

MCH EPI Conference

Plenary I: Measuring and Eliminating Racism and Racial Disparities in

MCH:

The Need for New Paradigms

December 8 – 11, 2008

WANDA D. BARFIELD: I would really like to thank our speakers for the excellent presentations that we had this morning. Now is an opportunity for questions, if you do have a question, please come up to the microphones that are located in the center of the isles, and we will take your questions. Also, if there is any questions that you may want to write down, Dr. Bill Sappenfield is here, and he will be collecting those questions. But I do want to start off with just a couple of questions for our panelists, for all three. How do you understand the role of genetics and gene environment interactions in the etiology of disparities, because I think that is an issue as Dr. Collin has eluded too that's been discussed and debated.

JAMES COLLIN: Yeah, I'll take that because I just -- actually just recently had a meeting last week, which looking for scientist -- looking at, you know, basic research, looking at this association with genetics and preterm outcome in general. I just want to make the point I think there is a genetic component to preterm birth. I think its part of all we are and who are as human beings. I don't think it contributes to the disparity at all, and I think we need to make sure that we make clear that that's the difference.

I think clearly the disparity seems to be driven by social factors. Preterm rates have gone up recently in the past eight years, it's hard to believe that's a genetic phenomena. The disparity has persistent for the past 50 years, it's hard to believe that's a genetic phenomena. And looking at the generational outcome of women across generations for both Mexican-Americans and African-Americans, it's hard to coincide those observations with a genetic model.

If you also go step further and you look at black women outside of the United States, you don't see the same type of tenacious disparity. The problem is there are only two countries that I'm aware of in the world that record race and vital statistics, South Africa, clearly things are terrible there, and then us. There is a study published in England looking at a hospital based data, looking at women from Africa, looking at a lower working class community and found out that the outcome of black women in that country was -- in that city, east London was the general -- the same as the general white population, but women who are born in the Caribbean due to social reasons had the worse pregnancy outcome. So again, what we see, in terms, of epigenetic phenomena is not consistent with the genetic model, but fits perfectly with the social model in my opinion.

CAMARA JONES: And I'd like to echo that -- did all that and say that confusion comes when people think that race is measuring genes, and so, we just have to be very clear, there is a genetic basis to a lot of things, but that doesn't explain

racial disparities, because race is not the pie slicer that we call race does not capture the genetic variability that we think it does. We recognize that there is genetic variability on the planet, and that is geographically based, geographic origin and all, but the pie slicer we call race doesn't capture it, because gives genetic variability in our families, you know, there's a genetic variability all around. So, I think that people say, why can't -- why do you want to dismiss genes -- measure genes all you want, but I think that when you try to map that onto how people are classified in a race conscious society, you will find that you do not have a good map. People have done that, (inaudible) has done that, people in this country could have come from Australia -- Australian aboriginal come from very different geographic origin and still be called blacks. So, I think that that's the confusion. I don't know if I've clarified it or made it more confusing.

VIJAYA K. HOGAN: And I agree with both of them entirely, and I just want to add when -- if you use that same criteria that Kington and Nickens used to determine if a factor was associated with disparities it had to be related to the disease, but also differentially distributed and when I read some of the genetic studies that claimed that they find this differential distribution, what they're actually measuring as far as I can see is differential expression, which I think is more environmentally mediated, so that's what we need to be looking at. What the environmental triggers are that turn on this adverse expression of genetic traits that create disease.

WANDA D. BARFIELD: Many of you are going through the process of doing performance measures for the Maternal Child Health Block Grant, and some of the questions that come up are, for example, residing in a state with few racial and ethnic minorities, how would one measure disparities if you don't have the adequate numbers to create adequate power, would it be fair to look at data, for example, over 10 or more years, is that appropriate given the context of the disparities. I'll open that up to any of the speakers.

CAMARA JONES: Well, I say yes, because these issues are longstanding and permanent, so, you know, I would think that if you're looking at racial ethnic disparities, use the data the best way they can.

WANDA D. BARFIELD: Are there any questions from the audience?

DICK NEUGENT: I'm Dick. Is this turned on --

WANDA D. BARFIELD: Yes.

