they're making it for a different reason than we want them to make it.

Sexually transmitted diseases. Again, women have very high proportions to those, and many of them have no symptoms. And so unless women are offered testing like chlamydia, they may not have the symptom, and they may not know it's happening

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to them for a while, so very important to continue to get tested for STDs.

And sexual practices. Some women, young people in particular, might opt to have anal sex rather than vaginal intercourse as a way to prevent pregnancy, or simply because partners prefer that type of sex. And it is happening in larger and larger proportion in this country. More and more people are "admitting" to it. I ran a focus group with a group of men one day, and the one request from one man was convincing the women, because they were going to be the focus group in the afternoon, convincing women that anal sex was okay, because it was so pleasurable to the men. So you just have to understand what's going on out there, and then try to understand how to intervene [inaudible - off microphone].

Lack of information and skills. So I've been saying to you over and over again, "Knowledge is power." Knowing things is critical. This little cartoon, "Agnes, this AIDS business makes me think we should stop sharing needles." [Laughter] It's just the way in which people can misinterpret the information that you give them.

And along with this, in the United States we are dealing with language barriers and we're dealing with literacy issues. I'm sure you've heard this, but this was shocking to me. The National Assessment of Adult Literacy is starting to release their 2003 results. And I know many of you know this,

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but for those of you who don't, there's an astounding proportion of the U.S. population that cannot do much beyond basic literacy. I mean, they can sign their name and maybe understand a few words of what they're signing. Maybe.

Five percent of the adult population is considered non-literate in English. This includes adults who did poorly on the easiest questions, and four million adults who could not take the test because they didn't speak either English or Spanish. They actually had Spanish interviewers. These are people who cannot speak other languages. Fourteen percent were categorized as below basic. This means 30 million people in the United States can only do the simplest of literacy activities. And 63 million have basic literacy, where they can understand a simple pamphlet in order to go through jury duty.

So if you think about this, nearly 50 percent of the population in the United States can barely read a pamphlet, and some can't at all. Now, as somebody who is trying to educate the population, how do you present information that people can understand and make sense out of? This survey has included a health literacy. They haven't released those results yet, but they're releasing them in the spring. It's the first time it's ever been done. It's an attempt to see how many people would actually understand their pill label. Okay? Things like that. So I think it's very telling. I suggest you look out for those results, because it will tell us something about the enormity

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of what is needed, and a basic thing of what is needed. We're talking about basic literacy skills.

And many other issues. Sexual silence. Parents and couples need communication skills [inaudible - off microphone]. Most parents in the United States will tell you, "I want to teach my children, and I want to teach them well, particularly about sex education." And I talk to parents all the time who are asking for this. We have a program that we've done and developed, and we've had parents just knocking at the door constantly. "Please, please, I don't know how to do this well. Explain to me how to do this." Couples need to be able to tell each other what's going on sexually for them if they're going to have successful, monogamous relationships if that's what they want. And we don't have places to provide that. We don't have a social acceptance of that kind of conversation. We need to allow that. It is part of one's developmental life.

We talked about sex in terms of the context of violence. I can't overemphasize, as was already mentioned, the amount of childhood sexual abuse and sexual coercion, date rape, et cetera, that takes place and puts women at risk.

Competing priorities. Women have always put others before themselves. This is so true around HIV that women will do everything to protect their children, including perhaps doing things that will get them into trouble around HIV.

Culture. I could spend a whole day with you talking

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about culture and the influences of culture on sexuality. All cultures. I know all of you can tell me a culture story of your background that has to do about sex, about how we view sex, about how we talk about sex, about how we talk about illness, about how we talk about death. These all influence women's decision making on a daily basis.

Within that culture, issues of gender roles. Now, in my family, there was still very clear division of labor. Who did what, and where the girls were—they were girls, not women—was in the kitchen. And many of you come from cultures that have that kind of background, where you never, never question male authority. This certainly has quite a dynamic under the sheets.

Economics. Poverty again. You've heard it's a major, major source of why women are finding themselves in situations that will put them at risk for HIV.

And the structural patterns. Lack of access to healthcare or housing. Lack of educational attainment opportunities, economic policies like welfare reform policies, immigration policies and employment opportunities. These are all things that have solutions. These are all things that would result in enormous change of women's health, and particularly HIV.

And the stigma of this country against people living with HIV is something that I've not been able to understand as

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a human being. I don't understand why we think that people living with HIV have something that we should be stigmatizing them. And that's something that we have to take on just as human beings in this country.

