

AMCHP Annual Conference, 2010

Moving Ahead Together:

Celebrating the Legacy, Shaping the Future of Maternal and Child Health

Collaborating to Reduce Infant Mortality among African Americans

March 6-10, 2010

SHEILA O'CONNOR: ...mortality among African Americans. My name is Sheila O'Connor, I'm from the Montgomery County, Maryland Improved Pregnancy Outcomes Program, and we have a couple of housekeeping notes before we get started. First, in order to receive your continuing education credits, you're being instructed to refer to the AMCHP website, to go onto that and then enter the name of this session, and you can go ahead and capture your CEU credits that way.

Second, oh, and if you could get those forms in by April 12th, I think that's the deadline for when they'd be able to award the CEU credits. Also, we'll be handing out evaluations right after our three panelists finish, so if you could take a moment and fill those out, we would be grateful. And third, last but not least, I want to mention that if you could turn off your cell phones, if you have those on, and you could turn those off, that would be great, and we will be holding questions until the three panelists have finished, but we'll leave plenty of time for questions and answers and still get everybody out on time for lunch.

It's my pleasure to introduce our three panelists, we'll start with our first panelist, Juanita Graham. Ms. Graham is the Health Services Chief Nurse for the Mississippi State Department of Health and serves in a nurse consultant role to the department's seven health services offices. She participates in a variety of activities, including grant writing, continuing education for nurses, logic modeling, and research. Ms. Graham holds Bachelors and Master's degrees in nursing science and is currently a full time doctoral student at the University of Mississippi. She teaches and develops online courses for several nursing and healthcare administration programs, including health policy, healthcare finance, healthcare law and ethics, and public and community health nursing. Ms. Graham serves as an adjunct faculty member at the University of Mississippi School of Nursing, and she has also represented several organizations at the state and national levels.

Our second panelist is Brenda Lockley, Program Manager of the African-American Health Program in the Office of Community Affairs at the Montgomery County, Maryland Department of Health and Human Services. She formerly served as the Project Director for the African-American Health Program, where she oversaw development of the Smile Program. Ms. Lockley received her Master of science degree from the University of Maryland, Baltimore, with a concentration in maternal and child health, focused on adolescent pregnancy and parenting. She completed her undergraduate BSN degree from Georgetown University. She has held a variety of clinical and management positions in the maternal/child health field, including Director of the Sasha Bruce Youth Work Residential Teen Mother's Program, Program Director of Healthy Families, Prince

George's County, and as a state family assessment trainer for Healthy Families Maryland. Ms. Lockley's nursing career began with three years active duty in the US Navy Nurse Corp, with additional experience in staff nursing, nursing management, and in-service and continuing education.

THOMAS STORCH: our third panelist, serves as Chair of the Montgomery County Fetal and Infant Mortality Review Boards Community Action Team. He is a board certified physician in neonatal, perinatal medicine, with a wide range of management experience in commercial and Medicaid managed care. Dr. Storch is a principal with Context, Incorporated, and his current projects include improving health outcomes by integrating healthcare with financial education and asset building. Dr. Storch has an extensive background in strategic planning and coalition building, disease population management, and employer-focused health management.

THOMAS STORCH: Sheila? Sheila? That's not important.

SHEILA O'CONNOR: Okay.

THOMAS STORCH: What's important is today's my birthday.

SHEILA O'CONNOR: Oh! We'll all take a moment and wish Dr. Storch a happy birthday! Well, happy birthday to Dr. Storch! There'll be a celebration later, I'm sure. Dr. Storch previously served as a medical review officer for the FDA's Drug and Evaluation

Research Unit, as well as Medical Director at **** Plan Louisiana and Coventry Healthcare Louisiana. He is also a tenured associate professor in the department of pediatrics at Tulane University School of Medicine.

So we'll start with Juanita Graham.

JUANITA GRAHAM: Good morning and thanks for coming to hear us today. I'm going to talk to you about Mississippi infant mortality, we are known very well for leading the nation in infant deaths and have done so for 100 years or more. But we know a lot about Mississippi infant mortality and we're paying attention to what we know and we're trying to work with that to come up with innovative ideas so that we can really take an aggressive stance on this and lower Mississippi's infant mortality and not be the one at the bottom of the list.

This is a ten-year graph of Mississippi infant mortality. It's been very stationary, very stable over the last ten years. We do, in Mississippi, we have the largest proportion of African-American residents and citizens and we also have a large disparity between white and non-white outcomes in the state. In 2008, we have our 2008 data, as of the end of September and we are down to 9.9, that's only the second time in history that we've had less than 10 as our infant mortality rate. The white rate and the non-white rate, there is a disparity there, but what we've noticed over the last few years is that we're actually closing that gap, those two numbers are coming closer together. The problem with that is that is that it's coming together for the wrong reason. We would like

to see the non-white rate come down to where the white rate is, but, and that's happening to some extent, but unfortunately the white rate is beginning to climb up to meet them, so we're doing what we can to address that.

This is the 2008 number singled out, as I was just speaking of them. This is a look at ten years of white versus non-white rates, you can see that at times the white rate, excuse me, the non-white rate, has been as much as three times the rate of white infant outcomes.

We look at our infant mortality in a number of different ways, the timing of the death, certain factors about the mother, different issues, the age of the infant at death, neonatal, during the first 28 days of life is the greater portion of infant deaths in Mississippi for more than a decade up until this very last, of 2008, this most recent data that we have, it's always traditionally been at least 60% of our infant deaths. We have just barely dropped below 60% during the 2008 year.

This is looking at infant deaths during 2008 by the months of life and this really illustrates how important that first month is, how it really impacts infant mortality in Mississippi and it seems that the longer the infant survives, the better chance of survival that they have.

This is looking at infant deaths by birth weight. And in this 2008 data, it was less than half the red proportion that were very low birth weight, under 1500 grams. That's also a

new finding for us, in all previous years, very low birth weight accounted for more than half of infant deaths. Low birth weight combined with very low birth weight accounts for almost two-thirds of our infant deaths.