DICK NEUGENT: I'm Dick Neugent from Arkansas, maternal child health director, and your talks bring us to the importance of the whole social impact of slavery, and history, and racism, and that's so important for us to understand. I like to focus my question in an area that I'm a little more involved in and that is in the context of the doctor-patient relation -- provider-patient relationship in the

health care setting. How does racism operating despite the best intentions of both parties?

VIJAYA K. HOGAN: Yes, go ahead.

CAMARA JONES: I'll start and I guess we just go down the line. One of the main ways that it operates is through assumptions about a patient's ability to understand, ability to comply, ability to afford, or whatever that sometimes constrains the presentation of treatment options to a patient in the first place. I think that often providers respond to patients in terms of perceived commonalities, and I -- and so, if there's somebody who comes in and looks like they're of your same class or your same grouping in whatever way then you tend to assume everything good about them.

So, I think that these assumptions can be -- we can get beyond that. People acknowledge that everybody has operates on stereotypes and prejudices, you just don't have to act on them in terms of discriminating, but if you -- one of the things that I've been thinking about in terms of cultural competence or all that is what we really need is respect for patients, and if it takes you spending a minute to identify what that patient has in common with you, you know, if you sit on a bus or in a plane next to anybody and talk to that person, you will find within about a minute that you have something in common with them. So, one of the strategies to put in the provider of thing would be to talk to the patient about who

they are and identify something that you have in common, and I think that will then mitigate against making the kinds of assumptions that this is some other that could not understand.

VIJAYA K. HOGAN: That was a great answer, and I just want to add that when we think about racism particularly when it comes to the medical practice, patient-provider interaction, we think about intentionality, the provider intended to exert this racist act, but intentionality is not a fundamental criteria of racism. It's more systematic, your sort of acting through what you've been trained by the people who came before you, you're acting through the institutional mechanisms that create these disparate mechanisms of care etc, so intention and personal attributes of the person is not necessarily determinant of the existence of racism.

JAMES COLLIN: Yeah, I think agree completely on, you know, I'm a little different in terms as a clinician, I'm just thinking of my experiences in neonatologist, I'm often struck by two things that happened. One, for my group of residence, we have a baby who is preterm, who's delivered to a mom who's an IVF mom, and you can feel the level of investment to make sure that this little child has everything in terms of giving the best opportunities to survive, understandable. But the same of group people have the same infants who happens to be African-American, who happens to be mom, who's 16 years old, who's like uh, this is just one of these cook babies again, why are we doing all of this all over again, this is ridiculous.

And the painful reality is just that but as physicians and clinicians, on peak of academic settings we have an opportunity to be role models, and teach, and engage in discussion. And I think an important step is to engage in discussion not only with your patients, but also with the people you work with, to really -- the world is getting smaller, and the clinical competence is something that's discussed a lot, but I think its best discuss one on one with a group of people, providing care to a group of individuals. And I think talking with your colleagues about race is a very important first step to eliminating the racial bias that we bring to our patient care.

CAMARA JONES: And I would say about race and racism, I'm afraid to go all the way there --

JAMES COLLIN: Yeah.

CAMARA JONES: -- and so, why is it that your valuing this one child more than the other.

JAMES COLLIN: Correct. Correct.

WANDA D. BARFIELD: Can we have the next question, please.

KIBA HENDERSON: Hello. My name is Kiba Henderson from CDC, division of reproductive health. The presentation this morning were excellent, however, my question sort of stands playing devil's advocate here. Many make the argument that racism is -- does not really exist, that it's more a perception on -- counterpart of those who feel they have experienced racism. How in your research do you tease out what is perceived by a patient or by a person versus what is actually there? There are many that make an argument that racism is only exists in the minds of those who considered themselves victims of racism.

CAMARA JONES: I think that the data that I presented this morning get beyond that because no -- there was no question about perceived differential treatment at all. We just did an analysis using what people reported, not thinking about racism about all, but the question was how do other people usually classify in this country and then by comparing those subgroups, so that's the first thing. But your question raises a very good point, if we're talking about racism within health care, should we relay on people saying, oh I feel like I was treated less than or should we actually examine differential outcomes, looking at structures over time, looking at patient outcomes over time, or across a lot of providers, and I think that gives us a better view, because often people will underestimate the amount of differential treatment that they have experienced. They don't like to report it.

