

**Kaiser Family Foundation – Women and HIV/AIDS in the United States: Setting an Agenda for the Future
Morning Session
October 23, 2003**

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DIANE ROWLAND: Good morning. I'm very pleased to welcome you to the Barbara Jordan Conference Center of the Kaiser Family Foundation. I'm Diane Rowland, the Executive Vice President of the foundation, and we're very pleased that we could be hosting this meeting today here in the Barbara Jordan Conference Center because I think it would be a meeting that Barbara Jordan would be very proud to have in a facility named to her honor, and much of the work that the foundation engages in today around issues of low income populations - minority health, HIV/AIDS - all came from the strong leadership Barbara Jordan gave us when she was a member of our Board of Trustees. So, I think this is a very nice way to continue the inauguration of this new center in her honor, and this day I think is a very special day for all of us. It's a day that's been long in the planning, and I'm really glad to see it's coming together and happening because we wanted to discuss today and strategize on the growing problem of HIV/AIDS among women in the U.S. The foundation has a strong commitment to it's work in HIV, but it's also to it's work across a wide variety of issues. We really have at this meeting brought together the heart of the foundation's work, not just HIV/AIDS but women's health policy, minority health, and our growing focus on coverage of the low income population and the gaps in care and disparities that the most vulnerable among us face. And, I'm very pleased today that as I look out at the group

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that we have assembled here, that we've also gone beyond the typical groups that meet when we have a meeting on HIV/AIDS here to a broader spectrum because these issues face all of us and challenge all of us and having the women's groups and others with us today, I think, is a very important sign that we're going to be moving forward after today to make progress as a community, instead of as individual groups around individual issues, and this issue is one that I think really has lapsed the public awareness that we need about the growing problem and about the effects it has, and I'm pleased that today we're focusing on an issue that's a domestic AIDS issue, not just a global AIDS issue, because we have to remember that this epidemic is here at home and it strikes many among us in a very desperate way. So, today what we want to accomplish is to shine a spotlight on the problems that women face in the US and especially the growing AIDS epidemic among them, to help figure out how to raise public awareness around this issue, and also to strategize about what effective solutions could be to addressing this problem and how to make it more of a part of our public policies to date and public policy action. We're going to be webcasting the event today through the luncheon speaker, but then we're going to be leaving you to strategize without our webcast cameras watching, but anyone who wants to tune in later to see this morning's events can do so on the Kaiser network. We're also going to be really challenging you

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through a lot of our presentations and also through a film we're particularly proud to present that Rory Kennedy and her team have put together for us, and I know that we'll be seeing that as a way to kick-off this conference. But, right now I'm particularly pleased to be able to turn over the podium to the moderator of the day, Jackie Judd, who is with us a Senior Visiting Fellow for the Kaiser Family Foundation. After a very distinguished and a long career as a key correspondent for ABC News, and someone who brought us issues of health, of women's rights from the first day that she began reporting through her very last day when she was covering the Supreme Court as I recall, but I'm very pleased that Jackie will be guiding us through this discussion, bringing our discussion to a focus this afternoon, and without further ado, I welcome you all here and Jackie to the podium. Thank you.

JACKIE JUDD: Good morning everyone. It's nice to be on this side of the podium for a change. Thank you all for coming. When Jen Kates and Diane first mentioned this event to me, I instantly understood the need for it. I confused to them as I will to you this morning, that even though I was a healthcare reporter at ABC News, I haven't done, proposed, or been assigned the piece on AIDS for about two to three years, and the last piece I had done which was way back, I think, in 1999 or maybe 2000, had two people suffering from HIV/AIDS and they were both men. So, I understood the need immediately. I

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know that my experience is not an isolated one, and so that today, we hope to begin this process of putting this issue back on everyone's agenda. Let's get started. We have kind of a tight schedule. Some housekeeping matters - there will be two brief breaks, one at lunch and then one a couple of hours later. If you need to use the phone or the rest rooms, they're outside through these doors. Ladies, if there's a line like there always is at the ball park, we have another set of rest rooms up on the third floor. You just go out this door and make a left to the floor and up the stairs. There will be two panel discussions this morning - one on the role of the media, the other on - lay the groundwork for us to understand what we're all talking about today. We're honored to have Senator Edward Kennedy, who will be here for a lunchtime speech, and then in the second half of the day, we want to build on what's been said in the first half of the day, and as Diane said have a conversation about strategy and direction. We're so pleased that we have so many leaders in this room in the HIV/AIDS community, in the women's health community, and in minority health as well. You are all people who can make difference, who can help us shake some things up, and that is the ultimate goal of this event. We are going to start with something special - a documentary from Rory Kennedy and her partner Jed Rothstein (MISSPELLED?). They are some of the premiere young filmmakers in the country. They are focusing typically on social issues.

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Kaiser, in this case, sought Rory out because we realized that when those rare instances when HIV/AIDS and women were discussed in the media, we were often not hearing the voices of the women suffering from this, what their experiences are, what their unique challenges as women are. So, we wanted to premiere this here today because women obviously do need to be heard from. And, we hope that as we go through the day, that you remember the voices, the stories, the faces, that Rory and Jed are going to present to us today. So, I welcome Rory who is the co-founder Moxie Firecracker Films, what a great name, and her partner Jed Rothstein, the writer and director of Hidden Crisis: Women and AIDS in America. Please welcome Rory.

RORY KENNEDY: Thank you. Thank you all for coming this morning. I'm very honored to be premiering Hidden Crisis here today with the Henry Kaiser Foundation. I'd like to thank the Kaiser Foundation for hosting this event and there are number of people who worked very hard to organize it and I just want to recognize them briefly - Marge Hillary Blanton (MISSPELLED?), Diane Rowland, Jennifer Kates, Sonia Ruiz, Usha Ronji (MISSPELLED?), and Alina Salganicoff. I also want to thank the Kaiser Foundation for making this film possible. They brought so much to this project not just in terms of funding, which is obviously critically important for documentaries, but also in terms of vision and ideas and they were a great collaborating partner. So, I want to thank them so much. I

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would also like to add how grateful I am to Jed Rothstein who was the Director on the project as well as the writer. He did, I think, a really extraordinary job. He brings vision and talent and so much energy to every project he does and with this project there certainly was no exception. And, lastly, I would like to thank the women who were featured in Hidden Crisis - Patty, Stacey, and Tammy gave so much to this film and to me, they're really the heroes behind it. They let us into their lives to capture some very intimate moments. One of which we want to talk to you afterwards about, one particular moment that was very difficult, and I think that they agreed to do this project because they felt that their stories could help other people better understand the AIDS crisis and hopefully contribute to the fight against AIDS. I now just briefly want to tell you about how I came to make this film. A number of years ago I was asked to join a White House delegation under the Clinton administration to visit Africa and look at the AIDS crisis there, and what I saw there had a very profound impact on me. I saw so many people who were deeply affected by AIDS, particularly women. I saw villages decimated, families destroyed, communities disappeared, and it was really quite heart-wrenching to see. At that time, there was very little awareness about the AIDS epidemic in Africa or in other parts of the world, and so when I returned from that trip, I decided that I wanted to expand the project to look at the global AIDS

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crisis and I was able to partner with the Gates Foundation with HBO and make a five-part series called "Pandemic: Facing AIDS" which was broadcast this June on HBO. On that project, our partners were committed to looking at the international AIDS crisis. We examined AIDS in India, Thailand, Uganda, Brazil and Russia, but as I learned more about AIDS in the experience of making this film, it became very clear to me that what was happening over there across the borders was also happening here in our backyard and I became increasingly anxious to focus the camera back to the United States. So, that when the Kaiser Foundation approached me during the midst of filming that and asked me if I was interested in doing a film about women and AIDS here in the United States, I jumped at the opportunity, and was very pleased to be able to collaborate with them. Many of us here are familiar with the statistics that there are 40 million people who are HIV positive in the world today and half of those people are women, that here in the United States 30 percent of new infections are among women, and in the year 2000 among African American women, AIDS was the number one killer. I knew these numbers and what stuck with me from my experience in Africa and other places around the world were the individual people who I'd met, the stories. And, so, when we decided to make this film and move forward, we decided not to focus so much on the experts or on the statistics about AIDS, but really look at three people who living with AIDS to look at the

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personal stories, to try to humanize this issue for audiences to remind people that ultimately AIDS affects people and it does destroy families and that we need to, I think, be reminded of that as much as possible. In making this film, we saw extraordinary instances of hardship and suffering and pain, but we also saw great hope and we saw women who were living with AIDS and fighting against it's further spread in their own communities and families. We also saw what happens when governments and community activists come together to make AIDS a priority and decide to fight against it's further spread and we have really seen AIDS beaten. And, we both became convinced in making this film that if the resources were devoted to the task, if governments made this a priority, that we could in fact beat AIDS. I believe that we are in a unique historical moment where we are in the position to affect millions and millions of peoples' lives. We know how to stop the spread of AIDS. We know how to educate people. We know how to treat people who are HIV positive now, and extend their lives and that we are not doing absolutely everything possible is to me unacceptable. It is my hope that in watching "Hidden Crisis" people will realize that we can in fact beat AIDS. Each of the women in this film, have done just that in their own families and communities. They have fought against AIDS, and my hope is that this film along with all of the efforts of the people in this room of the Kaiser Foundation, the people who are living

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with HIV positive around the world and who are fighting against it's further spread, that together we will achieve our joint vision and that is a world without AIDS. Thank you very much.