And this is looking at infant deaths by birth weight over a period of years and you can see, the red number, the very low birth weight has definitely carried the burden for us for the entire decade. It goes all the way back, just as long as we've been tracking infant deaths by weight.

Looking at some maternal factors in Mississippi, about a little more than 62% of our infant deaths occur among, excuse me, of our, I said that right, we have better outcomes with the married group for infant deaths. Infant mortality by race and mother's age, and again, we see that there is that disparity there. Also, not only are the non-white groups having a higher rate of negative outcomes, but it seems that the younger they are, or the older they are, there's a difference there. With the group of non-white women that are over 35 years of age having the worst outcomes of any group.

SIDS rates, we traditionally lead the nation in SIDS rates, and we always give a disclaimer on our SIDS rates. In Mississippi, the only qualifications for being a coroner is to be 21 years of age and be registered to vote, have a high school diploma or equivalent, and be registered to vote in the county of election. It requires absolutely no medical education whatsoever. So in my home county, for more than nine years, the local used car salesman has been our coroner. So you question, their capacity for

accurately diagnosing a death, cause of death. They do have some training in place, but like other government or government employees, they're understaffed, they're underfunded, and so not entirely by reasons of their, means of their own, they have a low capacity for accurately, making a cause of death diagnosis and SIDS, we do believe are one of those that falls ill to that. They see it so much as being any sudden infant death is a SIDS as opposed to a true SIDS definition of being a cause of last resort.

Infant mortality by the Caudle Check Index, inadequate prenatal care is the largest contributor to infant deaths with adequate plus being the next group. And the adequate plus is the group that sees, has more physician visits than the expected number and early entry into prenatal care and what we believe is the reason that they have some of the worst outcomes for us is that we have a lot of very high risk pregnancies that seemingly they get into prenatal care, they're followed very closely, and still it continues to have a bad outcome.

We've done a lot of studies about our infant mortality and of course, you know, we need evidenced-based for what we do and we need it to be specific to Mississippi and we need it to be culturally competent to Mississippi, so I'm going to tell you about a few of the studies that we've done. We did a retrospective cohort study using about 340,000 infants during 1996 to 2003. Well, actually, the population ended up being 297,000 non-Hispanic, white and black, singleton, live-born infants. And we were looking to see, one of the things we know about Mississippi is that we have not just the highest infant mortality rate, we lead the nation in other issues like obesity, diabetes, hypertension,

dialysis-dependent end state renal disease, cardiovascular disease, we have all of these problems and they're becoming more prevalent among younger and younger adults. So we looked, wanted to look to see if perhaps these things have a relationship with our birth outcomes. And we specifically looked at infant mortality, infant deaths, low birth weight, and pre-term birth, because low birth weight and pre-term birth are the leading causes of infant death in Mississippi.

This is a little hard to see, this is basically talking about the numbers that we looked at, the total numbers of births, in the live births, pre-term births, low birth weights, and infant deaths. We get over, looking at odds ratios, you see that the non-white group has more than twice the risk of having a low birth weight infant, and nearly twice the risk of an infant death. The age group with, the age group of 25 to 34 being the best possible scenario, we see that the older they get or the younger they are, the more likely they are to have a low birth weight, pre-term birth, or an infant death. And at Mississippi, another one of our claims to fame, we have the leading number of mothers between the ages of 11 and 14. So that is a significant number for us to have a category of 11 to 17.

Education level, obviously college is the best case scenario, and the less the education, the more likely the woman to have a complicated pregnancy.

Marital status, married seems to work better, of course, you have better support systems with two parents in the household.

Initiation of prenatal care with getting in early, having the best outcome, no care at all almost three times the risk of pre-term birth and over three times the risk of an infant death.

Tobacco use is a case-dose effect, the more cigarettes, the worse, higher the risk for the bad outcome.

And then looking at some maternal conditions, diabetes increases the risk of a pre-term birth, it doesn't increase the risk of a low birth weight, because diabetic women, of course, tend to have heavy babies. They're not healthy babies, but they're not low birth weight babies. And there's a 40% higher risk that the infant will die. For fluid disorders, hydramnios, **** hydramnios, there's almost twice the chance of having a pre-term birth, more than three times the risk of having a low birth weight, and more than four times the risk of an infant death in those conditions. And hypertension doubles the risk of pre-term birth, triples the risk of low birth weight, and slightly increases the risk of an infant death.

We did a study right after, about a year after Hurricane Katrina, to assess how the storm changed women's access to women's healthcare across the Mississippi Gulf Coast. You hear a lot about New Orleans and Katrina and the damage that was done, but you don't hear a lot about Mississippi's damage and we're actually the ones that the eye came on, on the Mississippi Gulf coast and we had a tremendous change in service systems across our Gulf coast. We were piloting a survey tool kit developed by the CDC's Division of Reproductive Health, that they originally developed to assess access

to women's reproductive health and interruptions in reproductive health among women who are displaced by war, like living in camps, refugee camps. They wanted to see if they could domesticate the survey instrument for it to be a post-disaster assessment. And we interviewed 108 women that we had access to that were visiting local clinics in the community health center on the coast. Now, nearly 90% of them said that they had no interruption in their method immediately post-disaster period, most of them either had a pack of pills that they held onto, or they were using condoms, or they were taking shots, and those things, there was no interruption by access to care.

Something we weren't expecting to find is that nearly 40% of the women reported that they currently most often receive their family planning services at the local ER, emergency room, or urgent care center. The explanation for that was that it's possible to get an appointment with the women's health center, but you may have to wait and wait and wait. And sometimes waiting's not an option if they've postponed it too long and they're about to run out of their pills or whatever their method is, and so they appear at the emergency room, they say they think they're pregnant, they get a test run, it's negative, and they walk out with a prescription for 90 days worth of pills. So very inconsistent, very inappropriate place for a medical home for women's health. They're not getting the proper education on methods and availability, not the kind of individualized services that they need. So that's one of the things that we have found out about.