Finally, very quickly, these are some of the strategies that are currently taking place. And while they've been very good and they have been very effective and they continue to be needed, I can't say more, though, that what we really need are some larger solutions. Condoms are one part of the solution. They're a very important part of the solution to keep the virus out of your body. But the needed changes are much more substantial, much more basic, much more about the decisions that you're making every day. We need improved education. We cannot have the illiteracy levels that we have in this country. Not only will it affect health, but it will affect our economic stability. We need good sex education. We need universal access to healthcare. We need to consider the fact that we don't let immigrants that have been here for less than five years have adequate healthcare. That has a huge impact. And we should be the opposite. We should be offering them more healthcare when they first get here, because moving to the United States is detrimental to your health. [Laughter] It is! No, you laugh, but we have research to show it.

So anyway, all of these other things, you have them in your sheets. Thank you very much. [Applause]

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Judith D. Auerbach, Ph.D.: Thank you, Dr. Gomez.

Sorry to hurry you, only because you started out speaking real slowly. You were trying really hard to do that, and it messed you up in the end. And I think, Karina, you're going to speak without slides, right? So we can just leave this up if you don't mind Cynthia's name behind you. It's probably prettier than something else we have there.

Okay. And our final presentation, to make this all very real and human, is Miss Karina Andrea Danvers, who is director of the Connecticut AIDS Education and Training Center at the Yale School of Nursing, and is a woman of color living with HIV. And she's going to discuss some of her personal and professional experiences and insights, which we hope will help all of us who have the opportunity to make some changes in addressing the epidemic get to it. So without further ado, Ms. Danvers. [Applause]

Karina Andrea Danvers, M.A.: [Speaks in Spanish before switching to English] Good afternoon. My name is Karina Danvers, and I thank you for this opportunity. My purpose here today is to bear witness to the suffering of people with HIV in the United States. I recall a beautiful New England fall day, when streets were dotted with school buses and children getting ready to start a new school year. I'm watching all of this activity from behind the windshield of my new toy, my 1994 Mitsubishi Eclipse. I'm wearing a blue pair of pants, size

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ten, a yellow sweater, and makeup.

I was on my way to do my first presentation as an HIV positive person. My best friend Sharla [ph] was meeting me at the school to provide support, and she's here today, 11 years later, providing the same support. My audience was a group of ninth graders: baggy pants, oversized shirts. They were curious but not really interested. I can't remember what I said or how I said it. I do remember getting to the end of my presentation. My audience now was looking at me with wide eyes, deafening silence and shock. I asked them if they had any questions. This little boy sitting in the first row with long curls and big brown eyes asked me, "How can you be so chubby and have AIDS?" From that question, I knew my presence had challenged at least one stereotype. [Laughter] I told him that most people with AIDS don't look like they have AIDS. But that was a good question this ninth grader asked. How come I could be so chubby and have AIDS? At size ten? [Laughter] What he was really asking was, "How can you have AIDS and look so healthy?"

And although at the time—and I did not have a very good answer to that question—11 years later, I do. Because I'm not poor. Because I have not only a good high school education but a graduate degree. Because I have good private medical insurance. Because I'm middle class. And although I'm a minority—I'm a Latina, not Hispanic—I'm bilingual, not

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monolingual. I'm a person living with AIDS, a person who has experienced nothing but good care and good access to medications.

But Maria, another HIV positive woman who I met while conducting research at Yale, would not likely be asked the same question by that ninth grader. When I met Maria, she was rail thin, dark chocolate skin, always fatigued, confused, and an exhausted wife and mother of two very active young children. Maria lived with her husband, her eighth grade sweetheart, who refused to practice safer sex; who refused to acknowledge that he had infected Maria; who refused to get help for his HIV; who wanted life to remain untouched by HIV. However, Maria's HIV infection was progressing rapidly, and denying was getting harder and harder to do.

Maria lived five miles from me. I don't know, as I tell you her story, whether she's alive or dead, for I lost contact with her. I can tell you this much, that stories like Maria are abundant in this country. And probably you will never get to see Maria in person, testifying in front of you. Instead, you will get someone like me, who can articulate my struggle and the struggle of others. Maria had access to the same HIV doctors I did; to the same HIV medications I did; to the same HIV services I did. But clearly, this wasn't enough. What was she missing?