HUMAN CRISIS VIDEO: (Unintelligible)

JACKIE JUDD: We have some time for questions from the audience, and just to get us started, Rory, two questions - what's happened to the women since they were interviewed? And, how did you make the decision to include that moment where Stacy finds out that she is HIV positive?

RORY KENNEDY: Well, obviously, one of the more difficult and dramatic experiences of living with HIV is finding out that you're HIV positive, and as filmmakers I think my experience and it's been that if you can show moments where people are particularly vulnerable and are in moments of transition that audiences tend to be able to identify with the people in the film more profoundly and more deeply and I think that we prefer audiences to really understand what it means to live with HIV or whatever the subject matter is that we're focusing on that it is important for the people who are filming to show some level of vulnerability and some openness so that audiences can open their own hearts to that experience. And, we were very lucky that Stacy had agreed to be filmed, we also after the moment when she found out that she was HIV positive which she clearly wasn't expecting, we did then say to her, she doesn't feel comfortable including that or if it was too

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difficult for her, if she didn't feel comfortable participating in the film at that point, we completely understood and we would be happy to take that moment out. And, that's generally our approach to filmmaking to - if you did film these moments that are particularly sensitive to offer the people who -

JACKIE JUDD: You gave them the choice?

RORY KENNEDY: Yeah, and I think that's important, and she really felt like she wanted to continue to participate in this project, and I let Jed answer the second one.

JED ROTHSTEIN: Yeah, just to second what Rory said, I think that all of the women in the film including Stacy really felt very strongly that this is the way that they can contribute to the fight against HIV and AIDS, and I don't think any of them decided to participate lightly, but they felt very empowered by allowing us to share their stories with everyone. Your second question is what happened to the women. Stacy right now is, as far as I know, is still doing well. I'm still in touch with the Street Beat people and she seems to be like we said in the film, raising her children and doing well. Betty had a couple of bouts of illness, but is also overcame them and is doing well and is still working helping other women in Mississippi, and she's really a tremendous deacon for especially some of the women from real rural areas who she helps arrange transportation of one and two hours sometimes to get to the clinic where she works and she's really an

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incredible resource for women in her community. And, Tammy sadly passed away last May from complications related to her pretty long illness. So, that's where it stands.

JACKIE JUDD: Okay, other questions in the audience?

There are mikes on each table and there will be traveling mikes through the days around the edges of the room. Yes?

FEMALE SPEAKER: I'd like to know how where the cities chosen and how were the people chosen? Was it call for "Do you want to be in a film" or something? How was it done?

JED ROTHSTEIN: Well, we wanted to have a balance. We wanted to represent - we worked with everyone at Kaiser especially to learn about where the issues presented themselves, and to try to give a balanced presentation of rural versus urban areas, a different range of people from different backgrounds, and also to find ideally programs or place where there was some type of hopeful program that was helping people. I think the Street Beat program in Brooklyn that they do really incredible work. I went out with them several nights. They drive their mobile clinic around the streets and reach a population of people who are underserved. Similarly, in Betty's case, her clinic is in an area that is also underserved and they really work to address some of the particular challenges that people with HIV or people who are in populations impacted by HIV in rural areas face, and then in terms of Tammy - we wanted to - Tammy was probably chosen less for where she was

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than for the fact that we felt that it was important to show people in different stages of dealing with HIV and also to show that one of the biggest challenges that women face is what to do with their children and how to address the needs of her family perhaps after their gone, and Tammy had been through a lot when I spoke to her, and she had a fairly difficult time as a mother even aside from her experience with HIV, but I thought it would be - her story would be inspiring because she really placed the concerns of her family first and foremost, and it affected the way that she chose to cope with her illness, and so, those were some of the reasons we chose the three women.

FEMALE SPEAKER: Just as a follow-up Jed, a couple of the women talked about the stigma still attached to AIDS, HIV/AIDS, so, how many women did you approach before you finally found the three who agreed to do this on camera?

JED ROTHSTEIN: Many, many women. Sadly, there is the stigma is still one of the biggest problems I think that faces people with HIV, and in making "Pandemic" traveling around the world, I think that Rory and I also saw this same problem is tremendously debilitating certainly Betty spoke to this issue when she was first diagnosed. Nobody even conceived that an African American women in Hattiesburg, Mississippi would have AIDS and people were afraid to be in the same room with her, and I think she's helped and other people in her community have helped lessen that stigma, but it's still something that really

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prevents people from speaking openly about their condition and certainly, it's what made it difficult for people to want to participate in the film. So, we really had to find tremendous - these three women who I think are tremendously courageous in deciding to share their stories despite the fact that this stigma still exists, despite that fact that even in a place like New York which has dealt with HIV for as long anywhere in America certainly, there's still the stigma there. For Stacy to have the courage to share her story, especially when this is something that she had clearly been dealing with at all in her life. I think it attests to the power and the strength of the women that we did end up with.

JACKIE JUDD: Any more questions from the audience? Yes?

FEMALE SPEAKER: (Unintelligible)

RORY KENNEDY: Sure, and even though I don't know if Kaiser wants to speak to that as well, but for this particular project we were targeting this audience. We really wanted to focus on policy makers and I think here today there are a lot of women's groups. It's not just age groups because we want to reach out to that community to let people know that this is an issue that affects women. The history of AIDS in this country is such that people have the perception that it's really a male disease and the fact of the matter is is that AIDS has really moved to more urban areas to poor more marginalized groups of people that AIDS has not gone away, and that's one of the more,

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I think, more significant messages of this film that we can't ignore AIDS, and I think if we've learned any lessons over the last 20 years is that when you do ignore AIDS, it flourishes. It breeds on that type of ignorance and awareness, education, fighting issues around stigma, have an enormous impact on decreasing the number of people who are HIV positive, and I think we've also learned that over and over again we need to reeducate populations and different populations as AIDS affects different people in different ways. So, I hope that answers your question. I don't know Marsha if you want to add anything.

MALE SPEAKER: I'm heartstruck by how dramatically those stories were told. I think it was really excellently done in that regard. It does speak to two perceptions that I think are present in a lot of communities where many of us in the audience work. One is the perception that there's no point in taking the test because you're going to get real bad news, and the second perception connected to that is that if you find you're infected, the medicines don't work anyway and you're going to die, so what's the point of getting involved at all? It's really important, I think, to have something that shows people in the process of getting tested. I don't think any of the films that I have seen over the course of the last 15 years have dealt with that issue in a straightforward way. I'm also pretty clear that there are very few films that have actually shown someone getting the results. I know people come in and

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sort of live in that moment. With that, I think there are a couple of opportunities that get missed because there's no opportunity to really follow people after that terrifying moment occurs, and if there's some way to complement or supplement what goes with the film so that folks who are dealing with those issues can have an opportunity to talk about them, to process them, I think it would make a really important contribution.

RORY KENNEDY: Absolutely, I agree and one of the reasons we decided - we had debated whether to do a one hour version or kind of what was the best format, and we landed on 15-20 minute version in part because we thought the project would be more effective if it was shown in formats like this where you could show the film and then have a discussion session. So, that the responsibility of the film is really to pull people in emotionally, and hopefully the discussions that are going to happen here today and the information that is out on the table out there is in fact a supplement to the film and provides more concrete information facts about AIDS, but I appreciate your points and thank you for making them.

