

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

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FEMALE SPEAKER: In the beginning of the epidemic, this was predominately a disease that was affecting men, but women have increasingly made up more and more of new HIV infections. Now about 30 percent of HIV infections are occurring among women particularly women of color, African American and Latino women. There are a lot of issues that are different for women than they are for men, and also a lot of issues that women are facing that make this a very challenging disease. As an epidemiologist, I focus a lot on the numbers and the statistics. If we don't see the faces behind those numbers, this isn't real for people. New York because the epidemic has hit hard is a city that does have a wide diversity of services, but still we're seeing more and more young women be affected by this disease.

MALE SPEAKER: (UNINTELLIGIBLE) it's a community in pain. It's a place where a lot of people have a lot of social economic issues, healthwise, economically wise, and it's a different community in need of help, and that's why we're here. We find a heterosexual community, especially Hispanic females and Black females are on the rise, and they're not commercial sex workers. They're not IV drug users. They're just regular homemakers trying to live like young ladies say from the age of say 18 maybe to like 25, 26, who have partners that aren't there, doing whatever they're doing, and coming back and infecting these women. We feel that we are soldiers by letting

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this epidemic for the past, I don't know I would say 20 years maybe - I think we're the only program that's out here on the streets meeting people where they're at, going to people where they congregate and providing this information.

STACI: When he came around, everybody was just getting tested. Why not? If I have something, I would like to know, keep myself healthy. The most important thing in my life is my kids. We live in a neighborhood where so many young girls got babies and their mothers take care of them, but when you walk around the street you hear them call their mothers by their first name, and their grandmothers "mommy". I couldn't do that. It's like she's my responsibility. When I got pregnant with her, I was all for being a mother. I didn't mind if I couldn't hang out. I didn't mind if I couldn't go to the pool, or go to Coney Island, I didn't mind because I was ready. Their fathers is there, but sometimes they do for them whenever they feel like they need stuff, but they're little kids. They basically always need something, and to me, as long as you focus, it's like you can do it.

MALE SPEAKER: Okay, Staci, I have the results here from when you got tested on the first, and your test came out positive.

STACI: Do I have AIDS?

MALE SPEAKER: You're HIV positive, which means that from this test you took, they have detected the antibodies of

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STACI: I don't believe this. Please take another test because I don't believe this.

MALE SPEAKER: What we will do right now, we will do a blood test, but this is 99.9 accurate as a blood test. I know, I know Staci.

STACI: Sorry about that.

MALE SPEAKER: Sit down, think about this. Think about it.

STACI: My kids.

MALE SPEAKER: I know, but let me ask you a question. When you had your kids did they ever test you? And it came out negative?

STACI: Um Hm.

MALE SPEAKER: I'm going to ask you another question - do you have any partners that you've been dealing with that you haven't been using protection with that you can remember right now? I know it's kind of hard to remember, but do you have any that comes to mind? Okay. Is this person a regular person?

STACI: Um hm. My son's father. I know it's him. That's the only person I've slept with in seven years.

MALE SPEAKER: And, you guys don't use protection or anything?

STACI: No, but that means evidently he was sleeping around.

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MALE SPEAKER: Okay. So, this is what we're going to do. I'm going to ask the nurse practitioner to come onboard. We're going to draw the blood and we're going to send this out this afternoon, and within two weeks times, we will get the results, and then we'll go from there. I'm sorry.

STACI: That's okay.

MALE SPEAKER: OKAY? But, we will deal with this together. All right? I know maybe she wanted to break down, but she held herself up. When she's by herself, I believe that's it really going to hit at that time, and I'm sorry I won't be there to console her, to help her out at that moment, but I think it will happen, and she will come to grips with what we told her to do with that positive result.

STACI: (UNINTELLIGIBLE) But, there's nothing I can do. I can spin back the hands of time, but I could live with it, deal with it until my day come. That's how I see it. Everybody got their day. So, until that day I'm going to be living my life the best that I can. That's all.

MALE SPEAKER: At any given time we're not sure what might happen. It could just go crazy or it just might be calm. But, we know some people want to commit suicide. We have some people who's angry at the world, and you have people who will just deal with it, and all I can see for right now is she is just one individual and I think she's going to do well with this. We've just got to wait and see and support her as much

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as we can.

FEMALE SPEAKER: Increasingly, HIV is really hitting women in the south, and most of that's do to heterosexual transmission. Because HIV is relatively new, because there's lack of knowledge, lack of services for prevention as well as care, there's still a lot of stigma and shame connected to this disease.

FEMALE SPEAKER 2: Good morning!

AUDIENCE: Good morning!

FEMALE SPEAKER 2: I don't know what you're trying to do, but I intend to praise the Lord. And, guess what I had a reason to praise the Lord because you know what? He brought me back to this place to let you know that God is alive, and he is with us.

I found out like in '91, and just had come out of an 18 year marriage. I had no idea of HIV and AIDS was out there, and I had started dating again. So, it was like - when did all of this come about? And, how? I thought I was getting ready to start my life over again, and it was like I had been handed a death sentence.

FEMALE SPEAKER 3: (UNINTELLIGIBLE)

FEMALE SPEAKER 2: I went to a dentist appointment. As soon as they read that I had tested HIV positive, it was like everybody in the office got ghost, nobody wanted to be around me. So, I just - I tell no one. I said if I'm going to die I

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want to do it fast, in a hurry. I just started partying. My cup of coffee was a 24 ounce can of beer. I came home from work, I might of drank six more 24 ounces and go to sleep, that was the only way I could cope with life. The (UNINTELLIGIBLE), suicide, and then I thought about if I kill myself, I've got three children that are going to be motherless. So, I said, "Okay, I've got to pull it together one way or the other." And, that (UNINITELLIGIBLE) the first black woman that was really willing to speak out about HIV and AIDS and admit that they were positive.

