MCHB/ DHSPS June 7, 2005 Webcast

More than Just a Number: Realities of Women and HIV/AIDS

BENITA BAKER: Good afternoon and welcome to the webcast. More than just a number. Realities of women and HIV/AIDS. This webcast is brought to you by the Maternal and Child Health Bureau, Division of healthy start and perinatal services in the Office of Women's Health in recognition of the national HIV testing day on Friday, June 24. I'm Benita Baker, project officer with the Division of healthy start and perinatal services. Before I introduce today's speakers I would like to review some technical information about the webcast. Slides will appear in the central window and should have advance automatically. The slide changes are sin con iced with the speaker's retations. You don't need to do anything to advance the slides. You may need to adjust the timing of the slide changes to match the audio by using the slide delay control at the top of the messaging window.

We encourage you to ask the speaker questions at any time during the presentation. Simply type your question in the white message window on the right of the interface, select question for speaker from the dropdown menu and hit send. Please include your state or organization in your message so that we know where you are participating from. The questions will be relayed onto the speaker periodically throughout this broadcast. If we don't have the opportunity to respond to your question during the broadcast, we will email you afterwards. Again, we encourage you to submit questions at any time during the broadcast. On the left of the interface is the video window. You can adjust the volume of

the audio using the volume control slider which you can access by clicking on the loudspeaker icon.

Those of you who selected accessibility features when you registered, will see text captioning underneath the video window. At the end of the broadcast, the interface will close automatically and you will have the opportunity to fill out an online evaluation. Please take a couple of minutes to do so. Your responses will help us to plan future broadcasts and improve our technical support. We're joined today by two speakers, Dr. Victoria Cargill, director of minority research and clinical studies, Office of AIDS research National Institute of health and by Alicia Beatty founder of the Circle of Care in Philadelphia, Pennsylvania. At this time I'll turn it over to Dr. Cargill. Thank you.

VICTORIA CARGILL: Thank you very much. I would like to start off by talking about the numbers and the fact that the numbers actually -- we'll go through the numbers and go ahead and talk about the cases.

Our next slide. Our goal this session just to remind you is to identify the impact of HIV infection upon women and to identify these women experience in seeking HIV care and services and also important to identify the factors to be considered when providing services of affected and infected women. If you look at the first slide, this is updated through 2003 from the centers of disease control and prevention. What you'll notice in the purple we have a cases in the turquoise and persons with aids and yellow persons living with HIV infections. There are a couple of benchmarks to note. In 1993 we changed the

case definition a bit and that's important. We're talking about women because the inclusion of some women specific diagnosis such as cervical cancer and another important benchmark is between 1995 and 1997 and 1996 the implementation of what has been called highly active therapy HART or anti-rectal vile therapy. Whatever your terminology the most important thing to note is the deaths beginning in 1995 with the continued and abrupt rise of the number of people living with HIV infections. That's important because of the number of people living with HIV infection increased the number of people capable of spreading and acquiring infection also increased.

Take a look at this case rate from 32 states that report HIV and AIDS cases among males. When you talk about females we have to talk about males. It doesn't mean we exclude women who have sexual contact with women but many women who have sexual contact in women have at some point in time had sexual contact with men. The green is for black or non-American or Hispanic. The turquoise, native America and Caucasians in the yellow. The most important thing to note and we're talking about race. It's the number of cases per 100,000 people. We can standardize in the population. If you notice when we're talking about males for black males we're talking about 100 cases per 100,000 black males. Contrast that to 40 cases per 100,000 for Hispanic and Latino males and contrast that for American and Alaskan males. There is a disproportion. We look at females we see a gross disproportion. In addition to the gross disproportion it's not as if the numbers are close together.

They're wide gaps. If you look at the green legend, African-American, the orange is Hispanic. American Indian and others, when we look at women in these on the 32 states reporting we're talking about 50 cases per 100,000 African-American contrast it to 10 for Hispanic and Latinos and as little as 2. Case rates that are 25 times difference by population, a clear-cut health disparity. The Institute of Medicine says HIV/AIDS says it is on their list. Looking at this, taking a look at cases among adults and adolescence by gender -- or sex as well as by behavior, and the main take home message I want to point out. When we're looking at males the red is heterosexual contact. But in females note that over 70% is heterosexual contacts. Another reason to talk about male partners. You can't talk about this disease in isolation. This again is what you saw earlier in terms of race in the population. This includes all states as well as the district of Columbia taking a look at male adults and adolescents. For 2003 we're reporting black males 12.8 cases or 40.3 in Hispanic males per 100,000. I want to draw your attention to African-American, Native American. They have 16.2 higher than their Caucasian counterparts. It's often to forget indigenous people because the numbers are small. This is a gross overrepresentation in their community.

Next slide. Again the same for the race but now we're looking at adults and adolescents for all states. Please note that the second population group black non-Hispanic 50.2 cases of AIDS in African-American women per 100,000. Please take a look at Hispanic 12.4 per 100,000 and American India Alaska Native 4.8. They are two times that of Caucasian women and less than 1% of the total population. For African-American 25 times that of their Caucasian counterparts. Hispanic six times that of their Caucasian counterparts.

Next slide, please. Finally if we take a look at the difference by age category by male and female as well as the rates per 100,000 please note while females do not begin to equate with males they peak slightly before males. The reason is the difference in age bias in terms of coupling and women tend to have sexual contact with males who are older. Therefore you see the women see it before the males do.

Next slide. Just to keep us focused on the fact that HIV, while important, is not the only cause of death, please note where cancer ranks as well as when we often tend to forget about heart disease and homicide. These are communities under siege with multiple problems. To look at this disease is isolation you miss the context of these women's lives.

Next slide. As you'll see here, this is the number of perinatal acquired cases by year of diagnosis showing this is a great success story that we can see very few children born in this country with perinatal acquired HIV infection. While we've been able to help this end please remember those who are carrying the perinatal children, we're seeing them as infected young adults reaching sexual mat urn -- maturity and have to encounter other things with sexual activity. Just a reminder that HIV infection, while it may be a disease is driven by many things in our society. We know that we have shown you improvement that there is a demographic bias in infection rate. It's driven by many things, racism, homophobia, it's a health disparity. Differential access to care, also substance abuse issues, alcohol abuse, immigration issues, people don't wish to come forward if they're undocumented. We have ages and biases in this country. We have a CIALIS and Viagra

outbreak. The stunning silence around this infection. The outrage and demand for access to care for additional medication is just quiet.