JACKIE JUDD: On the side there.

FEMALE SPEAKER: This is particularly a group of policy makers and people who have been involved in issues that I'd be curious, how many of you in the last week have gone out for or called in for (Unintelligible).

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RORY KENNEDY: For what?

FEMALE SPEAKER: For how many of the men here have played cowboys and others? I think that we have to be very careful about (Unintelligible) epidemic and clearly and tragically involving black and Hispanic women. There are also Native Americans and Asians women involved. While the numbers are lower, they are still their families hurt just as much, and if they participate in particular activities they get infected also, and I think it's very important that we do not have materials whether it's going to be those or in the Kaiser materials that I've (Unintelligible) where we discussed women, and then we only give three examples - white, black and Hispanic. Are we not women? Or are Native American women not women? I think that (Unintelligible) that we don't make assumptions or we don't leave people out. And, I'm very concerned about that. That people not leave here today among the policy makers and among the people who are involved in a wide range of activities that it is only black and Hispanic and white women who get AIDS.

JACKIE JUDD: Thank you, last question if you can make it short please.

FEMALE SPEAKER: (Unintelligible)

JED ROTHSTEIN: Stacy actually is Hispanic, but generally speaking we wanted to make a video that reflected a broad demographics of the HIV epidemic as it affects women, or

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as it's affecting women now particularly in the United States which is why we went to the areas that we went to and why we chose the selection of people that we did, but at the same time we didn't or we don't assume that that reflects the totality of the epidemic and certainly by not showing certain groups or certain types of people, we don't mean to say that they're not also affected by the epidemic or that we don't all need to be vigilant and aware and need to bring education to the broadest possible range of communities.

RORY KENNEDY: Okay, I would just add the reality of making a documentary is that you only have so much time to communicate so many ideas and of course when you're choosing people every choice you make is at the exclusion of all range of different issues. We could've made a film that had 20 different women who represented a more varied cast of characters and people who are living with HIV, but what it means is that you only have one minute with each of those stories, and as filmmakers, we feel that the more time that you can spend with individuals, and often I like to make a film like this that just has one character in it so you can spend the whole 20 minutes and really get to know what the person is going through and what it means to live with HIV and we did a five part series on the global AIDS crisis and we followed five people, and that's global AIDS, you know, it's absurd to think that that represents the experience of everybody living with

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AIDS around the world, but as filmmakers we make that choice, and I still continue to support it and feel like it's the right choice.

JACKIE JUDD: Thank you, Jen?

JENNIFER KATES: I just want to add. Is this on? This is the exact kind of conversation that we're glad it's started that we'll hopefully have when we get to the afternoon because I think it's pointing out a really challenging tension that we face at Kaiser and I think that all of us do in how to - what is the audience, and how do we get attention to this epidemic. When we can clearly not represent the complexity all the time to sort of a policy maker audience, let's say on the Hill, not to single out the Hill, but anyway, I really - as well as the need to target women who are at risk or women living with HIV, those are different kinds of audiences and it's not clear all the time what the right way is to get this information on people's radar screens. So, I hope we do come back to that or continue to talk about it throughout the day because it's something we've struggled with and clearly making a film when you have 20 minutes, it's impossible to do the complete representation.

JACKIE JUDD: Thank you, it is something we will return to particularly in the strategy discussion later this afternoon. Thank you both. You did an important work. We look forward to having a wide audience. And, I think Rory may be

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back later this afternoon so if there are any more questions, maybe you can just see her outside. Will the next panel come up? Okay. This is the first panel that as I said earlier is going to lay the groundwork for us - the history of women and AIDS in America, the data, the issues, the unique challenges, some of what we heard about in the film today. We have three national experts with us this morning. Each will make a brief presentation, and then as we just had, there will be Q&A from the audience. First, Jennifer Kates, the Director of HIV Policy, here at Kaiser who's going to give us an update on the epidemiology and the key trends when it comes to women and HIV/AIDS. Cathy Cohen, the Director of the Study of Race, Politics and Culture at the University of Chicago, Cathy is going to give us the historical perspective and Judy Auerbach, the Vice President for Public Policy at amFAR, who will talk about sex and gender differences and HIV/AIDS. We're going to start with Jen.

JENNIFER KATES: Good morning everyone. I'm very excited that you're all here and this is finally happening. We've been, as Diane mentioned, we've been planning this for a while, and I do really think this is a critical moment to be having this conversation. You might have seen outside we have a PSA example or an outdoor PSA that we've done as part of one of our campaigns profiling the point that women now represent half of all adults living with HIV around the world. That's a very

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alarming statistic, and as Marsha Lily Planton (MISSPELLED?) my colleague likes to say, our goal here in the US is not parody in that way. So, we don't need for it to get that bad for us to have this conversation and we're hoping that today we're here to make sure it doesn't happen here, and that we can affect that larger trend. So, just to quickly thank some of my colleagues who deserve as much credit for this presentation as I do, Marsha Lily Planton, Alina Salganicoff, Usha Ranji, and Sonja Ruiz were all here and also I really want to thank Jackie for doing this. We did get delayed in our planning of this, but I was telling her yesterday it was our secret plan to wait until she was here with us so we could have her as moderator. So, what I will do is provide a brief overview of some trends and key data all of which are in your packet in various forms. So, this is really just to get us all to the same page for the discussion today, but please know that all of the information is there in lots of detail, source, and all that stuff so you can find it later. Okay, so why are we here? Well, the trend - most of you are probably aware of this trend, but when we look at newly reported AIDS cases over a period of time what we see it that women are making up an increasing proportion of new AIDS cases. This is true if you look at new AIDS diagnosis, etc, but this is the trend that we're seeing. This is more than tripling since 1986. If you look back at the earliest reports, CDC reports, surveillance reports, women were in those earliest

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reports, but in relatively small, small percentages, and now we're at a point where it's more than a quarter. What we're not showing on these charts today is new infections, which the CDC estimates that women represent about 30 percent. So, that's the trend that we really need to be watching. Another trend is people estimated to be living with AIDS, and as we know the number of people living with AIDS in the US and living with HIV has been increasing and that's due to many different things, some good things and some challenging things - people are living longer, medications do work. We'll show some trends in this as well. So, you'll see that coming up, but we also know people continue to be infected and that the shift is occurring. So, what you see here is men and women estimated to be living with AIDS again, overtime. I just want to point out you might not be able to see, but the number of women estimated living with AIDS is growing at a faster rate than the number of men estimated to be living with AIDS. Again, reflecting this underlying shift in who is become infected and actually women are growing as proportion of people living with AIDS. The next trend is this estimated deaths among people with HIV by sex. The best news here is that deaths have been dropping, and we all know that from focusing on the epidemic and what the positive trends are. Again though, what I want to highlight here is that the drop has been much faster for men and it's been about half as fast for women, 39 percent over this period

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of time for women when it's been about a 70 percent drop for men and that's potentially something we want to pay attention to - why is that happening, and I hope that as we go through the slides and talk later today, we can discuss that and what it might mean. Really the story about HIV among women in this country is one about race ethnicity, and I don't have a lot of slides right now, but there are many in your materials. I just want to highlight this through looking at AIDS case rates per 100,000 women because this really, I think, provides the most clear example of a very disproportionate impact. You can see the disproportionate impact among women of color by looking at many different ways, but this is, I think, a very important one to look at in what you see here is that the case rate in the most recent year for which we have data among African American women for example, is about 20 times higher than the case rate among white women, and for Latinos it's more than five times higher. You can see across the boards some of the rate differences there. We're not, again, showing new infections by race ethnicity but if you look at new and estimated new infections among women in the US, two-thirds almost are African American women. So, of women becoming new infected in the US, approximately two-thirds are African American women. Another important issue that I hope we discuss in this representation from - even though we're a heavy DC audience here, I think there's representation from people from other places. It's this