JAMES COLLIN: I would agree, I think, it's interesting, we first did a pilot study looking at how can we look at measuring this in terms of interpersonal race or

discrimination perception of, you know, our women, you know, look dude, we got a lot on our plate, racism isn't one of them. I got -- they just not perceiving it as being a major problem, but if you look at some of the published data, it's the perception, which leads to a physiologic response. And objectively, you know, data needs to be done and confirmed that perceived is real, but I think it's going to be pretty right on, to be honest with you. If anything I think women are underestimating.

WANDA D. BARFIELD: Can we have the next question please.

ROGER ROGET: Roger Roget from Emory University. I too would thank you for your excellent presentations. I like to ask since 1965 within the United States, do you feel that racism is randomly and equally distributed throughout the U.S. and over time or has it changed, and is it different in different places, and is there anything we can learn from that?

VIJAYA K. HOGAN: I don't know how to answer that.

JAMES COLLIN: Wow.

VIJAYA K. HOGAN: That is quite a question.

JAMES COLLIN: Oh, we got Barack Obama, man. Come on. We come a long way since 1965.

VIJAYA K. HOGAN: But the election of Barack Obama does not signal the end to racism.

JAMES COLLIN: Amen to that. Amen to that.

CAMARA JONES: And also we would like to look at that. I think that racism have been lift in many parts of the country, feels different, but the structures -- it's structured similarly across this country, but there is a -- one of the -- another of the questions on the reactions to raise module is how often do you think about your race, would you say never, once a year, once a month, once a week, once a day, once an hour, or constantly. And we are thinking about using the distribution of responses to that question, stratified by race as the basis of a racial climate measure, which then if we -- if that question is included as we hope it will be on the core BRFSS questionnaire, right now it's part of the optional module. But if it is in the core and then can be -- we'll be asking all 50 states if we can create that racial climate measure and actually answer the question that you asked.

VIJAYA K. HOGAN: And I think that you probably could measure differences across different states, different cities, etc and racism and the impact of it, and just talking from personal experience, and different organizations or institutions

that I've worked in, the experience of racism is probably constant, but in some you might have some protections that help you medicate the effects of it, more so than in others. And I think the same probably applies State by State. Some States will have more protections or will have people who are actively working to undue the effects of racism so I think, that's where you will see the differences in the action that's occurring against racism.

WANDA D. BARFIELD: Can we have our next question please?

PHIL LUCENI: Hi, I'm Phil Luceni from Arizona, by training, I am a sociologist and Public Health is a relatively new venture for me. I really like the presentation because being trained in Sociology for me, this is, oh that's obvious, but looking at from a health disparity, I have this question, which I think kind of one of our colleagues asked here is of more in terms of reconciling the epidemiological problem in science itself where when we talk about social determinants of health versus clinical trials and there is this wide gap, we're the soft sciences, we are not really doing the evidence is not very good. I mean, I just read the couple of weeks ago, a paper on randomize control trial on impact of prenatal care on African American women and they said that in spite of augmented prenatal care blah, blah, blah, we could not see the impact on low birth weight or preterm births and my first question was, well, you are trying to historically undo something in the nine month period and try to see the impact on it and it does not make sense. So what is your comment on trying to look at even measuring racism, which is

underlying but we do not seem to institutionally capture that. Quite often we have census, we have this black and white categories of race as a more of genetic construct but not as a social construct, anything that we could do institutionally to be able to capture and to be able to bring this agenda back. Thank you.

VIJAYA K. HOGAN: I am not totally sure how to answer the question, but I will say that nine months is not enough to be able to measure the impact of any intervention that we designed to undo some of these social effects and that is why part of this paradigm shift that we are talking about includes looking at life course, because we can't just focus on the pregnancy period to expect to turnaround some of these effects. We have to look at entire communities across the life course to be able to see some of those effects and I agree with you, the science of developing an evidence-base for health disparity elimination has not caught up with the need. I mean, we have to develop new methods to be able to design science that's believable by people for whom a clinical trial is the gold standard.

CAMARA JONES: May I also add to that, I think that on the individual level, in terms of collection of data, we should continue to collect self-identified race/ethnicity, but consider also adding the socially assigned race question, how do people usually classify you in this country as well as adding measures of education, occupation, income and wealth, so that will help us, but the other thing is that, we will never fully understand things by adding questions to data intake

systems or to surveys of individuals. We actually need to examine structures, examine policies, practices, norms and values.