Next slide. Women are more than numbers. I make this point saying these are numbers that have faces. Next slide, please. I want to share with you a couple of cases. First case is a patient -- these are real cases. This is a 50-year-old African-American female had a long history of substance abuse, crack, heroin, Methylprednisolone. She showed up in our hospital the cab opened the door, kicked her out and there she was. She had been kicked of five emergency rooms. She couldn't stay with her friends because of her diarrhea. She yelled in the waiting room and told a social worker she would give her money. We need to talk about what failed. When she went to emergency room number one. There is a reason she went through five. The physician that saw her said there was no way he would treat her HIV infection until she cleaned herself up because of her drug problem. Emergency room visit two the patient walked out because she waited too long. We'll come back to all of these. There is another side to the story. Emergency room number three the social worker wrote in the chart the patient's language was foul. Emergency room number 4 she was kicked out because she was found stealing oxygen masks. Emergency room number 5 by passed these problems. When she showed up at our institution they referred her to the HIV clinic.

Next slides. Well, there is a story behind everything. We often hear at least three sides. Your side, their side and the truth. The patient had done her own drug treatment so she was quite offended that emergency room number one suggested she do drug treatment. It

may not be our drug treatment but if the patient perceives that what they've done we have to respect that. She walked out. This woman had diarrhea and incontinent. Nobody wants to sit with soiled clothing. In the third one the social worker asked about her children and her oldest child had been a narcoticly addicted baby when it was born. Her only child, her youngest child was a male, completed school and the child she had completely sober and his girlfriend had murdered him several weeks early and didn't want the talk about that. The oxygen masks is because she needed the money. They have a tube connection they could use it for tourniquets. You better understand their language and you understand where they're coming from. The doctor in 5 told her the case wasn't urgent. There had been a gunshot and the person that was shot to him or her it was not an urgency. Someone with seven days of diarrhea it's an urgency.

Next slide. There were some small victories. Her diarrhea was linked to eating from a trash cans. We gave her intravenous fluids to stop the diarrhea. I negotiated a contract with her and I wanted her in the office. If you want Darvon you would only get so much to hold you for a month and told call up my story about losing it. Her son's death had triggered her spiral but ultimately meeting her on her teams she was able to live for five years and she died not of HIV infection but of her crack cocaine lung.

Next slide. This is another young woman, 15-year-old Latino female sent to juvenile detention meaning she was unruly not coming home when she was coming home on time. She showed up there. Had a physical exam. Had three sexually transmitted infections, HIV test that returned as positive. Note the issue was not going to HIV test this woman.

They asked us if we thought they should. When someone shows up with multiple infections an HIV test was a good idea. Her mother was told about the results. Once she was found to be positive she was booted out of detention the same day.

Next slide. That's only the beginning of trouble for people who do not wish to deal with HIV infection I strongly encourage them to become partnered with people who do because shoeing the person out the door doesn't mean the problem doesn't go away but ends up at another person's doorstep. She became truant. We had a conversation with the school nurse. The school nurse thought if she was old enough to get HIV infection she didn't belong to school. Connie felt her mother didn't care. Started missing visits with our pediatricians. She admitted not having protected sex. When we offered treatment because her numbers indicated treatment, her response is basically, I don't need anything on drugs. So now looking at it from her perspective. Why should I go to school? No one wants me. There I have to live with HIV. I don't need to be bossed around by anyone. My mother isn't listening to me. I don't want to take those drugs. I heard the drugs make you sick.

Really, for her the bottom line and if you've never experienced it it is very difficult to have a 15-year-old look you in the face and said would you come I would speak at my funeral? I wake up every morning wondering if I would die today. We had to intervene. He found out there was a ton of abuse at home. We removed her from the home. The school nurse got a personal visit from one of our staff for some AIDS 101. Connie was moved to her grandmother's. We took her to a jelly bean trial before putting her on medication. Got her

switched to an adult service frame of mind. Her adherence continued until I left the practice. She was living, and not dying, with HIV infection. Before I go to my next to the last case I want to say that the file of the case may be offensive. It is not meant to be. The title of the case is actually something a provider said to this patient and if you find it offensive, I find it offensive but I'm showing you this to help you understand if you're a woman living in HIV infection and a provider says this to you and you already are in pain and agony for your HIV infection how much more an affront to your dignity would this be? A white girl with HIV? This is a 32-year-old white female employed near our offices and the manager of a transcription service. There is no privacy. She had a 9-year-old son from a previous marriage. Her husband died of hepatitis. She has a new partner, she's pregnant. She is a medical transcription service manager so she reads a lot and also reads the lay literature and we've got a lot of -- she needed an HIV test if they're pregnancy. They blew her off. What do you need a test for? It's not like you're a minority living in the inner city.

She got the test done after pushing. He called her at her job with her results saying, next slide, I've never seen a white girl with HIV before but don't worry I'll still deliver your baby. Now, I don't know about you but I was so overwhelmed when she told me this I had to walk out of the office. I couldn't keep my composure. I took me a good three minutes to calm down. Turns out we have to remember that women are caregivers. Women will die so their families can survive. Women will go through a buzz saw. HIV positive women are no different. Especially after the same OB that tested her son he declined. She gets her son tested. That test is positive and the same OB calls her at work again telling Health

Resources and Services Administration son is positive. When she falls apart he says counseling is not her thing. A pediatrician she saw referred her to us. Her mother-in-law has now known his picture. He had asked his mother at his bedside to not share that because he died of AIDS. Her partner was a long distance truck hauler and due that night after a long trip. You can imagine there were many issues to discuss in a short visit.