And then I already mentioned to the Mississippi coroners and we did a survey among our coroners to see if in fact they were using the recommended tools or if they were even following the law as far as investigating sudden infant deaths. And what we found out was that there were considerable discrepancies in the protocols that were identified, sometimes they, they sometimes are never even filled out, the infant death scene investigations, just bypass that altogether. Autopsy is required by law, but there's no penalty for not doing it, so they often bypass that as well, usually to save money for the county.

We did some focus groups among, because of the disparity between the black and white outcomes, birth outcomes, and of course all demographics are not exempt from SIDS, it could happen to anybody at any time, but our African-American population seems to have a higher proportion of those, even though the numbers are not reliable because of the coroners. We still wanted to look into that. We did a series of focus groups assessing the knowledge of SIDS—whoops, I got to hurry. Let me just skip on it, instead of passing all of this, what we came to the conclusion was with all of these studies that we did, was that in a nutshell, Mississippi women are not physically or fiscally or educationally prepared for pregnancy. And so that feeds a lot of our infant outcomes. So it was very obvious that we had to go an intervention that occurred before pregnancy, a pre-conception or inter-conception care program. While looking back at some of the data that we had, we know that very low birth weight is the big contributor. It's only 2-4% of the overall births in the state, but it accounts for more than half of the

infants that die. So if we work with, and we have a lot of women who have more than one very low birth weight infant just back to back to back to back.

So we have two programs that are going, the MIME and the DIME, DIME stands for Delta Infant Mortality Elimination, MIME stands for Metropolitan Jackson Infant Mortality Elimination, that's our most rural area in the state and our most urban area in the state. And what we're doing is working with women who have delivered a very low birth weight infant, no matter what the outcome for the infant, to provide her with up to two years of very highly focused case management and very comprehensive case management. Not just to help her become more physically prepared for any subsequent pregnancies, if that's what she chooses to do, but also working with her, if she wants to go back to school, if she wants to get that GED, if she has a mental health issues, if she has domestic violence issues, if she has substance abuse issues, whatever her situation is, we're working with her through a multidisciplinary group, nursing, nutrition, social services, and a peer educator that we refer to as a resource mother to provide focused case management and have contact with her at least twice a month.

And we've been recruiting patients since February of 2009 and in all of that time, up until just February of 2010, we had one lady to get pregnant and that was from day one, that was her choice, she said, "I'm going back to get pregnant again," so we still worked with her to help facilitate the best outcome possible and we're still working with her now that she is established as pregnant, she's been moved into pregnancy high risk management so that we can more closely follow her.

We have a lot of partners in this, the World Health Organization Collaborating Center For Reproductive Health, providing technical assistance, the Federally Qualified Community Health Centers provide medical homes and if you have, my time's up, so we talked about the intervention package and we're just going to have to let it go. But if you have any more questions at the end, I'll be glad to give you more information about the program.

BRENDA LOCKLEY: Good morning. I still can't get over the fact that coroners don't have any qualifications.

I'm going to talk to you about our SMILE program. Originally it was called Black Babies SMILE and SMILE means Start More Infants Living Equally Healthy. I'm from a very different community, locally, you know, right across the line here, a very large county, both geographically and population-wise. And I just heard this, this morning, it's number ten wealthiest county in the country. We were at one point number one, so this is a population or a jurisdiction that is a mixed bag. Because once you're known as one of the wealthiest, the dollars that you're looking for don't flow as readily and there's even a lawmaker in the Maryland legislature that calls us the State of Montgomery County.

We're also changing demographically. It used to be primarily white, primarily wealthy county and over the years that has changed. And in addition to African-American black in migration, we have a huge immigrant population of Hispanics, of Asians, and of,

within the last five to ten years, a growing influx of Africans, from both Eastern and Western Africa.

We're going to talk about black infant mortality in Montgomery County, and it was, it's serious, just like it is throughout the rest of the country. And you can see here that we have a big problem. And interestingly, it has really, you know, gone up and it's coming back down and we're really hopeful, but, you know, every year we have a blip downward and then it goes right back up. But I just want to point to the differences. At our very lowest, which was in '99 to 2001, and by the way, we generally do a three-year rolling average, because our numbers are relatively small. But even at our lowest, at the African-American lowest, it's still higher than that for whites and for that of the total. And, you know, trying to erase this gap is what Black Babies SMILE is all about.

And actually, infant mortality was the, can't think of the word right now, but this is what caused the African-American Health Program to come into existence, because a health officer at the time recognized the gap in infant mortality disparities and when they started looking at some of the other disparities, they were huge in other areas as well. So the African-American Health Program began with just a little bit of county funding, I think it was \$33,000 plan and grant in 1999, we're up to \$1.5 million budget, which is what they asked for at the beginning, but we got there and, you know, I don't think we're going to stay there.

But anyway, we continue to be funded by the department and two other minority health initiatives also formed, the Latino Health Initiative began the year after us, and several years later, the Asian-American Health Initiative has come into existence.

This is our logo for the SMILE program. And the SMILE program started actually as a pilot in FY '02 and we started out with one nurse, with 50 moms, and at most, 30 infants. And we took both pregnant women and high risk newborns. We now have 3 nurses serving 135 women and up to 90 infants, and we shortened the name to SMILE a couple years ago.

Our staff, it's an all RN staff. One of them holds an MPH, one is a Bachelor of science, they're all certified childbirth educators, one is a certified lactation consultant, the other two are lactation coaches. They all have L&D experience, one of them has extensive NICU and newborn experiences.

What we do, it's at its heart a home visiting case management program. But the nurses are really, really busy. At least twice a year and sometimes three times, this last year we've done it three times, there's a 12-hour childbirth and lactation education class for pregnant women and their partners as well. They are also in the schools, they're invited many times by the school nurses and counselors to come into some schools, especially those that have high teen pregnancy rates, to do pre-conception health. Now, we can't call it pre-conception health in the schools in our county because the parents get outraged, so we call it healthy living. But we talk about STD's and nutrition, you know,

the whole gamut with these kids, and we do it at middle and high schools. We also do pre-conception health education in the community, a lot of times at housing communities, social groups, etc., and they're always doing outreach, you know, our program, you know, spring, summer and fall, you know, every weekend we're at some health fair some place, and the nurses also participate in that as well.