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distribution of the epidemic around the country, and it's a different distribution than for men although there's some similar trends, but what you see here is the biggest impact in terms of case rates is in the northeast and the south, and hopefully we can talk a little bit about what's going on in the south without forgetting that this epidemic does affect women significantly in the north and the northeast and other parts of the country and in your materials you will actually see some more breakdowns by states in different measures that you can look at. I'll actually put a plug-in for state health facts on my website where you can find lots of data on HIV and AIDS by state. Okay, how are women becoming infected? This is estimated AIDS cases - these are estimated so it's after reallocating cases for which we don't really know but we have a good sense from the history and trajectory of the epidemic. Most women are becoming infected through heterosexual contact, and about a third through injection drug use, and that is an increasing trend, and you can see the pattern for men on the right, but we'll focus right now on women. That's an increasing trend - heterosexual contact as a main source of transmission and actually if you look at this across race ethnicity, you don't see a real difference. There's some slight differences, but women by whatever race or ethnicity are primarily becoming infected by heterosexual contact followed by injection drug use and we know that a proportion of those infected through

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heterosexual contact are infected through IV partners. So, it's just always important to remember the role of injection drug use in this epidemic, but women primarily becoming infected through sex. I want to highlight here the impact on young people and young women. This is just one slide to make that point, but it's clearly - this epidemic is about young people, it always has been, and it continues to be, and what this among the states that have HIV reporting looking at reported HIV cases among younger people in the last year for which there were data, and what we see is a pretty alarming trend, and you can see this increasing over time. Among 13-19 year olds, young women represent over half of those new reported infections, and you can see among 20-24 years old 41 percent. This is relative to what we estimate about 30 percent over all for women. What does this mean? Well, is this a harbinger for what's to come? We don't really know, but it's definitely an alarming trend that is happening. It's a relatively small number of reported cases, but it's still a very alarming trend. One I hope we can try to discuss what that might mean for our policy efforts and for our media education efforts as we go through the day. The next slide looks at some of the context and the characteristics that we know women with HIV their lives, and this, I think, is sort of the best estimate of the richness and complexity of why women with HIV face barriers as well as the challenges that women face and put them at risk, and this is from the HFCA's

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(MISSPELLED?) study, still the only national representative study that we have and it's a little dated at this point although I would venture to guess that the trends haven't really changed. If you look here at some key sociodemographic variables, women with HIV who were in the care system at that time tended to be poorer, have less education, and there are factors in your packets, have less income than men. A key thing that came out very clearly in the video and we'll see in other materials, women with HIV are much more likely to have children and children at home and this whole issue of being a caretaker and what that means for your own care is really a critical one. Then looking at insurance status, and we have this broken out in your packets in more detail, you can see women are much more likely to be covered by Medicaid than men - women with HIV, about similar proportion are uninsured, and all these things we know play a role in the seat of care, type of care, etc, and just going right to that point, again, look at the HFCA study, and this is 1998 so, looking at some key measures of access in quality care and there's statistically significant differences. So, essentially, what that means is women are fairing more poorly in these measures than men, so almost a quarter not receiving combination therapy in the past year, and that was women more likely than not having - not receiving combination therapy than men, and across the board these other measures, too. Women were less likely to be getting the standard of care

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than men in this case. Again, this is nationally representative. Okay, we know one of the factors that goes into what kind of care you're getting and also the outcome of that care is are you getting there and what are some of the complexities that you might face. Again, looking at the HFCA's study, so nationally representative, these are also significant differences, what we see is that women were much more likely to report very complicated reasons for not getting to care, for postponing their care - not having transportation, being too sick to go to the doctor, and just generally when you look at lots of different reasons that might compete with your ability to get what you need, women were more likely to have those intervening variables than men. Okay, we, and this is in your packet, we look at data a lot - all of us doing policy work, and we also know though that what women are experiencing in their lives is much more complex than just what the data tell us as we've already heard today, and so we wanted to provide a way for us and for you to hear more about the insights and textures of women's lives. So, we invested in some qualitative research through focus groups, both with women living with HIV and women at risk, and the executive summary of the report of women living with HIV is in your packet. The other report will be on our website at the end of the day, but I want to highlight for you some findings. These are not necessarily representative of the experience of all women living with HIV,

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but I think really get at a lot of the issues that we've already heard about in video, underlying the data, and really give us a lot to think about. The first is, and this came out clearly in our focus groups, how and when women learn of their HIV diagnosis, what kind of experience that is for them really affects their receptivity to care, their ability to follow-up, and get what they need for themselves and their family. That came through very strongly. The second is that having insurance coverage really makes a difference. Most of the women that - and I should that these were focus groups done in four places, Philadelphia, LA, Miami, and Savannah, and these were women living with HIV identified primarily through service providers. So, there are some limitations to we're not necessarily getting the people who are most disconnected, but still they had a lot of challenging issues. So, the second point, having insurance coverage particularly Medicaid had a big difference for the women that we talked to, being connected to an AIDS service organizations. So, those of you fund AIDS service organizations, the message is loud and clear, the women that were connected to organizations were doing much better in getting what they needed. Having an experience provider, particularly one that was experienced in treating women, was critical. For those women who did not have coverage or had sporadic coverage, they kept talking about Ryan White and (Unintelligible). If they didn't have that, they wouldn't be

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getting what they needed. The whole range of services - they weren't getting what they needed. Some of them knew what they needed, some didn't, but they weren't getting gynecological care, labs, mental health, etc. Again, the ones that were more connected were getting those services more readily, but those were real complex challenges for them. Many women faced lots of other challenges. We talked about parenting, putting others first, and stigma and misinformation, I think this is the most disheartening. We had some women in the groups that had been infected for a very long time, and they had seen a difference in stigma and misinformation being reduced, but still we heard the stories, and one was dental providers, and it came out in the video as well. We kept hearing about dentists, a real problem with dentists, and women with HIV or people with HIV, and the last thing that they want more information. They were very - many of them were very informed, but they wanted more information, actually shared information with each other in the focus groups. So, there was really still a need for information to reach them and provide them with the latest on what they needed for themselves. Turning now to women at risk, here's just some data in general. This is women overall of reproductive age and on a survey that we recently did to assess how many women say that they have been tested and a few things I want to point out here. Most of these women, again this is women of reproductive age 18-49, most say they have been tested

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at some point, 65 percent, but when we asked them "How did they know they were tested?" and there are a few things to highlight. The first is that most who were tested said they asked to be tested, that's good, predominately 46 percent, but about a fifth said they were told they were tested, and we don't really know what that means for informed consents. It just raises some questions. And, then the last point is, and I think this is - it's a smaller percentage, but it's a real challenge for those of us doing education - many people are under the impression that when you go to the doctor every year and you get tested for lots of things, you're getting tested for HIV, and if you don't hear about something a result, that means that you're okay. And, we see this with teens. We see this women and I think people overall. So, that's something that we want to make HIV testing routinized, but people might think that's already happening and therefore aren't realizing that they don't know their result. They don't know their status. One thing that's not here, we also had asked women how many of you had talked to your provider about HIV and STDS, and maybe a third have. So, it's not that women are generally discussing with their providers. Okay, we also as I mentioned these focus groups, the women at risk, and I want to highlight some findings here. There was concern about HIV, and these were women at risk. We define - consider at risk lots of sex partners, weren't always using protection, there was generally

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concern but not really - they hadn't personalized that concern.

They knew the basic information, but they still had misperceptions. They still had gaps. They didn't use condoms regularly and not a big surprise, it really depended on the context of their relationship - how well they knew somebody, how long they had been with that person. They were very open to learning more, but this is a real challenge that we identified, but they also say they know enough, "Yeah, we know stuff, but we want to learn more." So, what does that really mean for guiding our educational efforts? But, we did show them a lot of prevention messages and education messages, tried to see what worked, and for them what they said was real information and things that dealt with the issues that they feel are important in their relationships among trust and risk, and then finally, these were the stakeholders and informants that they said were the most affective for them - doctors, educators, and media. Okay, because we know you all like survey data, and we do too, we went - or maybe we like it more than you do, but we went into the field just a few weeks ago to try to get some hot of the press data on women - this is a representative telephone sample of women in the United States, to try to see where our women today with thinking about the epidemic in this country, and the next three slides - and these are in your packet - show this data. We haven't realized these yet. I guess we are right now. This is women's perceptions of progress on HIV in the US