Next slide. There are some points of reference. We can go through the details of this. The main thing is there has to be advocacy. She has to ditch the OB. Keep the pediatrician. Need the information. We had to teach her about HIV and pregnancy. What we can do to intervene and we didn't have to pretend on her OB. We linked her pediatrician with her son. We introduced ways of sexual safety and delay sexual contact until they had the conversation including offering that conversation in our office where she's safe and finally, we offered our availability in the office.

Next slide. I want to give you some take home points. We talk about these numbers and throw these numbers around all the time. Every number is a case. HIV isn't the whole story. I still see patients in D.C. where we have more than enough HIV and it's easy to get sidetracked just on HIV and it swallows up the whole woman. We have to continue to push for greater access to treatment, knowledge of treatment and advocacy for women and we have to stop taking no for an answer. My slide about being silent. No food, no care, no money is killing women everybody. The fastest way to get some money is to do sex on the street. You'll get more money if you sex without a condom than sex with it. HIV is more than a person in front of you. That personal comes from a social network. For everybody

who cares about them or cares for them is actually sucking the life blood out of them. It's a very wearing job. For providers HIV work is hard, not easy. There is not a long line of people behind us, you have to rest often, fight hard, stay focused, never give up. If Winston Churchill said not give up when bombs were falling, then we shouldn't give up. If you're here for an STD and that is the behavior we talk about, we need to talk about that behavior now. Learn as much as you can about female controlled methods. Male condoms still requires to partner to cooperate. We have microbe sides.

View her as a whole person.

Next slide. I have tried to share through the presentation numbers but also some suggestions and I do not claim to have the corner of the market as I continue to learn from my patients. This looks like a bad Baobab Tree no one person can embrace it. I'll stop here, thank you.

SABRINA MATOFF-STEPP: OK. Wow. Hi, everyone. I'm Sabrina Matoff-Stepp the acting director of HRSA women's health and I'm pleased to take a minute to welcome you all to this presentation. We have two fabulous speakers. You've heard one and how do you beat that? We're going to try here. Our next speaker is miss Alicia Beatty with The Circle of Care in Philadelphia and I'll turn this over to her now. Stay tuned.

ALICIA BEATTY: Well, you can't beat it so we won't try. The Circle of Care is a strong, vibrant voice for families in Philadelphia that are living with HIV and AIDS.

Next slide. In 1989 The Circle of Care became a reality, under the leadership of the family planning council this program was crafted for families, including women, youth, children and adolescents in Philadelphia with HIV disease. Next slide. Our mission is to provide the best HIV care that anyone in America can get. For our families struggling with the virus. Next slide. This presentation will cover an overview of the Circle of Care network, a chance to integrate family planning and HIV care, and The Circle of Care's perinatal services.

Next slide. The demographics you see are for the year 2004, not 2003. We currently have 1,100 families in our system and 1,776 individuals. Out of that, 76% of them are African-American, mostly women, mostly single heads of households. Our percentages sort of mirror the epidemic in Philadelphia when it comes to women. We have con -- these numbers are constant and have been that for about 15 years now.

Next slide. Our provider network is incredibly diverse and extensive. We fund four providers for intensive case management and case management services. Families are assigned an assistant case manager based on an acuity scale. If you have a low acuity you get a case manager that works with you and your family in the home. It was developed by one of our providers, funded by a grant from HRSA through a project for The Circle of Care. The scale is now used throughout our network and the system in Philadelphia. We have five contracts for primary and specialty medical care in our system. And they have a clinic-based case management system. Most of the families in our

network are seen through case management that is hospital based. In addition, we fund three organizations to provide counseling and testing and early intervention/case management. Then we have three health resource centers that are located in high schools in Philadelphia. They provide condoms, education and access to testing and counseling. A respite center is centrally located in Philadelphia. We fund that. They also provide on-site childcare at clinical settings. We also have a HUD grant. We have a large housing corporation in Philadelphia that takes care of 17 apartments that we have scattered throughout the city that provide two and three bedroom apartments for families.

Next slide. Our program is funded primarily through title IV. We are an all title IV program having been around for 15 years. We also, as you can see, have a range of other funding streams. I would like to just mention that the latest funding we got from the State of Pennsylvania, $225,000, is to promote and do city-wide testing events. We are doing seven events in communities heavily impacted by HIV. We have one tomorrow night for women only. And it is going to be a very festive occasion. We have a lot of prizes that have been donated, we have entertainment, we have a D.J. We have all kinds of food but the bottom line is to encourage women to get tested, to know their status and if they are positive, to get into care.

I would also like to mention in terms of funding in 2003 we revamped our funding system for funding of primary care and case management. We now fund those providers on a capitation rate. They get a set amount for the number of HIV positive clients, the number of affected and babies. We thought it would free up money to develop new programs for

women. That didn't happen because everybody is beating the bushes, getting the families in and so what we have now is the cleanest data you will ever see, and what we also have are providers that are working incredibly hard to make sure that people stay into care. So we'll have to figure out another way to get some more money.

Next slide. Our network is one that, because it's so old and so highly developed, we have had to centrally as The Circle of Care figure out what our goal in this besides a funder. We know that we are the glue. We continue to help the system be seamless so that families, women and adolescents can navigate the system in a seamless way. From prevention to care services and never have to skip a beat. They don't have to look around for a provider because we've got a provider right there. When we do counseling and testing, we have a social worker as part of that team, particularly for rapid testing so that they can immediately go into care. If it's Friday at 4:00 they go into care immediately because the social worker is right there and she's booking them up. What we know is that our providers rely on us to do the services. They are in the trenches every day. My staff has the flexibility to be able to look at the system and figure out what the gaps in service are and try to find funding to fill them. Next slide. This is just the array of services. I've gone over that so we can move on.

Next slide. Our network has done several things very well. One of the things that we pride ourselves in is listening to our providers, many of them are very anxious about losing funding right now, particularly in title II. We are looking to see how we can help fund those gaps. And most importantly, we are on the ground close enough to consumers, to women

and youth and families in our system, we know what's going on. We have constant feedback. We have peers on staff that are HIV positive women. We have focus groups. We listen. We have members of our board that are consumers. We want to know what the needs are so that we can match the needs with the resources and with the appropriate providers.