She was missing what most of us in this room take for

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granted: the ability to read and write at a high school level; the knowledge that it is okay to question your medical providers; the right to know that your opinions, suggestions and self-diagnosis count; the knowledge that you count; the ability to understand what is being prescribed, why it's being prescribed and what to expect from this medical treatment. Medications are not enough to stay alive. We need support services like case managers, care educators, social workers, mental health providers, medication adherence counselors, support groups, educational forums, and people who can provide the knowledge that people like Maria are missing.

I was making another home visit to another participant in our research study. Tamika [ph] was not doing well. Her immune system was losing the battle, and the HIV virus was getting stronger and stronger every day. Her physician, a knowledgeable and well-seasoned provider, was at a loss. She lived by herself in a small apartment on the third floor of an old home, about four blocks from the methadone clinic and the Yale AIDS clinic. I would try to make my visits before she visited the methadone clinic, because methadone, as with many people, made her very sleepy. It is impossible to conduct a meaningful home or office visit when your client is nodding 80 percent of the time.

On my first visit to her home, a lovely little place, I discovered that she did not live alone. She lived with an

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orange tabby cat who did not appreciate visitors, especially during his naptime. In the middle of the dining room/living room/eat in kitchen, there was a clear glass bowl full of HIV medication. It caught my attention right away. I was speechless to see the salad bowl filled to the brim with various loose HIV medications. I asked her why the medications were in this bowl, all mixed. She told me that her doctor had told her that she needed to take all her medications by the end of the month, and that he wanted her to bring the empty bottles to him at her monthly visit.

I was panicking. So I asked her to show me how she took her meds. She walked over to the salad bowl, took a fistful of random medications and almost took them. I think at this point I screamed. Three hours later, and way behind my schedule, I left her home. By the time I left, she had put all the medications back into the bottles. We had created a schedule of how to take them. And then she made an emergency appointment to see her doctor the next morning. Please keep in mind that I was not there to do a medication adherence visit. I was there to conduct [inaudible] interview for a women's health research study.

But the battle and the support do not end when someone learns how to take their medications. Side effects of HIV medications are brutal, although things have gotten better. I have lived on and off with nausea for the past 16 years of my

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life, and I've had more bouts of diarrhea than you care to hear about. Headaches are constant in my life, and I've gotten so used to having a headache that when I don't, I feel like I'm missing something. I feel like my head is not attached to my body.

I have lost some of my freedom by being HIV positive. I can't travel to some countries. And when I do travel, whether it's to Washington, D.C., South Africa, or Russia to work, my backpack, instead of being full of exciting books to read, is full of medications; medications to possibly prevent or cure anything that might come up on a trip away from home. Even when planning our honeymoon, my husband and I chose a place not only for its beauty, but also because of its good medical care and attitude towards people with AIDS. My husband, who is in the audience, is not HIV positive. And yes, we do have sex, in case you were wondering [laughter], which underlines the point that if people are aware of safer sex practices, have the ability to talk to each other about it, and have access to people to help them learn about safer sex, exposure and infection can be prevented.

If your head's spinning, and I lost you a few minutes ago, I'm sorry. But AIDS is an overwhelming disease, because it's medically complicated, because it's emotionally complicated, because we have made it socially complicated. AIDS carries so much stigma and taboo - sex, drugs and personal

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behaviors. In our country, it's not good, talking about this thing.

Before Martin Luther King died in 1968, he was in the process of leading a multi-racial crusade against poverty. He called it the Poor People's Campaign, and he planned a march on this very city, a march which unfortunately took place without him. The reason why I recall this incident is because today, we're not asking for help on a brand new topic. We're not just realizing that poverty is the root of so many ills in society. Maybe HIV/AIDS is just new to it.

Dr. King said that true compassion is more than flinging a quarter to a beggar. We don't need just coins. We need for you to understand why the coins we're asking for are so important. We need to continue funding access to medication through the AIDS Drug Assistance Program. Medications do help. Medications do keep people alive. We need to continue funding support services, because swallowing these medications on my own, without support systems in place, does not work well. We need to continue funding for research, because HIV medications have been mostly tested on white men. Side effects and metabolic issues in women are unknown, and research is desperately needed in this area. We need to continue funding for prevention, because so far, the only cure for HIV/AIDS is prevention. [Applause] Thank you. Prevention is like fixing the levees in New Orleans before a hurricane - a lot cheaper, a

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lot less suffering, and a great way to save lives. We need your compassion, because HIV/AIDS is not a disease that brings out compassion, understanding and respect. It brings [inaudible], shame, stigma, and as one well-known man of the cloth has said many times, that AIDS is God's punishment to society and proof of society's moral decay.