Now, who do we target? We target the black women of Montgomery County. There are other home visiting programs in the county, but because this is a serious issue in our county, we are the only ones that really just target the black community. And there are really no eligibility requirements, except to be black and to reside in Montgomery County, and sometimes we have a little trouble with that, because people across the line in Prince George's want to come into our program.

We continue to see high risk neonates, but not as much as we did in the past, because we recognize that the leading cause for us for infant mortality is again, low birth weight and pre-term delivery. So we really need to get moms early in the pregnancy. There are no income requirements, there are no insurance requirements, and no age requirements, it's totally voluntary.

One thing that's different is we don't focus just on first-time moms. And we have found that we can make a difference for moms who have had prior poor outcomes and there's a slide in here a little bit later.

One thing that we're not real happy about is that we can only see the family until the infant is a year old. We would like to be able to stretch that to two years, but it's a funding issue. In terms of our philosophy and our practice model, culturally sensitive and appropriate. Within the black community, there are many, many different cultures and from the beginning, we saw, and this was kind of an amazement to us, because we hadn't really noticed African immigration, about a third of our clients were African or Caribbean, and for the nurses, that was a big adjustment, because you know, home visiting, you're told, you know, you don't eat in the home and that went out the window, because it's an insult if the African family prepares something for you and you don't eat, so we had to do some adjustments and learning.

And along the way, our whole program, we looked up one day and half our staff was born outside the country, most of them are West African. So we have learned a lot, the rest of the staff have really, really learned a lot culturally.

It's family centered, whoever the family, the mom identifies as family is family. In the black community, there's an awful lot of **** kin, play mother, play aunt, play grandmother, play sister, neighbors, whoever is included that the mom says is family.

And it's strength based, we focus on identifying those strengths for the family and helping them to identify the strengths because a lot of times, they don't recognize what their strengths are. They're so used to a deficit model, where everybody's telling them what they can't do, what they don't know, how they don't behave. But we look at it from

the opposite direction and use those strengths to help them work on things that are obstacles for them.

The home visiting schedule is based on the individual's needs, but everyone gets seen at least once a month. But we've had cases where the nurse has been there every day for maybe two weeks, but that's depending on what the need is. There's a comprehensive assessment, including depression screening, both prenatally and after the baby is born. There is care planning with the patient, or with the client, not for them. There's case management referrals, we have found that many times the nurses are the ones who are able to get them access. Okay, I just remembered this one woman who was obese and had a preexisting heart condition and was not able to get an appointment with the cardiologist and she sat there in the office and tried to get an appointment, the nurse took the phone, they hung up, the nurse dialed right back and got her an appointment.

And there's a comprehensive curriculum that includes things like signs of pre-term labor, strong emphasis on smoke, smoking and smoking cessation and secondhand smoke and tertiary smoke. Breastfeeding, now 60% of our new moms are breastfeeding. Now, we want to get them all, they don't all breastfeed for a year, but we're trying to move them that way and you'll see in a minute, we have a breast pump loan program for moms going back to work.

We do HIV testing in the home, all the nurses are prepared to do HIV testing in the home and the breast pump loan program, which has been hugely successful. We've had to kind of scale back now who we give them to because we're finding everybody just wants them, but it was really intended for moms so that they could go back to work.

This is just a poster of our classes. The pregnant woman in the red up top is one of our nurses and she was pregnant with her fourth baby when that was taken.

Collaborations, you know, you cannot do this alone and we collaborate with everybody in the world. First of all, the African-American Health Program, has a coalition, infant mortality coalition, which includes members from the communities, hospitals, providers, you name it, they're on our coalition, and they really help us look at what's going on, they bring us data, they advocate for us at the County Council when it's budget time, which is really important.

We have recently gotten another grant, minority, or rather our Health Department, has gotten a minority infant mortality reduction pilot project grant from the state. And this is a little bit different in that it's a health promoter model and it's looking at the social determinants of health and we're looking to, we're working together with the SMILE program, but we're looking to see how that could be incorporated in what we do, looking at programs such as the Baltimore City Healthy Family, or Healthy Start Program, which uses a health promoter model and is very successful.

You'll hear about our collaboration with the improved pregnancy outcome, which is our fetal infant mortality review and community action team that acts on the recommendation of ****

Our nurses are part of the Child Safety Consortium, the Home Visiting Consortium, which includes infants at risk, it includes healthy families, it includes the county's nurse case management program, among others. Our nurses are involved in ICAPP, which is the Interagency Committee for Adolescent Pregnancy Prevention. **** Services of Greater Washington is the, Florence **** Services, and they have two programs that we support, Sneakers and Pearls. Sneakers is for at-risk girls who are not pregnant and Pearls is for pregnant and parenting moms and these programs are in selected schools in the county, so we support that and work with them.

Two very, very valuable partners that we have, our uniform services for the health services, which is located in Bethesda, in our county, and also West Dat, which is a national evaluation program.

And one of the things, you know, even with 50 clients, it was hard to do pencil and paper analysis, data analysis. So we decided that we wanted an electronic version, that was user friendly, that the nurses could use very well, but also that the managers could use to collect data, analyze, to do reports, whatever. And we were trying to develop a system, well, we couldn't do it by ourselves, so initially—guess I missed a slide—USES stepped in and they came to us when their center for health disparities was being

organized, had just been funded and we began working, as we had our monthly meetings, we talked about, you know, infant mortality, and we talked about the need for a data system, so they really, really went to bat for us and did the **** review for us, helped us identify all the risk factors that we wanted to look at, helped put it into place, and we ended up with a 32-page assessment for both prenatal and postpartum, and for the new baby. But that was really cumbersome, we wanted to do it electronically and we wanted to save the nurses some time as well.