Next slide. One of the things that we have learned is that we've got to stay ahead of the curve. So our evaluation director took a look at our extensive database and one of the things he found is that there was an enormous amount of women that were having tubal ligations as their means of contraception. Well, we paused and said that won't do. First thing we did was extensive education of survivors and then we said we can change this. We can fix this. The Circle of Care is a program of the family planning council, which is the big gun in Philadelphia for family planning services. The family planning council provides funding for over 90 family planning clinics in Philadelphia and the counties. So if -- beginning in 1999, we began to try to meld together HIV services and family planning.

Next slide. We had four major goals. The first goal was one -- one of the goals was to bring family planning services into HIV care settings. Another goal was to institutional counseling and testing in family planning. Also make sure women that present for HIV tests were also given a pregnancy test. And then to provide lots and lots of education and training for providers so that we could keep this system moving ahead.

Next slide. We also have found that one of the real jewels in the crown of the Circle of Care is the use, the employment and the listening to of women that are positive and are role models for other women. On our staff at any given time we have from three to five positive women. They have been the bridge between counseling and testing and moving women into care. They have worked on the tough issues that often providers hesitate to tackle. They help women continually with their -- we have several women that know all there is to know about medication and they take out pill boxes. Just the other day we cleaned out -- it was hard to find these pill boxes but we had several instances where women needed education on the spot. We got the pill boxes, we got them to the hospital and now that makes a difference. When you have a woman that is living with this virus that meets a woman at her point of need, which so often is when she gets the diagnosis that makes a difference in their lives.

The next slide. We have integrated the peer counselors, family planning and OB services. In one instance there is a family planning site down the hall from the OB clinic. The peer counselor checks in at family planning, she goes down the hall to OB. If there is a need for her to give a diagnosis, she is in family planning and she is weaving her work through family planning and obstetrics. So that is a connection that we're trying to strengthen at all of the large hospitals.

Next slide. One of the things that has happened in Philadelphia, we have lost hospitals that deliver women. As of -- prior to 2003, we had 16 delivery sites. Today in 2005 we only have nine. That's an incredible loss. What it has done, it has made it very difficult for some

women to receive prenatal care. What we have to do continually is bundle our services so that women can get them at their point of need. We've had to combine, as we said, the HIV and prenatal care services at those sites. We have intensive case managers there and we work closely with the peers, with case management assistants, with the doctors to make sure women stay in care.

Next slide. We know that if we are able to get on site at all of the hospitals. Let me just step back for a minute. In Philadelphia, our funding does not allow us to cover all of the hospital sites. So we are able to do four sites. Those are the largest sites. What we want to do. Our vision is that we're able to cover the entire City of Philadelphia. That's what we're working at. When you look at what our team looks like, a nurse case manager, a peer educator, and then linking them into the planning family services it is an intensive model that requires resources beyond what we have today.

I would also like to mention our perinatal review panel. It is fashioned after the mortality and morbidity review panel. It is a quarterly meeting where we have perinatologists that take a look at -- something happened in the last quarter. There was a baby born in Philadelphia that the virus was transmitted to. How does that happen? What went wrong? What can we learn from that case? And that happens on a quarterly basis. Thank god there are quarters when we don't have that. The providers are able, then, to share resources, to talk about other issues. It is a fabulous kind of snapshot at our system and I must say it is one that is so highly thought of by our providers because they all come and we get more and more every month.

Next slide. I would like to just highlight two programs that we feel are doing a phenomenal job in bundling all three of the services that we talked about. First is the partnership which is a program of a university. It is the largest provider of clinical services for women in Philadelphia. They have a very consciously developed a women-friendly program. That program includes family planning services. Prior to our move to put family planning into HIV care, the partnership was located on the second floor and the family planning services were located on the third floor of the same building and they never talked to each other. You went to HIV care and got a slip and you went upstairs to family planning. That didn't make sense. So now we have cross trained the nurse practitioner and she is able to give family planning services to a whole bunch of folks. 69% of her cases are female. 34% are males and they are over 70% use condoms as one method. But she definitely prescribes Deprovera. A woman goes to the Children's Hospital and provides clinical care for all the moms that are seen at Children's Hospital at St. Christopher’s. In 1989 when this model was formulated, you absolutely could not get care at a Children's Hospital if you were an adult. We changed that model and so Erika goes down there and takes care of the moms there. Also, at that hospital we are able to bundle all of the services that one can get through The Circle of Care. They get Title X funding now for family planning. They get Title IV, title I, they get all of the funding that is available through The Circle of Care. What we realized is that that one stop shop model is one that absolutely works because people are staying in care.

Next slide. What we've learned. We've learned that the network concept is one that needs to be continued. We have also learned that peers on an incredibly important link to support women into care. We've learned that assistant case managers who go into homes and support families with daily living tasks, with light housekeeping are an expensive part of our program but they're absolutely essential. We've also learned that we have to continue integrating HIV and family planning. Now, at this point The Circle of Care is using some of our funds to do that. But the staff of the family planning council have worked very hard. They've gotten additional money to integrate HIV into family planning settings throughout Philadelphia.

Next slide. Our future challenges. We know that we have an incredible job to do when it comes to adolescents. In one of our sites there has been a 30% increase over the last year of adolescents coming into care. We've also seen an incredible jump in African immigrants in our system. We don't have funding specific for this population but we are looking to partner with organizations that are already doing that work and to see what we can add in terms of our services that don't require funding until we can move to new money for new immigrants. We also know that we have to continue to get women into care better. We have to get them in earlier. We have to keep them in care. We have to understand what it takes. I think that's one of the things that we have to work on continually. Understanding what it takes to keep women in care. We need to be responsive to all the changes in our system and in the environment that we live and we can win on this disease. We can fix it, we can end it. Thank you.

SABRINA MATOFF-STEPP: Wow. Thank you, Alicia. I just want -- we went through those pretty fast. I just want to let everyone know we did go through the presentations pretty fast and this presentation, both presentations this whole webcast will be archived in a couple of days, you can view it back at your leisure, you can review individual slides, again, this is all going to be available to you as a resource in case you missed something, you can go back and look at it. With a we can do now, we have an opportunity now to really interact with all of you who are watching and take some questions, which hopefully you're all still sending in. We have some time here. I'll go down my little list here and hopefully just start with some questions that have come in. And ask the speakers these questions. So continue to send in your questions and I'm going to find the first one. Here we go. The first question is, I think, for Dr. Cargill. It refers to one of her slides. Did the 15-year-old girl receive treatment previously for the three STD's and did the school do anything to help her?