I'm here to tell you that AIDS is not God's punishment. HIV is a virus, and AIDS is a medical diagnosis, just like cancer, diabetes, heart disease and any others. Community education and prevention programs were routinely denied funding at the beginning of this epidemic. When AIDS was first identified as the killer it is, the United States government did not respond quickly or with the appropriate resources. Imagine if we had responded then as we have responded to the threat of anthrax and the bird flu. Public awareness prevention campaigns did not exist for AIDS when it was crucially needed. In fact, 1988 was the first time the government published an eight-page pamphlet on HIV/AIDS prevention, although C. Everett Koop, the U.S. General at the time, had issued the Surgeon General's report on AIDS two years earlier, and the CDC had identified this new emergency six years earlier. The government was also slow in providing funding for research and treatment access. Why? Because HIV/AIDS affected and infected drug addicts and homosexuals, the socially undesirables. Twenty-five years later, HIV is

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still affecting and infecting people with drug addictions and people who engage in unprotected sex, which is all of us, I hope. And it is also affecting and infecting the Marias and the Tamikas who are not the social undesirables but the economically disadvantaged.

I do not need your help today. My guess is, if you know someone living with AIDS, they might not need the extra help I'm asking from you today. The Brads, the Trevors, the Madisons who are HIV positive may be okay, too. But Maria and Tamika need your support. HIV/AIDS could have been a terrible footnote, not a pandemic. And I would not be here in front of you today, dying of AIDS. Thank you. [Applause]

Judith D. Auerbach, Ph.D.: Thank you, Karina. We lucked out today. We have two Karinas - not too common.

We have a few minutes left for some questions, and I'd like to emphasize questions rather than comments if that's at all possible. So if you do have one, I would invite you to come to the microphone, identify yourself, direct your question to whomever you'd like, and be as succinct as is humanly possible. And we have about ten minutes for that.

Suki Terada Ports: I just would like to thank both Dr. Paxton and Dr. Walters for including Asians and Pacific Islanders in either your slide from the CDC and in your comments, because while you've asked for just questions—maybe I can turn this around into a question—but I don't know how many

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of the men here have played cowboys and others [laughter], or how many of you have gone out and had other for fast food. [Laughter] I think, as the other part of the other, I have to ensure that you don't leave today thinking that it's only black and Hispanic or Latina and Native Americans who are at risk for the behaviors that everybody else is at risk for, for getting HIV and AIDS; that Asians and Pacific Islanders, while there's a model minority myth, the cases in China and the cases in India would prove that poverty and all of the problems that you've mentioned here in this country are just as serious as the situation this morning, when I went to a Social Security booth at the Health Disparities and asked for a brochure in Japanese. And I was told, "Well, we have Chinese and Korean. Would you like those?" [Laughter] There's a disconnect with our knowledge about the variety of over 50 Asians and Pacific Islanders. So please don't leave today and don't accept a community report or anything which does not include Asians and Pacific Islanders, because our cases are climbing, and it's a very serious issue in our communities, too. [Applause]

Judith D. Auerbach, Ph.D.: Do you want to introduce yourself, Suki? Just say your name. I know you, but they don't all know you.

Suki Terada Ports: Suki Ports, the director of the Family Health Project in New York City.

Judith D. Auerbach, Ph.D.: Thank you. [Applause]

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Others? In fact, if any of the speakers have questions they'd like to post to anyone else, you're welcome to as well. I know this was an awfully dense briefing, a lot of information. It's a little overwhelming, and we ended on a rather emotional note, so I appreciate that. But does anybody else want to pose a question? Even a comment at this point.

You're doing this very well, Desiree. Good to see you. Nice to see you again. Oh, excellent. [Laughter]

Desiree Flores: Hi. My name is Desiree Flores, and I'm with the Ms. Foundation for Women in New York City. And we run a Women and AIDS Fund where we support groups at the grassroots level across the country that are led by and for HIV positive women [inaudible - off microphone] advocacy work. And our whole goal, actually, is to bring together this network of women all across the U.S. to really start to impact public policy at the national level around women and AIDS-specific issues. And so my question is—and I know this is a huge question for the amount of time we have left—but just any kind of thoughts you have or advice on how HIV positive, infected and affect women, could really start to not only articulate what the different needs and aspects of HIV [inaudible - off microphone] in their lives, but really get to the table the power, where you don't just have kind of one HIV positive woman in a room, but it's really those women leading the journey to public policy that really puts their needs at the forefront.