So West Dat, about the same time, became our evaluator and they looked at our program and it was like, we can't evaluate, because you don't have any kind of system for your data. So they helped us put both our SMILE program and our diabetes information into an access space system and the nurses have tablet computers and they go out and they use their tablets and after their visit, they can even write, you know, in long hand and it transcribes it into printed material, really fancy. But they go out and then they come back and upload it to the server, where it's available to everyone else. It's not totally fully functional yet because we found that we had to go enter 30 pages of data for each of our clients that we had had, and we don't have any money to pay anybody to do it, so it took us a while to get that done and we have most of the data in now, we're beginning to be able to get information back out.

But that was a really, a wonderful collaboration with our vendor, which is Beta Associates, who hired the nurses, with West Dat, with USES, and with the Department of Health and Human Services, because they loaded this new tracking system onto the

county server, because that's the system that our program uses. So, you know, that, that was challenging.

Another way we collaborated, one of our USES interns was a physician going back for an MPH and she worked with us and she did a study on the first 100 or 125 of our clients, just to see, you know, what it was we were doing and whether we were on the right track. And what she did, we couldn't find a comparison population, we had a lot of trouble doing that, so what we looked at were, the moms that came to us after they had had their babies, and the moms that came to us prenatally. And we know that's not the most ideal, but it did give us some hints, and we found that the moms who came into us while they were at pregnant, were at minimum 60% less likely to have a low weight or pre-term baby.

But one of the things is we really want to, you know, find some comparative population so that we really could do this because we really want to know what is it that we're doing that works, because we are beginning to show that what we do works.

We've had a total of 535 clients and as you can see, at the beginning, it was really kind of split between prenatal and postpartum, but as we have gone along and really wanted to put the emphasis on preventing the pre-term and low birth to begin with, you can see that our population, our enrollment are mostly prenatal.

And again, this is just by referral type.

Low birth weights by referral type, the maroon are postpartum, so you can see that most of the babies that were in our program were high risk newborns.

Of the 321 prenatal clients, clients that entered prenatally, we've had 5% have been pre-term deliveries and 3% low birth weight, and that's for just single deliveries, we've had a number of multiple deliveries.

Entering by trimester, this is what we are really, really concerned about, because as you can see, most of our clients come in the third trimester, it's a little late. We really want to get them in the first trimester, so we're working at doing some outreach to physician's offices, to other places, and this is where the new grant comes in to kind of identify women and steer them to our program through their referrals in the first trimester.

Of moms that had, that came to us that already had poor outcomes prior to entry, we had had 14 moms who had had a stillbirth. We've only had 1, and that was a mom, she was an African immigrant, who had had one home visit, that was the enrollment visit, and before the nurse could get back again, she had lost the baby and it was a cord anomaly.

We had had moms that had nine infant deaths, we've had one. Again, this was kind of an anomaly, it was an African immigrant who had gone back home, had come back and was reentering our program, had called to sign up, and when the nurse went out for the

visit again, the baby had died because the babysitter had given her an overdose of medication. So that kind of said to us, we need to do some education with the moms about how do you choose your caregiver? That was really, really sad.

62 pre-term birth, we have had 20 and 40 low birth weight, we've had 9. So, you know, you can see that we are making a difference, but we need to be able to get more evidence and we really be able to prove it. But we are well received in the community and we are growing as more and more families hear about us. And again, we have a proportion—oh, one of the things that wasn't in the slide that I really want to point out is, most of the moms in our program are educated. The vast majority have completed high school and then another large number have post secondary education as well, but what is really striking is that the majority of our moms are unemployed and that we've got to go back and tweak our system because we never thought to ask why were they unemployed. So now we've got to figure out why they were unemployed.

So, this is our contact information, if anybody's interested.

THOMAS STORCH: Let's see, it's still morning, good morning. I'm going to say some controversial stuff, because it's my birthday and, you know—okay, let's see, I hit enter, okay.

Okay. Talk about collaboration, a little academics, then some personal observations. I would conclude that collaboration is necessary, but certainly not sufficient to reduce

infant mortality. Okay. Some definitions, there's cooperation and there's collaboration. Cooperation is kind of informal, usually takes place within the same organization, it's working with a colleague or working with a couple of colleagues, maybe we're working with some colleagues in a different organization. But basically, it's very informal, it's individual driven.

Collaboration is something entirely different. Collaboration takes place at the organizational or agency level and involves organizations cooperating to share information or solve problems that really can't be done by a single organization. And often that sort of collaboration gives rise to a new organization and we'll talk about the various models of collaboration.

Why collaborate? If you've seen some of the data in infant mortality, and by gosh, if you go back ten years, the numbers are the same as they are today, nothing really has changed and that may be a cynical point of view, but I think the data backs me up, the infant mortality rates in 1999 are the same they were in 2009. So it's a tough problem, it's a very tough problem.

And in order to solve tough problems, there are obviously political considerations involved and people need to be included in formulating the problems and formulating solutions. The other, and I think this is reality, is infant mortality reduction programs compete with other worthwhile, worthwhile programs for resources and I don't just mean road building, we have a lot of road building in DC. They compete with education, they

compete with healthcare for the elderly, a whole variety of things. So in order to get resources, one needs to form collaborations. Okay?

But there are some more specific reasons for collaborating to reduce infant mortality. This is from a recent study by Robert **** Johnson and what it says is that the rate of infant mortality is 15% healthcare, and by healthcare, I mean, what happens in the doctor's office, the hospital, and also access to those services, access to those services, and 85% socioeconomics—that is education, jobs, housing, environment, neighborhood safety. 85% are socioeconomic driven, 15% are healthcare, including access to healthcare driven.

How can one do anything about infant mortality by just relying on the Department of Health? Ain't gonna happen.

Okay. Here's another reason why relying on the Department of Health, I don't mean to pick on the Department of Health, but ain't gonna happen. This is some data from Virginia, 2006, I believe, and it shows two gradients, percent low birth weight, under 2500 grams, for by education, which is a proxy for socioeconomic status, if you will allow me that, and by race. And what you see, the more education, the lower the infant mortality rate, and that applies to both blacks and whites. But even more significant is the gradient between blacks and whites. That is, for the same educational level, blacks have a much higher pre-term birth rate and hence infant mortality rate than whites, and that is persistent across all educational levels.