VICTORIA CARGILL: She did receive treatment for her three sexually transmitted infections. Treated waiting for the results of her HIV test. The school nurse refused to do anything to help this child. She felt very strongly that if she was grown enough to have sexual activity and acquire sexual infections she was grown enough to be out there on her own. That's why I paid her a personal visit.

SABRINA MATOFF-STEPP: You did?

VICTORIA CARGILL: And it was ugly.

SABRINA MATOFF-STEPP: OK. Next question, I think this is also for Dr. Cargill. What is a jelly bean trial?

VICTORIA CARGILL: As I licensed to Alicia talk about adolescents. It adds gray to my hair, it is so important now especially because of the multitude of drugs that are available that we be clear that people are ready to enter into treatment. I think we have a tendency to think that because we have a pill in this country for something to fix it, we give it to people. HIV infection is different. High blood pressure if you take 80% of your pills we can take care of you. I have made myself feel better because I've given you feels and made you in trouble because eventually you'll have so much resistance all that is left for you is something like T-20 that is an injection. A jelly bean trial. I pick a candy. If somebody likes me M & Ms it has to be a candy that's different colors. I'll tell them. We'll set up a pill box for you, red jelly beans will be the same thing. Blue jelly beans if you get something else. These jelly beans and we go through the whole process. I want you to take these. The ones you miss I want you to leave here so I can see them. It is OK. I've never completed a full course for strep throat so I'm not here to be judgmental. We have to get to where we can get to 90% of this box being done. This is the total number of pills. We'll do a little math. A little math is X, see me in a week. If you can't see me, I have to call you. The first week is usually disaster. You cannot expect that. They'll say I like this much I hate the whole box. If you ate a whole box of real pills it would kill you. It takes, two, three, four weeks to get it done and I say to them, are you ready for me to make these jelly beans pills? If you are, I'll tell you what, you have a reward system. Every time you take the pill

you got a jelly bean to wash it down. And then we wean off the jelly beans and go on to pills. Something at the time I started doing this I had young children of my own and I knew about rewards so as a result I've incorporated them into practice.

SABRINA MATOFF-STEPP: There you go. Creativity. OK. Next question. This is, I think, sort of a more generic question and give both speakers a chance to answer this. Do you know a way to help a pregnant woman whose PDK count is 43 and pregnant with twins understand the importance of taking her medications. She's not adherent to the case management or medical appointments. Anyone want to start with that question? Maybe -- does everyone watching, just to explain what a CD4 count of 43 maybe explain what that is. It might add some context.

VICTORIA CARGILL: In the definition of HIV infection one someone has a CD4 count of less than 200 or a number of infections called ADI or AIDS defining illnesses they have clinical AIDS. The CD count of 43 is discouraging and a worry for several reasons. First, anyone who is pregnant naturally has immune dysfunction. It's how nature keeps you from rejecting your own fetus, whether you look at malaria. They all occur in pregnant women for the most part in their third trimester because you have the decline of virus and fungi and cancer fighting immune system cells. If a woman HIV positive the lower her CD count is below 100 and she didn't get to 43 without having a viral load the greater risk of transmission. For those individuals it's that group that is more difficult to prevent transmission. Even with treatment we have some transmission and it is more likely to be in those groups. That's why this is essential. I have some thoughts, I think Alicia, go first.

ALICIA BEATTY: I would suspect there are social issues involved here. We had a case similar to that recently. One of the peers came back from the hospital, Joyce, who said to me that she had a young woman that was very -- she would not take her meds at all. After counseling, folks were getting really frustrated by it. They asked Joyce to speak to her. Joyce spoke with her she found out that this young woman lived with her grandfather whose house was rat infested and the young woman was afraid to go into the kitchen at night. And so Joyce came back, we talked about it. What we said to her was ask her to call Philadelphia Corporation for the aging. They came out, sealed the house, the rats went away, the young woman is now taking her meds. I think what it takes is looking at it from every angle, not just from medical but the psycho social issues. Most of us know that they outweigh all the medical issues and they are in so many ways the reasons that people are not adherent.

VICTORIA CARGILL: I would like to add I think it's also important to make sure this woman understands the risk to her fetus of not taking her medication. Now, we have learned some lessons from the AIDS trial in the protocol which is when we first did this we did focus group work. This is critically important. Many women have understood for a generation, you don't take medicines when you're pregnant. What you take will affect your baby. So there are women who believe, I don't care, this is a virus I can't see, I don't feel that bad. I can't feel any worse because of the pregnancy. They take me to take the pills so strong they can kill a virus and it's multiplying. Isn't my baby is growing and multiplying, how do you know you're not going to hurt my baby. Also you have to decide and learn who

do these pills mean to this woman? I had one woman like this. Her issue was being pregnant is the best thing that has ever happened to me. Taking these pills make me realize the best never happened they could turn out badly. I don't want to take these pills because I don't want to deal with it. I don't feel I have HIV. The only time I think about it is see the pills and you see and I don't see either of you. We linked her with a woman who was HIV positive who had had three pregnancies and lost two babies. A third baby she got to keep because she took the pills and she has an HIV negative child. It's more powerful than what I can do. It ain't life. Life is on the hoof.

SABRINA MATOFF-STEPP: This question is to Dr. Cargill referring back to one of your case studies about the woman -- the last case study. The woman who came in that was pregnant and the question is, was the baby born positive? Her new baby.

VICTORIA CARGILL: Mary is a wonderful story because we were short on time I didn't give the epilogue. We took -- I went into teacher mode. Married had cards. She knew the protocol. We would say when do they clamp the cord? How long does it run, when did they dose the baby? It turned out that when she went into labor the OB supposed to deliver her, the one who was very difficult was not on call. The one on call was a new partner that just completed his residency and new the delivery protocol for HIV positive women. This child was nine pounds 14 ounces, 23 inches long and although obviously he had maternal antibodies we knew they would be anxious. Because I'm at a research site we cultured her and could tell her quickly you have a healthy, fat, negative baby boy.