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So, again, a huge question, but I just would love to hear your thought on that.

Cynthia A. Gomez, Ph.D.: I think my rather brief response to that would really be to encourage more programs, such as the one, Desiree, that you're speaking of that Ms. has done, and I know that other private corporations are getting involved in creating opportunities for women and women of color to come together, and particularly for women living with HIV to come together, because there's amazing leadership among women in this country. And there's an amazing amount of emotional resource and thought resource in those groups. And I think that continuing to provide venues where women can start to create some real advocacy on behalf of women in this country is really the critical step towards that solution. I mean, again, as I spoke earlier, there are multiple places that the solutions lie, and so we want to make sure that all of those are being addressed simultaneously. But to keep the voices of women alive, we need a lot of support, both private and public funded.

Charlene Doria-Ortiz: My name is Charlene Doria-Ortiz. I'm the executive director for an agency in San Antonio called Center for Health Policy Development, founded as Chicano Health Policy, so our focus is on—we ran a project for the CDC called Latina Women at Risk for HIV Because of the Experiences of Their Male Incarcerated Partners. And it got truncated and

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only funded for about four and a half years as a training and technical assistance system. And it brought together to the table public health providers, Latino serving CBOs and women's groups and Latino HIV/AIDS providers. And everybody told us we would never be able to build coalitions between public health community based organizations and the criminal justice system. And we were able to do that, and then the funding stopped. And so it was recently interesting to me to see in the CDC thing it was their next steps by going, "Excuse me. Been there, done that. We've already done that." But nobody built upon that, because either you find two types of funding: one, it is for women who are incarcerated or males who are incarcerated. And yet, almost all of your research and profiles show that it's the unsuspecting woman who does not see herself at risk who is the one that's vulnerable.

So my question is: Where's the Department of Corrections? Where's the Department of Justice? And when is their funding stream going to be blended, along with the CDC that receive ursa [ph] funding stream in order to put an injection of funds into this to build the kind of collaborative efforts we need for not only women who are incarcerated, but because the rates for HIV/AIDS in incarcerated facilities is five times higher, and we all know that the incarceration facilities do not need affirmative action plans, because that's where you can find Latino males and African-American males.

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Hello. [Laughter] So when we know that, if we know that, discharge planning for not only—because you know prisoners get released at night. And you know that many of them are tested when they get into the facility, but very few policies about testing men when they get out. Hello. And so they may not even know their status. What are we doing for improving discharge planning and resources for the unsuspecting women, in particular women of color, and when are we going to bring the prison system and correctional help into the funding streams to provide training, technical assistance and the kind of programs for women who are vulnerable? [Applause]

Judith D. Auerbach, Ph.D.: Very excellent point. I think your question and comments and those preceding make the point that it's about bringing together individuals and groups and organizations and aspects that we haven't necessarily done well at in the past. I think there are a lot of efforts related to trying to bring in organizations and agencies that deal with prison populations. That may not yet be obvious but [inaudible - off microphone], and to link those to healthcare research organizations.

Celia? Dr. Maxwell, did you want to say something?

Celia Maxwell, M.D., FACP: You know, excellent presentations from all the panelists. But I think, in answer to one of the questions about what we do: well, there are a lot of women in here. This is 2006. You can make the difference.

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

It's called a vote. You make sure that you get people here that have your best interests at heart. That's the way it works. And that would be my strong recommendation [applause], that we all look to making sure that we put people that can understand our issues in positions that can make a difference in our community.

Judith D. Auerbach, Ph.D.: An excellent note on which to end a Congressional briefing. [Laughter] So, on behalf of the cosponsoring organizations, amfAR, the Society for Women's Health Research and Women's Policy, Inc., and all the numerous other cosponsors and supporters, I would like to thank you once again for coming to this briefing. Hopefully, we'll continue the discussion, we'll have follow-up meetings and briefings, particularly with Congressional staff. Please do pick up whatever information is left outside, and contact any of us with any follow-up questions or interests that you might have. And would you please join me once again in thanking all our excellent speakers one last time. Thank you. [Applause]

[END RECORDING]