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and their personal concerns, and what you see on the left side is there is sort of a mixed perception of "are we making progress?" This is specifically US "Is the country making progress in addressing HIV among women?" - the problem of HIV among women, and 41 percent said yeah, we're making progress, 31 percent said we're losing ground. So, it's sort of a most - more think we're making progress than not, but it's kind of mixed there. And, then on the right side, personal concerns. Most women if you add "Not at all concerned" "Not too concerned", aren't personally concerned about this, just highlighting that. And, actually what we're not showing here today is we've been tracking this overall trend about personal concern for several years, and we see that personal concern is waning. People aren't as concerned as they used to be. The next slide- this is women's knowledge of the epidemic's effect on women. Do we think - do you think it's gotten worse, shifted more towards women for example, shifted away, stayed about the same. Women generally say it's stayed about the same. A little more than a third said it's shifted more towards women, which is would be the right answer. And, then on the right, we asked maybe you would think most women wouldn't know this anyway, but we wanted to see would women correctly identify the percent of new AIDS cases that women represent, and they were most likely to say the right answer, though it's about a third, 25 percent, 26 percent, which is the right answer - that's 36 percent of

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women. Okay, then the last survey question that we asked - this is of interest to I think all of us doing educational work is where women are most likely to get information about HIV today, and 73 percent said from the media which of course makes it very important to figure out what the media's telling women and what role we're playing in guiding the media in that discussion. Okay, so some policy issues just to think about summing this up as we move through the day. I'll quickly go through these and these are somewhat artificially divided into these areas that we all work through - prevention, how do we do a better job of reaching younger women and women of color to not to get to the parody situation that we do not want to be at. How do we reenergize this issue in our public education efforts? Care and treatment - how can we improve access to care and support services? This came through in our focus groups that support services and a range of services out there not just medical care, were really, really critical especially for women. What is the best to integrate reproductive health care and other key services with HIV care since so many women get their care in the reproductive health setting, and we know that women aren't really talking to their providers about this. How can we do a better job there? Research - what are the major gaps that we still have in our research agenda? How do we increase the participation of women particularly women of color and young people in clinical trials so that we're getting the

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information that we need to do a better job with treatment and prevention? Some cost-cutting issues, and this is an overriding one - number one, raising this issue here in the US. Who do we need to raise it with and how do we do so? Financing mechanisms - given that we have cutbacks in Medicaid, limits on ADAP (MISSPELLED?), Ryan White (MISSPELLED?) reauthorization on the horizon, all these other things and the fiscal crisis that our states are facing, what does this mean? What we have in place right now is probably not adequate, so what are we going to be doing? And, what are the initiatives that are underway or being discussed that really stand to affect women and the conversation of the impact on women may not be front and center. How can we make progress towards eliminating disparities by gender and race ethnicity in this epidemic, which of course speaks to that largest challenge? And, how do we work to more effectively get the voices of community-based agencies at the table? This is something we feel really challenged to do too. There are people who wanted to come today who couldn't. We tried to get as many people here as we could, but there were people who couldn't be here. And, then finally, what role should key institutions play? That's governments, media, us, HIV organizations, women's groups - what role should we all be playing together and in our own spheres to really make a difference? And how do we engage all of us to keep doing that? But, thank you and I hope that provides some food for

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thought today.

CATHY COHEN: How's everyone doing? Desire - all right, here we go, here we go. First I want to thank Jennifer, Marsha, other members of the Kaiser Family Foundation for the invitation to come and speak with folks today. And, I want to confess up front that I'm not a historian, and I would say not necessarily the best person in the room to recount the historical development of the epidemic in relationship to HIV and AIDS and to women, and some of you and I'm looking at Bob and Sue and others have come with the themes and experiences that I'm going to highlight today. So, I am honored and humbled to be in the room with these folks, and need correcting what I've left out, and hopefully we can have a discussion about this. Again, my work instead really focuses on the political response to HIV and AIDS in particular in African American communities. I also feel like - very quickly, I want to apologize for not having PowerPoint. One of my students explained to me, he said, "You're not only a second wave feminist, you're a second wave academic." He didn't say "second rate" "second wave" in the sense of resisting all technological advances. So, instead of really presenting what undoubtedly would be a kind of piecemeal, chronological history of women in HIV and AIDS, I'm going to talk a bit about four categories that I think loosely correspond to kind of the historical developments in the epidemic that also give us, I think, some

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ways of thinking about what we faced in the past, and undoubtedly what we'll face again in the future, and specifically I want to use these categories to talk about four different ways of seeing women or basically not seeing women in particular women of color, and I mean the range of women of color throughout the AIDS epidemic. Now, I should say that none of the experiences or categories I'm going to offer up this morning will be new to folks involved in service provision, advocacy or political mobilization around women's lives and women's issues. An unfortunate part of this story is that the neglect, invisibility, and even the struggles around mobilization that I want to highlight could probably be a part of any narrative in terms of women's issues especially their political activity. Moreover, the categories I'm going to introduce are kind of fluent and dynamic and they're not static, right? So, while we might talk about one form of exclusion early in the epidemic, unfortunately that form of exclusion reappears later in the epidemic and so it can be combined. Now, and I'm going fast because I only have 15 minutes, right, to do a history of women and the AIDS epidemic. So, maybe I have 15 minutes left over. The first category of framework I want to present is not that surprising and it's invisibility. Now, again, it's not surprising that as researchers at the CDC and practitioners around the country were confronted with a new and puzzling medical occurrence that

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would eventually be classified as AIDS that they focused on predominately those kind of identified cases, mainly those cases of gay men I would argue with insurance who appear to assert an institution that they focus on those institutions to kind of create a kind of medical knowledge around HIV and AIDS. However, I think that many feel that the CDC was so intent on limiting the kind of impact of this medical crisis to gay men that they ignored other data that was relevant that would signal that HIV and AIDS also threatened other groups of people including women, injection drug users, and more generally folks of color. Gerald Freeland (MISSPELLED?) prominent AIDS doc suggest that these early case definitions were and I quote "constructed without enough sensitivity to the already evolving demography of AIDS so, the definition excluded a lot of things and resulted in underreporting of the disease among injection drug users, women, and people of color" end quote. Now, he goes on to say that people lead us to bias in this early understanding of AIDS were represented everybody knows as a gay white male disease. That's the early bias in the data collected by the CDC significantly shapes how we think about this epidemic today and who we think about it when we raise the issue or the idea of HIV and AIDS, and generally we don't think about as it being attached to or impacting women. Now, of course, the initial invisibility of women in the early research and definitions of this crisis was not the only problem. Having

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initial assumptions about the causes and associations of a disease is part of really any theory of process that any kind of any process of theory building and investigation. However, it was the CDC's unwillingness to revise it's initial assumptions in the face of new evidence about AIDS which really, I think, caused again not only to women invisibility around HIV and AIDS, but also their systemic marginalization in a kind of social, political, and economic field. Now, let me hint that it would later be the CDC's position of non-revision around the case definition that would really kind of help generate the significant mobilization from women living with HIV and AIDS and their allies that we witness later in the epidemic in the late '80s and early '90s. And, while women may have been invisible on the national front and in the political realm of during this stage, we have to kind of be prepared to be complex in our analysis and recognize that they were doing much of the care work at home and in their communities. They were starting new organizations, taking care of family members, and confronting community and local institutions that would deny the existence and importance of HIV and AIDS in communities and in particular communities of color. Now, I also want to suggest that the pattern of invisibility was not specific to the CDC. Unfortunately, the incidents of HIV and AIDS among women was also largely ignored by the media, but also organizations reportedly representing the issues and

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concerns of women and people of color, women's organizations and civil rights organizations. Now, I've made the argument before that I'm sure part of the denial or lack of interest and really kind of focusing - already? - on women of color and women with AIDS had to do with kind of responding to the regressive policies of the Reagan Administration that was really kind of forming the political environment at that point. Second category I want to call your attention to because I have less time than I thought, is something you might call symbolic deployment. Now, what I mean by symbolic deployment is the use, and I put that in quotes, and betrayal of women and their children as the innocent victims of the epidemic and in need of assistance. In the speeches about AIDS made by public officials in the late 1980's, there's a consistent theme that can be identified of the importance of responding to the needs of innocent victims. And, now clearly part of their express concern had everything to do with the pressure that they were feeling from AIDS activities who respond and also their interest and responding in a way that didn't implicate them in what they considered to be the problematic behaviors of certain groups and certain individuals that were partly - that were defining the epidemic. In this case, women were not only kind of deployed or used as cover, they were offered up as a respectable or moral counter for those who are supposedly morally wanting members of communities. In the case of African