So that is another whole longer conversation but it is not going to be at the individual level and then finally, we have enough information to actually start doing interventions that we think would undo racism and then the evidence might be that if we are doing the intervention undoes racism, that might be inclusion of people in decision making, it might be all kinds of things that we could think about how to do those interventions, but it might be that in the trial, we have the demonstration and the evidence. So let us not keep trying to document document, let's start thinking about what we can do to undo and then maybe the results of that undoing will be the evidence that we needed.

WANDA D. BARFIELD: Next question please.

WENDY NEMHART: Wendy Nemhart from University of South Florida. Excellent presentations to all of you. I have a question and a comment at the same time. I really think that by lumping all blacks in the United States into one category, we are missing a really important differences and I think and I am wondering if there has been studies that have looked at or perceived racism by country of birth, because I would argue that, depending on where are you from, their perception of racism is very different for blacks that live in the United States who are not born here, but currently reside and I am wondering if there are any plans or if

anybody has actually done that, would they have looked at perceived racism depending on the country of birth as well as the pregnancy outcome associated with those perceptions of racism overtime, because blacks coming from other parts of the worlds, I was not born in the United States and I know that I will be in a situation where a colleague who was born in the United States perceived that racism occurred, were I never saw anything that occurred and so our perception and interaction with the system that exists in this country are completely different and so are methods of coping with those encounters are very different as well. So, I think, if we start doing studies like that, we might be able to find maybe, for interventions or and also important differences.

JAMES COLLINS: Yes that is an excellent question and a comment. I have not gone any work or data looking at actually measuring discrimination, the perception for women who weren't born in the United States, but I think you are pretty right on the target and I think there is also a perception that can vary geographically like say, lumping all women together is not something that is best for teasing out individual differences.

VIJAYA K. HOGAN: If you were interested in doing that study, that black women's health study, has the first, I guess it was, I cannot remember the year, we will have to look at it but, it has information on where were you born and where were your parents born and it has a whole group of racism measures. So

potentially, I do not know how big the group of people who were not born in the US is in that cohort but that is a potential data source.

WENDY NEMHART: Has this also been done on Mexican-American or Hispanics as we call it in the United States? I know, Dr. Collins, you mentioned that the second generation phenomenon, but has discrimination or racism questionnaires has been an instrument on those populations as well as based on the country of birth?

JAMES COLLINS: That is a good question. I am not aware of any racist questionnaires looking in just from Mexican-Americans, the big brunt of the research has been that we are looking at diet and acculturation. Well, two good points, Thank you.

WENDY NEMHART: Thank you.

STEVEN KORGENOWSKY: I am Steven Korgenowsky from Michigan. I had a question kind of getting back to Dr. Jones had previously spoke, regarding the intervention and evidence base and I wonder if you think the for the lack of an evidence based if you think that is primarily due to a lack of programming or a lack of evaluation, or a lack of effect of those programs and if you believe it is a lack of programming, what programming would you recommend to start with? To build that evidence-based.

VIJAYA K. HOGAN: There are a lot of factors that contribute to that. I think, part of it is the lack of programming, because we do not have the funding to do the intervention and so you cannot develop a science-based unless you have the funding to actually put something into practice and evaluate it. And there are a lot of steps in that process so you have to conceptualize what an appropriate intervention would be and I think that's the stage where we are at now. You have to actually implement it and do it correctly, that takes time. We haven't really gotten to the point where we have completed that step. You have to make sure that you evaluate it and have good evaluation measures and that is where I think the science may not be caught up with our need, because we have certain expectations for what that evaluation should look like and what those measures are and our current standards won't fit these types of interventions so we have to modify that.

So I think we have a long way to go and a lot of fronts to beat at the point of developing an evidence base, but it starts with trying, as Camara said, we have enough evidence to start trying some things that have conceptual validity at the very least and we need to start there and then begin to develop the process to develop those science

CAMARA JONES: And so the conceptual thing would be, first of all, understanding racism as a system of structuring opportunity and assigning value. We would have to go right there so it would be about equal opportunity so it

might be about strong social security for children. Maybe we can give equal opportunity to everybody at first but let us start with the next generation with our future. Let us talk about fully funding excellent educational opportunities for all children, this would be the kind of theory driven intervention that would be needed and also the thing in terms of equal valuation so that is media stuff and curriculum staff and all like that.