MALE SPEAKER 2: That is one of the main things that have helped. I need to turn my life around whereas just watching her and I'm (UNITELLIGIBLE) you know that, and I mean anything is possible.

FEMALE SPEAKER 2: If my children can deal with it, that's the best thing I can have, but hey, I'm the one that's got to live with it. (UNINTELLIGIBLE)

But, you never know how many days you have to feel good and until you have a lot (UNINTELLIGIBLE)

Everyday that I'm above ground and I can get out of that bed is nice. That makes me want to go and have somebody else. My greatest hope for the future is that people will be able to face this disease, not only medical people will be able to handle it, but the person that has to live with it will be able to stand up and to say, "Hey, I've got HIV or I've got

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AIDS, and I'm determined to live." I'm determined to fight my way back to health, to good health. I'm determined to live a more effective and positive life.

FEMALE SPEAKER: Because this is a disease that particularly affects people in the reproductive years of their life, many of the women who have HIV and AIDS are women who have children, and have to think about what they're going to put in to place to ensure that their children have a good life after their gone.

MALE SPEAKER 3: How are you doing at home? Do you have fevers at night?

FEMALE SPEAKER 3: Yeah, I have bad chills and sweats. I get the chills so bad (UNINTELLIGIBLE) and I'm shaking so hard it makes my whole body hurt.

MALE SPEAKER 3: How are you doing as far as your appetite is concerned?

FEMALE SPEAKER 3: I don't have an appetite, and that's the reason my case manager said I need to get home delivered meals because I'll eat something, because it's already prepared for me I don't have to get up and prepare it for myself.

MALE SPEAKER 3: How are you as far as (UNINTELLIGIBLE)?

FEMALE SPEAKER 3: I'm trying to be very much walking on, and I tire real easy and I have to be careful because I get real light-headed. I have to grab a hold of the walls or

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something to keep from falling.

I came here to die. I don't want my children to see me that way. I had gotten to the point where I told my children, "if you come home from school if I'm a sleep, wake me up. If I don't wake up you call 9-1-1."

It gets to the point where I just want to lay down and go to sleep, but not wake-up.

FEMALE SPEAKER 4: You don't expect to die with children. I mean it's just not something you expect to do. Until it gets in your family, you never think about AIDS. People don't. You don't. And, when she told me she had full blown AIDS, it was like somebody just reached in and ripped my heart out of my chest. I've talked to the Lord about it, and I begged him not to take her until her children were grown because they need their mother.

FEMALE SPEAKER 3: If my children weren't happy at my parent's house, I wouldn't be living in Horizon House even if I had to live with a mission with my children. I really believe they've got a chance at life now where if they stayed with me, they may not have. They get to do a lot of things now that I've had to cut out with them, because I wasn't able to get them there or - they stayed home with me. They wouldn't go to do other things that they could've done at home because we need to be there with mamma.

MALE SPEAKER 5: Dear gracious heavenly Father, we thank

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you for this day that you have given to us.

FEMALE SPEAKER 3: Now, with being at nana's they kind of get to do things that they stopped doing. That's good.

MALE SPEAKER 6: How are you doing?

FEMALE SPEAKER 3: Just tired.

MALE SPEAKER 6: We did your blood work last week, and let me go over two of the more important tests that I think you need to know about by heart. One is the T-cell count, which like we said before is a measure of your bodies immune system. The higher the number, the better. 750 is normal. 200 is AIDS. Less than 50 is advanced AIDS. You have a T-cell count of 5. So, if this is 750, this is 200, this is 50. Your T-cell count is very low. It's not good.

She's going through a rock and a hard place. She's not able to be (UNINTELLIGIBLE) with her medications, because she feels bad. She doesn't have the energy level to take her medications, and yet as a medical provider, I'm telling her that she has to take her medications a hundred percent of the time in order for her to improve. It's very difficult, again, because her quality of life at this point is very compromised and it's like a dog chasing it's tail.

FEMALE SPEAKER 4: You can't imagine the heartache, the pain, that you live with everyday watching your child die a slow death, and that's what it is a slow death. The medication sometimes I works, sometimes it don't - watch them be so sick

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10/23/03

they can't - you have to hold them up. Each day, you look at your child and know there's nothing, you know, I can't fix this. This boo-boo mamma can't kiss and make it well. I'm going to outlive my child.

FEMALE SPEAKER: The drug regimes don't work all the time and they don't work for everybody. They're complex. They're expensive. They have side effects, and just like Tammi who developed resistance to these drugs, and so why they have made a huge difference. They are not a cure, and they don't work for everybody all of the time. 1991, when Betty was first infected, there probably weren't even services available. Betty was a real pioneer in many ways. She has opened up the path for other women with HIV in her area to handle the situation much differently and probably easier than she was able to. Women with HIV and AIDS who also have children face many challenges. Most of all this is a disease that requires a lot of time taking care of one's self. So, it's difficult when a woman also has children to take care of, but Staci may actually be in a better position than a young woman who lives in a rural area or a young woman who lives in a city and hasn't had the long experience with caring for people with HIV like New York has. People still die of AIDS because we have not found a cure for AIDS, and women who have HIV face a variety of different challenges that their male counterparts don't. Most people still don't think of HIV as a disease of women. We have to do

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Kaiser Family Foundation

12

Women and HIV/AIDS in the U.S.: Setting an Agenda for the Future

10/23/03

more to make a difference in this epidemic.

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