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Americans, they were a counter to black gay men, black men who slept with men, and black injection drug users. As these women were held up as innocent victims, men - in particular gay men and men who sleep with men - were being demonized and in some cases criminalized, and we shouldn't lose kind of light of what that dynamic was about. Of course, I think it's awful important to remember that the category of women that was being deployed was not available to all women, right, we're talking about respectable women. So, women - I like the mm hm, I can tell folks are saying okay - all right, so women who were injection drug users, women who were sex workers - mm hm - women who sought to infect their children, right, didn't sit under the category of women in terms of innocent victims, right? And, I have to say again, sadly, it wasn't just public officials. I think at times it was women's organizations and civil rights organizations and primarily, gay white male or AIDS organizations who had no interest in those "more morally wanting of the women's population." Now, two final points about this category - first is the realization that the deployment of women as innocent victims is not about the empowerment of women, but the instrumental use of women in a public crisis, and black community public officials indicated that they were especially concerned about the threat that HIV and AIDS posed to women because it threatened them during their child-bearing years. So, it was about women as a vehicles for procreation

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and not about kind of saving and protecting women. Finally, in terms of women's presence during this stage and both innocents victims and I think immoral sweats, we should not lose sight of the fact that women were also part of the management of this growing crisis. They helped traditional service agencies and - I'm going to slow down, you guys take, I'm sorry I'm going to go over time. Thank you. All right - they held traditional service positions, right, ranging from social workers to prison guards and were therefore part of not only those who were infected but also those who were affected by this epidemic. These same women help create some of the services geared specifically to women with HIV and AIDS, but they were also intention at times within AIDS organizations especially AIDS organizations that were created by black or in my case, the work that I do, black gay men and kind of an intention by who would control those AIDS organizations, another issue that we want attention to. Now, the third category that we might be use, I would argue, contested mobilization. I think too many of us really forget about the significant organizations collective mobilization b y women, infected and affected by HIV and AIDS in the early '90s. It was the activity of largely women's AIDS activities that began in the late '80s and again early '90s that culminated in a revision of the case definition used to make an AIDS diagnosis. Women activists from ACT UP organizing in concert with women of color AIDS activists throughout the

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country pushed numerous government agencies to acknowledge first their complete mishandling of the epidemic as it related to women - no research, no inclusion, and generally no interest in women. The political work of these women included things like phone (Unintelligible), sit-ins, there was a full page ad in the New York Times about kind of women's issues as well as local acts of resistance which opened up resources for women infected and affected by HIV and AIDS. Again, it led to the adjustment and a case definition to include those opportunistic infections and medical presentations of HIV and AIDS seen exclusively in women. Revision of the case definition meant that the number of women classified as having AIDS increased and provided a new empirical visibility to women with AIDS, and unfortunately we just saw in the last presentation hasn't continued. Now, I have called this category kind of contested mobilization because while there were important efforts of activists to work across race, class and sexuality lines, the truth of the matter is there were really difficulties in this area, and I think we need to learn from these difficulties. For example, some of the white women who were AIDS activists deployed what we might call a universal idea to women and AIDS, neglecting or kind of negating the privilege they embodied in their protection from high levels of risk and compromise. Women of color in marginal communities operating with fewer resources and less privilege, often voice their resentment

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toward women that they believe were taking too much of the leadership of this movement. It seems clearly that the question of coalitional work around issues of women and HIV and AIDS as well as how work will be framed. Will it be framed in terms of women, will it be framed in terms of African American Latino women, or will it be framed in terms of women of color are important issues that we have to decide as we proceed forward if we're going to, in fact, work together. Now, the final category for your consideration is cultural professionalism, and here I'm going to draw your attention to what I consider to be the increasing professionalization of the response to AIDS generally in communities of color and also as it involves women. The work of activists has reached a kind of incredible point where we now have culturally sensitive services, where more women are living longer with AIDS, and where we've involved traditional organizations within our community, and I think we have to applaud the work that's been done largely by many of the people in this room, however, any review of the statistics reveal that there's much more to do. Women receive as a gender the worse medical care in response to HIV and AIDS. Women with AIDS tend to be more resource poor than men living with AIDS. Furthermore, under the Bush Administration, women in particular women of color, have once again been made invisible with the administration focusing their attention internationally and doing what appears to be nothing on the

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domestic front. Now, when I say nothing, I don't mean that they're doing no harm, right. When I say nothing, I mean that they tend to kind of underscore the idea that AIDS is no longer a problem in the US, but however daily women find themselves being denied the drugs that they need, as well as other resources because of government cutbacks on the ADAPT (MISSPELLED?) program, Medicare and other services and programs around the country, right? I could go on but I don't have enough time. Then of course, there are kind of the existing evils of misogyny, racism, class exploitation and homophobia, just to mention a few, always kind of lurking in the background or the foreground to make the lies and in particular the sexual behavior of women of color an object of the Naziation (MISSPELLED?) and I suppose justification for their continued marginalization. Here's the bottom line - my bottom line is that I'm concerned that in this political environment, we focus on securing services and prevention programs, which to me, I think, are worthy goals, but have moved away from the organized mobilization that won us our most important victories. I worry that our 501-c-3 status and constant search for funding has meant a corresponding demobilization with regards to politics and in terms of the cause for kind of doing anything and using all means necessary to secure the survival and the progress of women and in particular women of color during this period, and I also worry that women's organizations and people of color

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organizations with skill and expertise around advocacy still do not see this as an issue and still do not see these communities or constituencies as essential to their mission and their work. The bottom line is I think we have to mobilize on multiple fronts. We have to figure out how we will frame this issue, and we have to commit ourselves to not only saving women's lives from HIV and AIDS, but also the multiple other kind of issues of oppression that they face. Okay, thanks.

JACKIE JUDD: Thank you Cathy. While Cathy catches her breath, Judy Auerbach minus three minutes will wrap it up.

JUDY AUERBACH: Just kidding, no way. Thank you to Kaiser Family Foundation for inviting me to present, and for amassing such a wonderful group of people. I'm very pleased to be here. I'm going to present a scientific talk that is almost data free, so you'll forgive me for that. I'm going to talk about sex and gender differences and HIV and AIDS, and of course we need to begin with some definitions. The ones you see here of sex and of gender come from the Institute of Medicine and the World Health Organization, and of course there are many others, but as you can see, generally speaking sex is taken to be a biological category, and gender really refers to a more cultural and social category. While they're often discussed separately, sex and gender overlap in importance and often complicated ways. Although both sex and gender usually are described in binary terms, male/female, masculine/feminine,

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they actually represent continuum as made clear by perhaps the existence of intersex people and transgender people. Sex and gender are dynamic phenomenon. They change and evolve in relation to age, to sexuality, and to sexual identity and other biological, social, cultural and environmental factors. Gender is not a proxy term for women or for sex, although it's often used as such. Gender applies equally to men as it does for women. Indeed, if we really focus on sex and gender as interactive dynamic phenomenon, we should be focusing on men as well as women whether gay, straight, bi-sexual, transgender or intersexed. But, since the purpose of this meeting is to focus on women, you'll hear me say a little bit more about women than about men as I talk about sex and gender differences.

Biological, psychological, social and environmental factors operate simultaneously and interactively in all aspects of HIV and AIDS listed here, and we need to understand these interactions better and take what I would call an intersectional - not to be confused with intersex - an intersectional approach to the role of sex and gender in the HIV and AIDS epidemic. As an example, an adolescent girl in some societies might be at elevated risk of HIV infection because she has an immature cervix, physiological issue, she lives in a high prevalence community, an epidemiological phenomenon, and because she's forced or coerced into having intercourse because an older man believe he can purify himself

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or cure his own HIV infection by having sex with a virgin, and this girl does not have the physical, the psychological or social capacity to resist because she's young and she's lives in a society with significant gender inequities. So, in order to affectively address this girl's vulnerability to HIV infection and her subsequent experience of the disease should she acquire it, we must understand her body in it's social context not one apart from the other. but, let's look more closely at how sex and gender appear to be operating in the HIV/AIDS epidemic. Begin with exposure, Jen has already noted that the sex and gender differences, so I won't repeat them - compared to men, women are particularly vulnerable to acquiring HIV infection through penile vaginal intercourse. Research on sero discordant couples, that is one HIV positive one partner HIV negative, in the United States found that male to female transmissions was eight times more efficient than in reverse, but it appears this difference is mediated by the presence of other sexually transmitted diseases, STDS, in men and women. Other studies in populations with higher STD prevalence have found nearly equivalent female to male and male to female transmission rates. The biological factors that contribute to women's greater vulnerability to HIV infection include the make-up of the vaginal floor and the presence of genital ulcers and inflammation. Prior genital herpes also increases infectability and herpes is much more efficient in transmitting

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from males to females. There are also factors which enhance any biological vulnerabilities include coercive sex, which can produce genital lesions, but also usually involve the non-use of condoms. In many societies, women have less access to health care generally including prevention services than do men due to inequitable allocation of such resources in families and communities. Sex education often is inadequate or non-existent for girls and women, often for men and boys as well because the strong cultural beliefs that deny or conversely fear female sexuality. There is a double standard in many societies that permit men to engage in sex outside of marriage or regular partnerships, but strongly condemns and often harshly punishes women who do so. Many women are infected by their husbands who engage in commercial or other extramarital sex, and these women have little power to insist on safe sex or the use of condoms within their primary relationships or their marital relationship. Biological susceptibilities operate in concert with social and cultural forces to produce different levels of vulnerability to HIV infections for women and men. Moving on to disease progression, beginning with diagnosis in the United States it appears that men and women have different reasons for getting an HIV test in the first place. In a large CDC surveillance study, men were more likely than women to report having an illness as the main reason for getting tested, although this is the most common reason in fact for both sexes.