SABRINA MATOFF-STEPP: Good story, though. OK. I think everyone really is interested in that case study. Here is another question. I think we're outraged about the clinician. Did anyone provide any HIV education training to the doctors who handle the cases that Dr. Cargill mentioned number two and number three?

VICTORIA CARGILL: In the case of the person for number two, because of the detention center called for me because I ran -- I developed and ran an aids education intervention program for adolescents who were site visited by HHS for our work. I provided that. But for the third case I had multiple interactions with this provider. He was not only not interested in HIV education, his ignorance showed. He tried to send this patient to us for an -- we explained it is not done. He said I'm looking to see if the baby was positive. He did not understand. We could not get through to him. Ultimately what we did is reported him to the Ohio medical board.

SABRINA MATOFF-STEPP: Good. OK. Next question, and I think this one is for -- more for Ms. Beatty. The question is, I realize this may be a different kind of question and she is new to this area of care. Is the problem with tubal ligations the invasiveness and permanence of the solution or that this solution still leaves the door open to HIV?

ALICIA BEATTY: I think, yeah, that is a good question. The perspective we looked at in 1999 was that, you know what? Women should have babies if they want to have babies and HIV positive women should have babies safely if they want to have babies. What we found is that providers were counseling them to get their tubes tied because they told

them they shouldn't have babies. It was just that simple for us. So when I said we needed to do some provider retraining and reteaching, it all had to do with the reduction of perinatal transmission and our push to have safe births. That was it. But from a medical perspective it has to be something else.

VICTORIA CARGILL: I do think the issue that women who are HIV positive should have the option. I feel I would be remiss as a provider to not explore with them not only the options available for conceiving but the fact that while we have taken for granted that 076 and other interventions to prevent mother to child transmission have been very successful it is not 100% successful. I want to make sure if women tell me they want to have babies they're truly prepared to accept the risk that there is a chance, even if it's small, that you may have a child who from the time they're born is HIV infected, a child with AIDS, a child with a lot of struggles. Having said that I think women need to be counseled if they're discordant relationships. They're positive and the partner is negative because we have many ways to intervene that these women can still conceive. I do believe strongly that women should have the option to conceive. I don't think you should take it away from someone. If you have an illness that is transmitted, you need to know what the risks are. The thing I don't want to see anymore is a woman sobbing in my office at 4:00 in the afternoon because she has a baby with a temperature of 105 and fry eggs on his head and saying no one told me that this could have happened. There is really nothing I can do accept say I'm sorry, I understand, let's see what we can do for this baby.

SABRINA MATOFF-STEPP: OK. Next question for Dr. Cargill. Would you agree that the real quark of the matter is how to reduce the incidence in the African-American male population? Most of my patients are African-American women infected through unprotected heterosexual exposure.

ALICIA BEATTY: I wouldn't say it's just African-American male. I say that for a couple of reasons. I think that in African-American communities there has been a longstanding, if you will, almost tension or battle between black males and black women. I don't particularly wish to add to that. I think the issue is that we're seeing the fruits of our mistakes. And that is the mistakes that I own and anyone should own. If you only talk to one segment of the population everybody else thinks you're not talking to them. If you look at a poster talking to gay men. I'm a black women you can't be talking to me. If I'm a black woman looking at a Latino poster. We have to make it a disease of everybody. If you're having sex you can get HIV infection. I would also say we need to look where our black men end up. One out of four are incarcerated. One infected goes in, 15 infected goes out. Despite what you'll hear from certain facilities people have sex in prison, they do use drugs. They come out and don't want to talk about that but engage in sexual activity with women, unprotected and they therefore transmit infection. It means we have to talk to everyone, male and female, about protection. It means to understand the dynamics of that conversation so that when I'm asking do you use protection are you hearing me say I don't trust you which opens up the other issues like women being beaten and killed because they've asked for protection because domestic violence is real. We have to empower men to feel if they want to have sexual activity with multiple people they have to use protection

because it's taking care of them. You don't get men to that point if it's a black men you've seen as a parasite in society because my wife is not worth saving so why should you care about anything else? HIV is not one disease, it's forced us to look at all the baggage in our society we've chosen to ignore. All the stuff we swept up under the carpet is such a big pile we're tripping over it.

SABRINA MATOFF-STEPP: Any other thoughts on that?

ALICIA BEATTY: No. I guess I just want to echo that it is the sum total of all theisms in the United States and we cannot look at it in a vacuum. That's so true.

SABRINA MATOFF-STEPP: Very good. Next question, how do we get the schools to see the importance of educating our teens about HIV? We have many rural schools and communities who don't believe HIV is affecting them. Who would like to take that one?

ALICIA BEATTY: That's a tough one. But I can say in Philadelphia we have some history with working with schools on this issue. When we first began, the notion of providing -- distributing condoms in schools was a revolutionary idea and we were able to make that happen. So we've moved now to the point where we have testing for Chlamydia and Gonorrhea in schools. With the support and partnership of parents and communities, if we have their support, then we can move to HIV testing in schools but it is going to take the entire community. So what I would say is that if you have not begun, you have to establish a dialogue with the powers that be in the school system and you really need to start with

community support. You are part of that community, you need to coalesce with other people that are like minded and take your ideas to the school system. It has taken us 15 years to get to this point in Philadelphia and we still have a very long way to go.

VICTORIA CARGILL: I would just say that schools often are reluctant because principals have to account to school boards who have to account to parents. One of the issues we have is if you ask a room of adults if they think that teen sexual behavior is a problem everybody's hand goes up. If they think their child's sexual behavior is a problem no one's hand goes up. That is where the crux of the problem is. We told them we wouldn't promote any one particular kind of behavior and people in the communities in some of the schools living with HIV infection, god bless them willing to come out and say look at me. I graduated from here ten years ago and I'm going to die from this disease. That's how we went on to peer education.