Now, the theory behind this are one of two camps. One is that it's genetically determined, and we're learning a lot about molecular biology and the differences between blacks and whites. The other, and I'm not sure if one, you subscribe to that or not. The other is that what determines the difference is plain, is, can range from anything from a doctor not being culturally competent and that shoots both ways, across the races; two, plain old discrimination, and a number of people hold to that. If one subscribes to that theory, then there is no way a Department of Health working by itself can correct that problem.

Okay. Get off some hot topics and go to a little academia. Robert **** is a professor **** at Indiana University and he developed a system of four collaboration models, informational, developmental, outreach, and action. And I'll go through each of those briefly.

Informational is just what you might think it is. Folks from various agencies get together, get together in a formal sense to exchange information. Other than just a controversial, I'm sorry, a casual conversation at the water cooler, these networks have a number of participants from a variety of agencies and they also formal, in other words, they meet formally, some have charter, some don't, but they're, and that enables continuity and focus. But that is **** obviously it broadens perspective, it raises awareness, and to me, the greatest benefit, it potentially sets the stage for the next collaboration, or type of collaboration.

The next one is something that he calls developmental, and that is it develops the capabilities of the participants in areas of management, program, and policy development, and it does this in a variety of methods. It can be the publication of a newsletter, it can be a website, some of the programs have active consultations, and they hold conferences and workshops. So it's a capacity development type of collaboration.

The third is something called outreach, and that goes beyond simply information sharing or capacity building. And what that does is, a group of members from various agencies get together and develop proposals to attack a given problem. They craft the proposals, but the actual implementation of the proposals takes place within an individual agency, each takes a sort of portion of the pie and works through it.

The final is something called an action network and these have a legal mandate to carry out, to formulate a program and carry it out. In addition, they have the financial resources to carry it out and I think equally or more important, and we'll talk about this a little later, they have oversight capability and they are accountable for those results. And an example of this would be, I believe in Montgomery County, the Collaboration Council for Children, Youth, and Families, which has a state mandate, has resources, and has accountability and oversight for a number of programs that address issues of children, youth, and families.

A little bit about the organization that I chair. It's called Improve Pregnancy Outcomes Program for Montgomery County. It consists of, you're probably familiar with this set up, two organizations, one is FIMR, Fetal and Infant Mortality Review Board, and basically this is a forum to review infant deaths and to come up with systemic reasons for those deaths. This is not a case of individual fault finding, **** times kind of sort of skew into this medical review board, it really is supposed to find systemic reasons for infant mortality. Recommendations are made to the Community Action Team, which then is supposed to take these recommendations and hopefully turn them, or advocate for policies and programs to correct them.

My own experience is that the CAT has basically three functions. The one that I find the most interesting, and may reflect your own organizations, can be summarized in the phrase, "May I have your business card." I am struck by how many members who come to this from various organizations in the Montgomery County Government, know little or nothing about what an organization is doing and I won't say that Montgomery County Government consists of a 1,000 different silos, but it almost seems like those working in the same area have never met each other, have never communicated with each, it's striking, and I count success of this meeting as to whether or not someone says, "May I have your business card," and there's a business card exchange. It is sad but true, and I think that having said that, that it's still a useful function.

CAT also has an advocacy function. For instance, if we learn that the county plans to cut mental health services for pregnant and postpartum women, the CAT will, under its

authority, write to the various people in the county executive or the county council, stating the problem, stating why this is going to be a larger problem if it isn't addressed, and hoping that funding will be restored, and we've actually been successful in those types of endeavors.

The third is increasing awareness. And I give you an example of that, it grew out of, I think my and a number of others' frustration with the constant parade of data in infant mortality, but the lack of presentation about programs that actually work. So we organized, if you will, a symposium, invited three participants, actually from around the country, to talk about successful programs, present data, and then in the audience we tried to invite, and actually came, as many people who hold the purse strings and have political clout, and so we got representatives from the County Council, including two of the County Councilmen, we got representatives from state government, we got **** the assistant secretary of health for Maryland, came as well, I believe? And that, to me, I think was a very, very important function because it not only said, "Here's the problem," but here are solutions that work. And the hope is that we'll put the onus on them now that they things worked to actually do something. For instance, enhancing Brenda's program.

I put this up because I might say some stuff that might make people mad. I want to distance Brenda, and Sheila from that, maybe. Okay.

This is my own personal observations on what works and what needs to get better, what isn't working. I group them into three categories, team members, goals and performance measures, and that ill-defined, but important term called leadership. This is the CAP. I know I'm not supposed to ask questions until the end, but you can see the membership, what's missing? Who's missing? We have county government, we have the president of the county schools, we've got some non-government organizations, we've got hospitals, we've got health plans, we've got WICK. Any, take a guess?

Pardon me?

SPEAKER: The community? **** Community members.

THOMAS STORCH: True.

SPEAKER: Business.

THOMAS STORCH: What?

SPEAKER: Business.

THOMAS STORCH: Beautiful. Anyone else, you get one more shot.

SPEAKER: ****

THOMAS STORCH: Yes! Did you see my slides? You bet. We don't have a single one member, I believe, from the business community on that team, on the Community Action Team. My own, clearly the employer benefits, if infant mortality goes down, his insurance rates go down, or least they don't go up as much. Productivity of the workforce goes up, and he also, or the employer, he or she, the company, gets to do some public service, which companies need to do.

From the point of view of the CAT, employees, especially large employers, are perfect conduits for communications to their employees, to their clients, to the Chamber of Commerce, clearly important. They also have political clout, they vote, and they contribute. And something that I think is equally important, they focus on results and they focus on results that mean something. And they know what it means to be accountable and to be responsible for those results.