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With respect to other reasons, women were less likely to report belonging - self-identifying as belonging to an at risk group. They were more likely to report having an at risk partner and more likely to have a test offered by a clinic or recommended by a healthcare provider than were men. Once infected, we see a number of differences between women and men in how HIV disease manifests and progresses. HIV infection exhibits much greater viral diversity in women than in men at time of infection. This may have something to do with the different physical immunological environment in the male and female genitals, but it's not entirely yet understood and is the subject of much research. HIV RNA levels or viral load as you often hear it discussed are 30-50 percent lower in women than men at the same (Unintelligible) count, but this difference is greatest after Sero conversation and this is the case over time. Some of the sex differences in viral load may due to hormonal influences which I don't have the time to explain. Initial studies report faster rates of disease progression in women than in men, but subsequent research shows that there is no sex difference in disease progression if access to care is similar. This later research occurred before the broad use of antiretrovirals, so in fact, this question is still under study with respect to the impact therapy on disease progression and possible sex or gender differences. Survival is also similar between women and men at the same CD4 (MISSPELLED?) levels.

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Prior to the advent of the highly active antiretroviral therapy or ART, there were notable sex differences in the manifestations of HIV disease. In women, HIV was marked by two specific gynecological complications or conditions - recurrent vaginal candidiasis and cervical neoplasia, while in men it was common to see Kaposi's sarcoma and a viral agent which is in AIDS. In suppressing HIV, these antiretroviral therapies have ameliorated much of the risk of invasive cervical cancer, which has previously been the most common AIDS related malignancy in women, but of the diseases or conditions that are not sex specific, women appear to be more likely than men to exhibit bacterial pneumonia, oral or esophageal candidiasis and herpes simplex virus, while men are more likely than women to exhibit Kaposi's Sarcoma and recurring pneumonia. In many cases, sex specific differences will be these manifestations mainly the results of differences in exposure rates to the infectious agent. So, here we're bringing environment back in. For example, among HIV infected persons, a HSV, Herpes Simplex Virus, appears to be more prevalent in women than men, perhaps because it's more prevalent among women in the general population. Moreover, the greater prevalence of certain behavioral factors among HIV infected women compared to men, for example, the more frequent transactional sex, that is sex for money or drugs as an exchange, may result in reactivation of disease in the same person rather than increasing the actual

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number of new infections. Possible sex and gender differences in the mental health aspect of HIV infection have not really been fully investigated. Some studies, however, indicate that women with HIV infection and AIDS have a greater risk of psychiatric disorders, with stress and other mental health problems than men. For some women, these manifestations result from the realization that in fact their only risk for HIV infection was the behavior of their male partner as we heard from Stacy for example. Other explanations for gender differences in psychological stress relate to women's roles as primary caretakers in families, greater likelihood of being poor, and greater likelihood of being victims of abuse including sexual assault. HIV positive women of reproductive age also face very difficult choices and considerations about whether to have children. This in itself can produce significant psychological stress - the decision not the children. (Unintelligible) We're moving on now to response to treatment among those who are infected. Several recent studies have reported no sex differences in response to HIV treatment, but others have indicated that women may achieve more rapid and durable biological suppression than men. Some studies have indicated that the greater CD4 increase among ART naïve, meaning women who have not previously been on this medication, than their male counterparts. There are covert studies in England and France have shown no sex differences in hospital

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admissions for AIDS, disease progression, or death among women and men on these antiretroviral therapies. However, there appear to be significant sex differences in drug toxicities and side effects despite similar responses to therapies. Women are more likely to experience neurological complications, lactic acidosis, skin rash, and liver toxicity in particular in relation to a certain class of drugs. Men and women also exhibit fat redistribution differently, but all in all little yet is known about sex differences in the pharmacol, genetics, and the pharmacol dynamics of antiretroviral therapy and it's various combinations in women and men and this is an area in need of greater research. If we look at access to prevention and care services, Jen has covered more of this so I'm not going to repeat it. let me just add a few key points. In some poor communities, when multiple family members are infected with HIV, females are less likely to be given care (Unintelligible) than are males. In the US and elsewhere, health care providers generally are not talking to women about their HIV risks and opportunities for prevention. Studies show that less than a third of all women regardless of HIV sero status report talking to their health care providers about HIV and AIDS, risk of infection, or HIV testing for a count. Clearly, much of the important prevention and treatment information about HIV and AIDS in women is not being appropriately disseminated or integrated into other venues for

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women and girls who seek health care services such as family planning and STD clinics. One of the important ways to gain information and access to clinical care and new HIV treatments for HIV infected individuals is to participate in clinical trials. To date, many clinical studies have not had sufficient numbers of women to vigorously examine possible sex and gender differences. Women who now constitute about 20 percent of NIH sponsored clinical trial participants, which is close to their proportion of AIDS cases in the United States, this is from the data, although not to the rate of increase of new infections among women and girls. Can I go back? There are many barriers to fully integrating women and girls into HIV related clinical prevention trials. These include the lack of information about the existence of such trials and how to participate in them. There are logistic issues such as taking time off from work, having transportation, finding someone to look after their children, and of course, there still is a lack of trust among many women especially women of color in the research establishment especially the federal research establishment. In some societies, women are in fact required by law or by custom to obtain the permission of their husbands, their fathers, their other family members to even participate in research. In many cases, this would involve revealing one's HIV status where one has not yet chosen to do so and could pose significant safety risks for the woman. Okay, there's many other sex and

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gender issues in HIV and AIDS so, I'm just going to mention a few final ones. I've already said a little about the role of hormones in HIV disease progression, but there are also data to suggest that some antiretroviral agents interact with oral contraceptives diminishing the effects of those contraceptives, although this area of research is still very much under study. As HIV positive women live longer and enter mid life in older age, it will also be important to look at the impact of hormone replacement therapy with respect to disease progression and the interactions with HIV medication. Women and men with HIV infection often have other illnesses or conditions that are frequently called comorbidities including other STDS, hepatitis, tuberculosis, as well as mental illness and/or substance abuse. Little yet is known about sex and gender differences and the potential interactions between antiretroviral therapy and medications whether those are legal or illicit drugs to these cooccurring conditions or circumstances. In many if not most societies, women and girls and I think we all know are assigned subordinate status to men and boys. They are not afforded equity in legal, educational, employment opportunities, and are rendered financially and social dependent on male family members. This makes it difficult if not impossible for them to protect themselves, to speak out against systems that fail to respect their rights, if those even exist, and to advocate on their own behalf for

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greater access to care and services. Now, where do we go? And, I'm again just mentioning a few areas - research, practice and policy. Although it often requires extra effort, it is important that researchers conducting HIV related clinical studies ensure that sufficient numbers of women and men or boys and girls are included to allow for meaningful analysis of any potential sex and gender differences. When sex and gender differences do occur, some are possibly based on biological factors, some on social factors, and some on both. To be able to explain and thus of course eventually address these differences, it's important for researchers to be trained with appropriate theoretical and methodological tools to conduct gender analysis, not just sex difference accounts, but the actual kinds of gender analysis that are pretty lacking at this point, why these differences occur. We need more individuals in organizations to advocate on behalf of women in the HIV epidemic as Cathy has already mentioned, to ensure greater access to information and HIV prevention and care services. This includes HIV/AIDS organizations, women's health organizations, health care providers, and the media. Finally, and perhaps most importantly, we need to embed our struggle against HIV and AIDS in a larger to promote greater gender equity in the United States and elsewhere. And, I just want to end by acknowledging a number of people, documents, organizations for whom I have borrowed liberally for this

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presentation. Thank you.