SABRINA MATOFF-STEPP: OK. Next question is for Alicia. Is it against the law for hospitals in Pennsylvania not to treat an HIV positive patient who isn't combative?

ALICIA BEATTY: Not to treat? Should they treat?

SABRINA MATOFF-STEPP: Is it against the law to deny services?

ALICIA BEATTY: Absolutely. Absolutely.

SABRINA MATOFF-STEPP: OK. That was an easy question. It was—

Anything more to add? OK. Will these slides be made available for us to download? Yes, the whole Power Point, as I understand it, I'll follow up with our webcast crew, this whole presentation will be archived and you will be able to download slides, read also more about our wonderful speakers. We wanted to save as much time as possible so they put their bio sketches up on the website where you registered to find out more about the wonderful work and things that they've done, you can read more about that. We'll make this all available to you after the webcast. The next question, what kind of outreach do either of you recommend when working within a juvenile delinquent residential setting?

ALICIA BEATTY: Well, you have a captive audience, so I think it's -- you know, one of the things we all know is that it's that human contact, that ability to relate to that person that is sitting across from you. And quite often that takes -- if you don't have someone that same age, it has to be someone that is sensitive to the issues of that population. And that is building a relationship. It's not -- it doesn't happen overnight. In many instances it takes long term talking with and looking at issues that are not HIV. One of the things we have to figure out is that in most folks' lives HIV is not the sum all and be all. We have to be able to dialogue and converse with people about the things that are in their face at that moment.

VICTOR SABRINA MATOFF-STEPP: OK.

VICTORIA CARGILL: I agree. Peer educators.

SABRINA MATOFF-STEPP: OK. Next question is for Alicia. Is it a federal standard of defining adolescents at ages 13 to 24?

ALICIA BEATTY: That is the title IV definition of youth. That's the one we use in our program. So a federal standard would we say that?

VICTORIA CARGILL: What's the federal standard—

ALICIA BEATTY: It's a federal standard.

SABRINA MATOFF-STEPP: Only in the context of Ryan white. But in other potential circumstances it might not be. Adolescents could be defined at other ages.

SABRINA MATOFF-STEPP: The next question. Here. How do you work with HIV positive women who are pregnant who are also substance users, what is an example after treatment plan?

VICTORIA CARGILL: My goodness, well, you certainly have your hands full because when you have a pregnant woman who is using substances, you need to first and

foremost make sure you understand your state laws. If you live in a state where there is a harm to the fetus clause and start writing in the chart you'll never see that woman again. I point out to you the case in South Carolina where the woman won the Supreme Court judgment after being shackled to their beds and their babies taken after delivery. At the place I practice currently, I do not see a woman who is HIV positive and pregnant without other three other people. One is the substance abuse counselor, case manager and the other is the adherence counselor. One of the non-adherence, we see the patient together and arrange the visits on the same day and speak frequently. Our adherence counselor will go to someone's home if they haven't shown up. We use that treatment plan. Depending upon her drug of choice it understands us what we need to do in terms of detoxification. What is open to us and what is not. I wouldn't use some drugs on someone who is pregnant.

SABRINA MATOFF-STEPP: This is for Alicia. Do you have any recreational programs for children and families at the Circle of Care?

ALICIA BEATTY: Yes. We have a group called project empower and it is a group of women that are infected and affected. Each year for the last 15 years we have something called fun day for kids where we bring all the children together for a great day of games and activities that they do on our site. In addition to that, that's just what we do centrally at the Circle of Care. Our case management units have organized recreation activities for families throughout the year, so recreation is seen as an integral part of our case management program.

CINDY: Talk about your baby showers.

ALICIA BEATTY: My staff would kill me, thank you. Oh, for pregnant women we have quarterly baby showers. All the women in the program are invited to come down to our office and participate in what has turned out to be a fabulous event. They have educational activities, they have a speaker, it could be adherence, it could be nutrition. Anything that helps them stay into care and then they all get big baskets of goodies for the baby. We have people bring in clothing that are gently used and the women are able to take those. They have a complete meal, and they have a cake and women have said that those -- they have never had showers before. And so for them now they're bringing their moms and their aunts so it's a great thing. Thanks.

SABRINA MATOFF-STEPP: Next question. We've got a few more -- a little more time for a couple more questions so we'll do as many as we possibly can. How would you deal with a positive woman, HIV positive woman who refuses to disclose her status to her sexual partners and refuses to use any type of barrier?

VICTORIA CARGILL: Oh, I've been through this one. It was not pleasant. Again, I don't know where the person is writing from. You need to know. I strongly encourage you have to know the laws of your state, county, city, municipality. Where I encountered this problem was not in the Washington, D.C. area but in another state and there we had two things. We had individuals who went out and they were called contact tracers so they

could do contact tracing and we also had people from the health department who actually come into the office. I took care of a young woman who did not believe she had HIV infection and she came with her partner and we did education so at least he knew. What he then told me was that she had shared with him not only did she not think she had HIV infection but she was going to go back to commercial sex work on the block. He wouldn't tell me where she was. Not only did she return to commercial sex work she made the mistake of going to what are now closed up but basically the plasma donation center to get money. When they took her blood they did not have the ability to test for all the various I.V. drugs. They can allow them to see that someone has organic substances in the blood. She left behind a piece of paper with my name on it. They called me. I had proofed after they faxed me she had gone to a plasma donation center and the word written in the chart that this is what her partner alleged she was on the block. We found her and I said, indeed this woman is in counseling, indeed she knows and she's wantonly doing it and they put her in jail. You don't let someone with a gun go into a mall. With a woman, I won't let her destroy a community. She needs to go to jail and get some help.

ALICIA BEATTY: I think one of the issues that we face is not the newly diagnosed, it's women that have been living with the virus for a long time. Quite often providers will only ask newly diagnosed women who their partners are. If you've been seeing a provider for ten years, they may not ask you again. And most of the women have new partners. So what we have to be vigilant about is helping providers understand that you have to talk about sexual partners on a routine basis so that you can then continue the process of counseling women about disclosure. It is something that you have to do for the entire life

cycle. And we face the problem of not disclosing the partners on a daily basis. And it is tough.