Religious organizations, again, a conduit for communications, a source for volunteers, and what people have referred to as the bullet pulpit. Sermons from the pulpit mean something, mean something to the congregation.

The second is goals and performance measures. I have not, I have the most difficult time in getting the CAT to take accountability for infant mortality or pre-term births in Montgomery County. But the Board even set a goal for infant mortality or pre-term births, goals, this is not a goal, setting a workshop, but basically it's a point of reference.

It's a mechanism to gauge effectiveness, and it fosters that dreaded accountability that we all like to duck.

Performance measures, they're inputs, you know, how many nurses do we have, how many hours did they work? Their outputs, how many brochures did we send out? What's our website doing? But the most important thing are outcomes. That really reflect the concerns of the stakeholders and by stakeholders, I mean, the families. The infants, the mothers, the fathers, ultimately we're talking about what's the infant mortality rate and what's the pre-term birth rate? And it has so far been difficult for, the Improved Pregnancy Outcomes Project, to focus on outcomes and to take responsibility for outcomes, and there are a number of reasons for that, and we can talk about that.

Last, but not least, let's talk about leadership, you can see why I issued the disclaimer. This is the number of county collaborations that are directly, or pretty much directly involved with infant mortality and pre-term births. There's the Improved Pregnancy Outcomes Program, there's the Commission on Health, the Commission on Women, the Collaboration Council, the Infant Mortality Coalition, and the recently formulated, Minority Infant Mortality Reduction Coalition. How can we reduce infant mortality when there are at least six collaborations working on it and no one of those collaborations is willing to take responsibility for the ultimate outcome, which means, how many children are alive and how many children are born healthy?

So I conclude, hopefully on time, collaboration is necessary, but not sufficient. And what I call leadership, leadership involves three areas, I think. One is the proper collaboration model. I think we're beyond the informational and I think we're beyond the developmental. I think if there is a collaboration, it needs to be in the outreach or action, which means that it needs to actually have a program, have the funding to make that program go, and the responsibility for the outcomes of that program.

The leader also is responsible for getting the right organizations into that collaborations and the right individuals from the organizations.

And finally, the leader has to get his collaborators to focus on outcomes, to focus on results that matter. Absent that, the grafts of infant mortality are going to continue to be those straight lines.

So, I'm very interested to know what collaborations you participate in, what outcomes, not inputs, you achieve, why it worked, and basically why it hasn't worked. Okay. Thank you very much.

SHEILA O'CONNOR: All right, thank you to our three presenters for those terrific presentations. We do have time for a few questions, so if anybody has a question, if you want to address it to the panel in general, or someone specific on the panel, just let them know.

SPEAKER: Hi, I just wanted to know from the last speaker, how long did he ****

THOMAS STORCH: How long have we been going, Sheila?

SHEILA O'CONNOR: It pre-dates my participation on it, but I want to say, it started off, the FIMR started off, my understanding is, with a Community Action Team, it was folded at one point into the FIRM, and then became a separate entity again. I want to say four years ago, or would it be a little bit longer than that?

BRENDA LOCKLEY: Little bit longer, because it was in effect when I came in 2003.

SHEILA O'CONNOR: All right, so at least—

THOMAS STORCH: And I started chairing about 2007, 2008, I think, probably 2008, I would guess.

SHEILA O'CONNOR: So at least six, seven years then. Don't know specifically.

THOMAS STORCH: Why do you ask?

SPEAKER: I was wondering about **** as far as goals in having, you know, firm goals set and **** and if it was a newly-formed thing, then I would be able to **** I'm wondering what you think might be ****

THOMAS STORCH: I think the problem is a complex one, that's sort of a wiggle. I think that, we're all volunteers. I think that we have really no financial resources absent some money to pay for cribs, to attack any problem. And I think it's scary if you, I mean, personally, it's scary if you take responsibility for this. If you announce that, you know, we are taking, we hold ourselves accountable for this outcome, you put yourself on the line and people are reluctant to do that. I think, I'm in a position where, because I'm independent and consulting, I've got some freedom and some luxury to do that, a lot of members are members of the Montgomery County Government and they, for various reasons, may not want to do that.

But I think that someone, to my knowledge, and Brenda might correct me, no one in Montgomery County says, "Here is where we are, here is where we need to be, and we are the lead agency that's going to solve this problem and here are our goals and we're accountable for the, you know, short, long term, etc." I think until that happens, nothing is going to change, because, you know, no responsibility, no outcomes. I hope that answers your question, it's a very personal view of the world, but there it is.

BRENDA LOCKLEY: And I can kind of piggyback on that, because I find that the African-American Health Program, we only touch 135 moms per year. So it's unrealistic to expect us to be accountable for the entire county, and I think that's been, you know, as Dr. Storch says, who is going to be that entity who really says, "We're accountable."

SPEAKER: Does the team have the last **** so if you want to touch more than 135, you've touched them in this specific way, the Infant Mortality Coalition touches them this way, and so that you might be able to touch more than 135, all the different organizations as defined by your funding.

BRENDA LOCKLEY: Defined by funding.

SPEAKER: Yeah ****

THOMAS STORCH: But let me say something on funding, and I've said this before. You know, the infant mortality graft has been flat for, I don't know, ten years, probably ten years before that, but those ten years we've had budget shortfalls, but we've had tons of money and budget surpluses. So I don't think this is a money issue at all. I think, and I've said this, this is a political will issue, this is not a money issue. I think the resources are there and I don't think there's yet been the political will or someone smart enough to go harness those resources, but I refuse to believe that there's a shortage of money to do this and one can make graphs to show that, you know, a pre-term birth costs a ton of money down the long, you know, in the short run, in the NICU, which I have a lot of experience, and also in the long run, because these kids are developmentally handicapped.

And so no one has yet made the case forcefully enough that resource, you know, we've got the money, let's do it. The hope is for this new, this new sixth collaboration, is to try

to enhance Brenda's program, both in terms of quantity, but also in terms of quality, and at the last meeting, I raised the issue of, let's do a three-year pilot and see what happens.