Then the other, another kind of how would you start would be the element of self-determination which are the power to decide, the power to act and control of resources. So giving that power to communities would be another way when you think of what do we do and then finally, we have to recognize what Vijaya said before about the uneven burden that people of colors especially people of African descent have right now and so we are really giving attention to how would we do reparations for that long term and continued historical injustice. So those are three things that we could start out as starting points. Well, we have a political will to do that, well hopefully so. We will work on that.

TALETHA DARRINGTON: Hello, my name is Taletha Darrington, I'm at Boston University and (inaudible) University and I also have comment from the social policy side of things to public health and I agree that we need to stop adding to the laundry list of differences and start explaining why and how to address those. So I worked with a population based link data system and I am curious to learn

from you how we can use that data system to build an evidence based about why disparities exists and how to address them.

VIJAYA K. HOGAN: It really depends on what is in the database and what I found is that most existing population base data systems don't have the types of information that we need. The breadth of information that we need to really understand causality, but if you are building a database or if you have the opportunity to add variables to be collected, I would go back to that list that came from the Kington and Nickens' article and be sure that you are able to collect information on some of those factors, because that at least helps you understand causality. That being said I want to go back to something Camara said in terms of we probably know enough right now to start doing something and to the extent that these databases can help evaluate what we are doing, not necessarily in terms of achievement of the ultimate outcome, which is elimination of the disparities, but that defining some intermediate outcomes that we can begin to look at so that is where I think those databases might be particularly useful.

TALETHA DARRINGTON: Thank you.

DAISY CHRISTENSEN: Hi, Daisy Christensen from the Developmental Disabilities branch here at CDC. I wonder if you could briefly comment on inter-generational effects of birth weight and maternal nutrition and how the

experience in previous generations of deprivation and poor pregnancy outcomes may be perpetuated through success of generations.

JAMES COLLINS: Yes, that is a good question. I think one of the best data, which give us an indirect window of that is looking at the Dutch family, I mean, we all know that women who were severely malnourished during the first trimester of their pregnancy, those fetuses that were conceived during the time period grow and it was during the first trimester, I remember graphically that they are more likely to have a low birth weight infant for women who are severely malnourished during the third trimester, they didn't see that same effect. So it seems like under nutrition during the first trimester is very important for pregnancy outcome for subsequent generations. Clearly, in the United States, we do not have the same degree of caloric malnutrition per se looking at nutrition result has come variable. Looking across generations that something indirectly related to maternal nutrition is maternal birth weight. I mean, that a mom with a low birth weight could have been a low birth weight due to the effect that her mom was also low birth weight for whatever reason, we do know that if a mom is low birth weight, she is more likely to have a low birth weight child herself and that it seems to be independent of socio-economic status, independent of prenatal care usage, maybe there is a genetic component to that, maybe that is also an epigenetic phenomena where under nutrition early on in pregnancy is affecting pregnancy outcome of the next generation.

DAISY CHRISTENSEN: And I wonder if there's evidence for other, maybe less easily measurable factors like stress.

JAMES COLLINS: That is good question. We are just nothing has been published. We are looking at now what effect stress has across generations. Speaking with mothers and speaking with their mothers and seeing how that links with birth outcomes. I am not aware of any published data on that.

DAISY CHRISTENSEN: Thank you.

JAMES COLLINS: You are welcome.

WANDA D. BARFIELD: We have time for just one more question.

STEVEN KORGENOWSKY: Thanks again, earlier I neglected to complement you on your presentation. It's very,very excellent, excellent, interesting presentation. And last, I'd like to ask you if you are thinking about modules or modular questions that could be added to PRAMS to begin sort out some of these problems?

VIJAYA K. HOGAN: I can actually answer this, for the Phase V PRAMS questionnaire that some of you know, there was a module that was from reactions to racism that Camara and her colleagues had actually provided.

However, what happened during that process was that those questions were actually broken out and so some States may have asked one or two of those questions, but they may not have the complete set and I think that maybe something important for States to consider that there is the opportunity to consider that in the future in terms of questionnaire revisions I am looking at that module a bit more specifically and I think that there were also be other questions that are being generated as well.

WANDA D. BARFIELD: At this time it is, first of all, I just want to thank our presenters once again for just a fabulous presentation.