VICTORIA CARGILL: I think when someone is not disclosing and actively engaging in high risk behavior. I have patients that won't disclose but are using barrier protection. That's different. I'm on her because I think someone should have the choice of do I want to have sexual contact with you with barrier protection. If someone is engaging in sexual activity in a commercial transaction and not protecting those people that's a very different kind of behavior.

UNKNOWN SPEAKER: Absolutely.

SABRINA MATOFF-STEPP: OK. Trying to get to two or three more questions before we'll have to wrap it up. Obviously there is a lot of interest here. A question here about Ryan White which may be better directed to -- we have Cynthia here who is a project officer in the Title IV division. The question is, what is the number of AIDS cases that a state can apply for Ryan White money and does the money get distributed to the state or one city?

CYNTHIA: I'm not sure I understand the question.

SABRINA MATOFF-STEPP: The threshold for it.

CYNTHIA: I don't know. It is -- there are different requirements for different types of funding from the Ryan white care act. There is the Title I which funds eligible metropolitan areas that have to have a large number of HIV positive patients accumulated over a period of five years, I think it is. And Alicia and I are thinking that's 10,000. I will apologize I don't have that number in my head. It's not an area I work in. Ryan White title 2 there is no threshold number. Just that the states apply for Ryan White title II funding and they subcontract with organizations like Alicia's to provide services to people with HIV. Title III is for clinics that provide HIV primary medical care and hopefully also a continuum of services that includes services we've talked about here. Title IV is directly addressed to organizations that are working with women, infants, children and families that are affected or infected. And generally those programs are fairly large but there is no threshold. There is no minimum required. So -- then there are other pieces to the Ryan White care act. I think those are the biggest pieces that you're asking about. I can certainly investigate, yes. This is the website, the Ryan White HIV website. With that information, it's all available to you there.

SABRINA MATOFF-STEPP: Good.

CYNTHIA: I will say, however, right now that mostly the Ryan White care act is going back funded and we're going backwards with the rescission, they're reducing budgets by 1% a year. 1% of a $50 billion budget is significant. So we're not able overall to fund new organizations without unfunding existing organizations. That isn't something we do lightly.

SABRINA MATOFF-STEPP: OK. I think we'll take maybe two more questions from the webcast and then if there is -- are there any questions? We have a number of people in the room here. Were there any questions in the room? Why don't we take one from the room here. We have some people listening in the room here.

PHYLICIA: My question is -- [inaudible]

VICTORIA CARGILL: Well, since as someone who now will show my age since I started doing it at the end of my residency. My first HIV case then I saw. In retrospect what I wish I had known is medical schools do a horrible job of teaching clinicians how to take a sexual history. No one is going to tell you their sexual history if you're rubbing your feet on the floor because you're so uncomfortable they are uncomfortable. People to learn to ask questions with a straight face. Part of the genital/urinary review of systems. I encourage people to know more than the $25 words for sexual organs. Many patients may not know or use the term. The second thing is understand the terminology around sexual practices whether they're gay, by sexual, heterosexual. Again people do not use elaborate English for Webster's terms for sexual interaction. And the third is, really understand your biases. There is nothing like HIV that is going to bring out your own personal prejudices. For anybody listening to this sitting there saying I don't have any personal prejudice, you need to go to the bathroom, shut the door and have a really hard conversation with yourself in the mirror. We live in America and we all got brought up with them. If you aren't in touch with them the person across the table who triggered one of them will feel it because it will be a subtle eyeball roll. That communicates everything. People who already are in this

situation are looking for anything to give them a sense you're being judgmental. The last is be aware that your teacher and best teacher may not be your textbook. The best teacher may not be the smartest person in HIV and your best teacher may not be what you're asked on your boards. Your best teacher as it was for me a 45 year old woman who never called me a doctor in five years. She called me baby girl or so many other things I can't say on the webcast. But Sara taught me a lot and I miss her every day. Girl, you can't go in there. That boy is chasing a dragon. How stupid are you, he's chasing the dragon. When you do that you've passed the litmus test. You're able to say I don't come from the mountaintop. I come here at the street level and only by the grace of god that I'm not on the other side of this desk.

ALICIA BEATTY: I would say see your patients as your partners in their care. Recognize that HIV is not the biggest thing in their life. Sharpen your negotiation skills. And change your mindset. People say to me, women in our program say, I'm not living with this virus, it's living with me. I don't like it but I've accepted it. It is not going to kill me. This has changed the mindset that people are living with this virus. And that way you can see some hope for people. They can see it in your eyes. They can see it in your demeanor. What you want to project to them is their ability to cope with this virus.

SABRINA MATOFF-STEPP: Good. That's really a good. We'll probably have to wrap it up here. It's almost 2:30. That's I think a good ending note for all of us. I know there are additional questions and what we'll do, we'll get a report from the webcast team and we will follow up with you on your questions. Each question is very important to us. We know

people who took the time to tune into the webcast. You're working with HIV positive women and their families and you're looking for some answers and we'll follow up with you. So at this time I really would like to thank you all for joining us, to thank our webcast team at the University of Illinois at Chicago who does all this fabulous behind the scenes work to have this available. A lot goes into that. I would also like to thank our speakers, who, if they don't inspire you, I don't know what does. I have the good fortune to hear Dr. Cargill before and each time I'm impressed even more and now I have another person to be impressed with with Alicia. These are women who go out and do the work and they're just heroes. They are fabulous women who really care about what they're doing. The last slide that you see on your screen, I think there is a typo. Thank you to the viewer who caught this. To see the archive of this event which will be available in several days you'll want to go to mchcom.com. Just make a note of that so you can see the slides, hear the presentation, refer to it, refer your colleagues to it. We'll make it available as soon as possible. And as Benita said at the beginning we're always looking for topics to do webcasts on. If you liked this webcast and if you want to follow up on this topic or some other topic related to caring for women in whatever work you're doing, please let us know. You can send a comment on that to info @ mchcom.com and we'll try to schedule some additional webcasts that will help you do the important work that you're doing. So thank you everybody for participating. We will follow up on your questions and have a great afternoon. Thanks so much.