Certainly also, we know what works and we know what doesn't work, I think we've gone well beyond that, now it's a question of political will, a long answer to a short question.

SPEAKER: I have a question **** for both and **** both of you have been **** areas of outcomes in programs that you have, how are you using that information to help **** of the system? For instance, like you said, you've seen 135 families **** a year, and you've seen the **** can't solve the problem yourself, how do you employ other systems to do what you're doing? You know, they ****

JUANITA GRAHAM: I didn't get a chance to talk about it, but we are a collaboration as well, it's Mississippi infant mortality obviously is more than just the Health Department can handle. We have multiple partners in the program, including the University of Mississippi Medical Center, the federally-funded community health centers, and several other partners.

We are piloting the DIME and the MIME programs in two areas of the state, in the rural area and in an urban area, and we're very closely tracking the data in a scientific method and we intend to use that data to request waiver or other funding sources to be able to take the program statewide.

And also, the collaboration in the state, there, he really hit on it, a lot of the problems that we have as far as competition. There's plenty of indigent mothers to go around in Mississippi, but we seem to be working for those who have some kind of payment system and focusing on those first, and different organizations. What's different about the DIME and MIME is that we're, rather than competing with community health centers, and with the clinics for the University of Mississippi, we're working together and making, in developing a referral system in between those to really change the system, of how we deliver care for this particular group of women who've delivered a very low birth weight infant.

Is that what you're saying?

BRENDA LOCKLEY: I want to say that also we recognize that so many times, we just preach to the choir. And our audiences who know about this problem and what we are beginning to do is to look outside and as Dr. Storch talked about, the business community, which can have a major impact. We have talked at one of the CAT meetings about maybe doing, trying to do breastfeeding programs in some of the local businesses, prenatal care programs in some of the local businesses.

But I think what we recognize is that we have to go outside of the usual audience. And with our new grant, we have some PSA's that are going out to just raise the awareness of pre-term birth and father involvement and low birth weight.

SHEILA O'CONNOR: Yes, I think you had your hand up earlier, the gentleman.

SPEAKER: Yes, this is a controversial question, but I think we need to talk about it more, and that is the issue of racial discrimination. On both of your projects, I'm sure are dealing with women **** and probably have experienced racial discrimination and is there somehow in the context of the provisioned healthcare we can begin to deal with that problem, at least at the level of ****

BRENDA LOCKLEY: We are very aware in the county of this whole concept of cultural competence, and I think it's something that we really need to do more work with, because a lot of people don't recognize that they're not culturally competent and a lot of people don't recognize what it is to be culturally competent, you know, I'll use our program as an example, we didn't know how to be culturally competent with the immigrant community, so it's, there are so many levels that have to be addressed, but I think that it really goes back to advocating for cultural competence, education and nursing schools and medical schools, you know, at the beginning to help people understand what it is and not be so quick to point fingers, you're not culturally competent, but to help people understand how you get to be culturally competent, how you work with different communities that are foreign to you? How do you get to know what the practices are in a community? You can ask, but there's a sensitive way to ask.

SPEAKER: And you mentioned that you have a **** and looking at that, you realize after a few generations that they're five generations.

BRENDA LOCKLEY: No, not even five generations, five years.

SPEAKER: But they're outcome for **** and so I'm wondering about, you said that you see 135 women, I was wondering how many of them are African and then on to the whole issue of breastfeeding **** that those numbers of women breastfeeding from Africa are probably higher for ****

BRENDA LOCKLEY: That's a really good question, because, one of the things that really spurred us to develop our data system was, we couldn't figure out if the African women in our program were skewing our results positively, and that was a real concern to us. And yes, almost all of our African women breastfeed.

SPEAKER: That's right.

BRENDA LOCKLEY: And they breastfeed for longer periods. But, you know, we have seen this, you know, especially in a county that has a such a diverse immigrant community, it's about five years, once they're in the country and they start adopting our bad habits, you know, McDonalds and driving everywhere. It's amazing, I had an intern, she was from Nigeria, and it was in July and she had walked probably about seven or eight miles to my office just to get one piece of paper, and she walked back because

her car was in the shop and I'm like, **** you walked? And it was hot! She said, "We do it all the time at home." But, you know, after about five years, you know, the built environment sometimes does not lend itself to what they were used to at home. You know, if you don't have sidewalks in your community, if your neighborhood, all it has is fast food restaurants, if you don't have any grocery stores where you can get fresh vegetables. So yeah, that is true, but normally, the new immigrant in our program have better outcomes.

SHEILA O'CONNOR: Yes.

SPEAKER: I'd like to ask this to Dr. Storch, have you ever considered the difficulties around collaboration in a philosophical context as to how the challenges are part of being human and what makes us human tick and given that undefined power role and under those circumstances, have you liked to share? I'm in the federal government and **** been at this for 40 years, and at times its senseless **** working with seven different, a community that has eight different collaborative efforts, I've worked with Mississippi where something is going on the Governor's office and they're competing for a grant that's coming down in the legislative office for two different task forces. And it seems that there's something about human nature, perhaps, that—well, I don't know, you know more, but I think you get the drift and if you have any comments about that.

THOMAS STORCH: Oh, herding cats comes to mind, or nailing Jell-O to a tree. You know, again, you ask the question so I'll answer personally. The CAT chair is a

voluntary position and it really shouldn't be. Running this committee, I think, especially given **** is a job for a full-time professional. And I will give you an example, we did this equity seminar in which we hear these programs and we got all these wonderful, high-powered people to come, and forgive me, it's not, there was no follow up. You got people excited and aroused and someone needed to come around and say, "Would you join our committee?" Someone needed to follow up with a county counsel to say, "Hey, what do you need to push a program through?" There needed to be a lot, and a lot of follow up and there's no one to do that and the county health officer and her assistant are tied up with a whole bunch of other stuff, so I think the problem is fixable, it certainly has enough emotional appeal. I mean, you know, healthy babies, just, Americans loves kids and it's getting the right people in place and the right positions to herds the cats, and I think that's critical.