JACKIE JUDD: Thank you all. You've really set the stage beautifully for what we're going to do this afternoon. The day's going so well already, but we're already behind schedule. So, we're going to have to save the Q&A session for a little later. We do have time? Forget what I just said. So, the day is still going really well, right? Jen I'd like to just ask you the first question, and if we could really be succinct we'll have more time this afternoon for discussion, but succinct questions please. You had made mention that in the focus group, you noticed a relationship between the circumstances under which someone was diagnosed and the subsequent care and treatment. What's the link?

JENNIFER KATES: What we heard from many of the women in the group is - they talked about when they had learned their diagnosis, and that's a pretty common thing for women. You put a group of people with HIV together, they'll talk about - we began to ask them questions, not many of these were trained focus group people, not myself, and what they said was the moment at which a physician or provider said, "You're HIV positive." And how they told that to them if they said it in a harsh way, an uncaring way, it really had an impact and a lasting impact in their minds. So, for example, one woman had said she was basically told her diagnosis and that was that, and she wasn't given a follow-up. She wasn't given support. She

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wasn't given any kind of connection at all, and it took her a couple of years on her own to really battle what that meant and find the connection that she needed. Whereas, other women told of great stories of getting the support they needed and that linked them immediately. Now, that is not to say that all of them had their own internal struggles with learning their diagnosis like we saw with Stacy, but not having that network and being told in an uncaring way really impacted them.

JACKIE JUDD: Yes, ma'am?

FEMALE SPEAKER: (Unintelligible).

JENNIFER KATES: We didn't really get that. I don't know the answer to that although maybe Alina's remembering more than all the findings then I do, but it was the provider's that seemed, that women could relate to, made a difference. It was kind of an incidental diagnosis, like women found out to because they were tested because they were pregnant. So, they found out there. Other times, we had women who found out that they were HIV positive because we had a lot of women in Florida who, for the focus group in Florida, who found out because their husbands were given an AIDS diagnosis. So, there husbands were hospitalized. So, in many cases they find out because their partner has a diagnosis. So, in other cases, there were women who were incarcerated who found out there, and those women are women who had been arrested and then incarcerated, and those, not surprisingly were women who really said, they

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were devastated by their diagnosis, and it was very, very poorly handled, and that women who were more in the health care setting and by experienced providers did much, much better.

JACKIE JUDD: Yes, Denise?

DENISE: Just data clarification. You said that viral load was 30 or 50 percent lower in women than it was in men with the same CD4 count. Was that in people that were positive or negative?

JUDY AUERBACH: Positive.

FEMALE SPEAKER: I guess I want to suggest that maybe we're already - if you saw our future, we're already at parody even if the CDC doesn't take our data because it's not named. Our HIV data looks the same in terms of what the differential split is, where girls are exceeding the boys, and I guess I want to put in a plug and maybe ask a question to all to it to expanding on the kind of sex and gender analysis against both sexes, both genders, anyway you want to look at it, because after we take care of the ten percent of both that are infected by their own intravenous drug use and of course we always forget that women should shoot, all the boys are primarily at risk because of their sex with other men, and all of the girls are primarily at risk because their sex with other men, and we've been making an assumption that the literature, I think, has guided us to which is "Oh, and those girls are having sex with older men, and that's where the differential risk is."

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But, also being the only state that same sex sex behavior information, the behavior risk survey, we believe we have to look at that assumption again because of the level of same sex as well as other sex, sexual behavior that is going on among you. And, so I would put on the table, how do we open up that conversation at this time?

JUDY AUERBACH: Well, one of the things you raised Jean, which I think is real important and often completely unaddressed in this epidemic is the relational nature of transmission. We tend to look at individuals and their own risks or their own behaviors in transmitting rather than looking at the interaction between two people which has to occur almost everytime for HIV infection to move from one person to another. So, even your throwaway at the beginning, quite innocent about people in their own injecting behaviors, as if that's a solitary action. The infection is only relevant if it was acquired through the needle or in the blood or another facet of drug injection that came from someone else. So, even there, there's a relational transmission. So, I think that's part of how we have to begin to talk about this because we have categorized people, risks, exposures, and behaviors in ways that are not particularly helpful or meaningful.

FEMALE SPEAKER: (Unintelligible) left us there with how we have particularly categorized people in ways that are not particularly helpful and useful to use now 20 years into the

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epidemic. Cathy Cohen spoke how the invisibility and the continuation of it in the CDC's risk categories that kind of led us to this 20 years later, people still saying, "I didn't think it was me. I didn't think it was me." What are we going to do about it now 23 years into it? And, hello our dear friend Ron or whatever over there representing the CDC, but no, because this is - I want to ask the question, do we think this is a serious problem, and Cathy used the word "contest mobilization". Now, we are expecting the government to do something that the government didn't do to begin with, and so here we are 20 years into this, 23 years into it, we keep thinking women are invisible and on the other side of a man, always on the down low, black and white, young and old, there has always been a woman, and they have always been invisible, and so we have now suggested that the numbers are large enough that we need to do something about it, but we are looking for the government to do something that they haven't fixed yet the problem that we started with. So, is there a way that we can do this? And, I would like to ask the three, because Jen you're included, to speak to it, because you have stated the problems correctly.

JUDY AUERBACH: Happily, I'm not in the government so I don't have to speak for them anymore, but (Unintelligible) because there may be things going on that we just don't know about like a behavioral preventative effort that maybe getting

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a little closer to understanding more truthfully what's involved in transmission of the infection, but, I've always thought that problem with categorization is so severe because not only are people and their risks categorized but they're sort of mutually exclusive categories that don't capture the fact that we're all combinations of many things, and in relationship to another person. So, if I'm an African American young man who has sex with men on occasion and sex with women on occasion, and I live in rural Alabama, what of all of those features of my personhood are really the ones that matter about my risks and my capacity to protect myself and other people. We tend to think, well it's your ethnic identity, or it's your age, or it's your sexuality or it's your geographic location. We don't know how to put that all together, and think of the person, the whole person in the whole environment, and then again in relationship to another person who are then being seen in a social environment, how we get there, I think, is a major undertaking. Social scientists, I think, have been arguing this forever, on how you are going to operationalize that in standard epidemiological field, by making a huge challenge.

JACKIE JUDD: (UNINTELLIGIBLE) is Ron (Unintelligible) with the CDC with us, and he agreed to say something. He gave me the nod. So, Ron do you want to take any of this on?

RON: Well, two points, we certainly want to recognize that the government has an important and ongoing responsibility

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related to the domestic HIV/AIDS epidemic, so I don't think that any of you should let us off the hook, but I do want to follow-up on one thing that Marsha said that it is clear that government alone can't address this issue, that no matter how we look at it. I mean today we're looking particularly at the issue of HIV/AIDS among women, but no matter how we slice it, government alone can not affectively address is. I also think that a larger context that we're dealing with is the overall complacency in the United States around HIV/AIDS, that it's no longer a problem, and several speakers referred to this that the treatments are such that it's not that big of a deal to become infected. Now, when you overlay that on the end of particular issues related to women, especially women who've maybe socio and economically disenfranchised, it's a really deadly combination. So, I do want to say, just make a couple of points that government has an ongoing responsibility and all of you should continue to push government whether that's CDC in terms of it's prevention policies, NIH in terms of the kinds of research it's funding, Hersaw (MISSPELLED?) in terms of treatment for people living with HIV and AIDS or SAMSA (MISSPELLED?) when we're dealing with substance abuse and drug use and other mental health issues, we all should continue to keep pushing us in that regard, but my point is that this problem is complicated enough that we cannot do it alone, and community mobilization is clearly needed at this point in

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JACKIE JUDD: (Unintelligible) Thank you all. Thank you. We're going to take a brief break. There is lunch outside. You can grab a box and bring it on in. I also wanted to mention to you if anyone wants a DVD or Rory and Jed's fine video documentary, it's out at the registration. So, come on back real soon.

[END OF PRESENTATION]