

## **AMCHP Annual Conference, 2010**

### **Moving Ahead Together:**

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

##### **Preconception Health: From Concept to Measurement to Action**

March 6-10, 2010

BILL SAPPENFIELD: And it looks like we're ready. We all...you know we all start those initiatives where you're not really sure from the start exactly where you're going to go and you wonder if you're going to get there and this is one of those initiatives that's really turned out to be a fun, exciting, challenging...but an initiative where we think is going in a very good direction with clear evidence of being successful. I'm going to be talking about From Concept to Measurement and how we do the measurement pieces for the indicators and then my colleagues are going to talk about how we try to use these pieces that we've developing. In this session we're going to be talking about the purpose of what we are trying to do, the processes we've been using, the products we've come up with and the possibilities of how they can be used and what's happening towards the future. Just a reminder about preconception health the whole idea is that you don't think about preconception health you're starting too late. This is the gestational ages in organogenesis of the different systems in the body of the fetus that starts and when they start to develop and the missed period occurs about this fifth week and then mean entry into prenatal care is about the eleventh week so if you look about it most of the key organogenesis actually occurs before most women even start prenatal care. And this is a strong indication of the need to why we have to do something prior to

when prenatal care begins. Another way to look at it is if you're familiar with perinatal periods of risk where we try to break up fetal infant mortality into prevention periods using birth weight and age at death, there's maternal health prematurity, maternal care, newborn care, infant health. If you take that and you look at some of the data that City Match has done for the U.S. and then for the largest 66 cities you can see that maternal health prematurity, the idea that we need to do prevention in terms of getting women healthy before they become pregnant or doing something about prematurity is the leading areas where we need to be focusing. So all of this has been driving us to needing to start earlier. The way I like to look at it is aware that my European colleagues put it out as only in the United States do we think we can cure 20 years of ill health in 9 months of pregnancy. Nobody else would try to do that. What's exciting is the great leadership that CDC's been offering along with other national public health partners in trying to move the preconception health agenda forward. As Nan mentioned there's been a summit and a select panel and the recommendations that were published and then they started the different group meetings and this whole series of journal articles as we start to try and define what is preconception health and what are some of the best practices and what do we need to be doing and it's exciting to be to that stage, but in some ways for us at the state level, we still were at the concept framework and we were trying to get down to what is it that we're actually trying to measure, what is it we're trying to change, where is it that we can make a difference? And so it was really boiling down to how do we measure it? And in Florida as I came on board to work with Annette and being in the state Epidemiologist role we had all these discussion about what do we assess? What do we monitor? How do we evaluate. We started to look at what others

had done, our colleagues in California had put out their first preconception health report that gave us some indicators to get started, but it was clear to us it wasn't a lot of consensus where we should be and where we should focus and we just didn't want to go off on our own ravaged trail. We really wanted to go together. What was nice is we got together with some of our colleagues, about seven states were very interested in starting to talk about measurement of preconception health, what that might be looking like and how we could do that together and so we really teamed up in an initiative with California, Michigan, North Carolina, Rhode Island, Texas and Utah and this is an initiative which everyone signed up for and everyone had to work hard. And I think if they actually had to know how much work it was going to be by the time they finished they wouldn't have signed up. The good news is everybody stepped up to the plate every time we needed to do something. But we reviewed and evaluated potential indicators and we really wanted to come out with a recommended initial set...let's just talk about some of that process. But before we do here are the heroes and the seven states. I particularly want to highlight Dr. Danielle Brossard. She was a CDC CSTE MCH Epidemiology fellow with us in our department and she took on the lead of staffing this and working us through each of the stages and she could not be here, she would otherwise be doing this presentation and without her we would not have reached conclusion. She put in a lot of time and a lot of effort and had a lot of interesting discussions throughout this track because there was a lot of debate.

We had some very major assumptions. And the assumptions are important. First the indicators need to be currently measurable on an annual basis. And I say annual

because at BFRS asked sometimes we were willing to accept every other year. And it needed to be a core or optional component. So it needed to be something that would be available in every state and we chose 2009 as the year. So if it was not available by 2009 we did not consider it. The indicators needed to be population based and be at the state level. There is clearly a need for local indicators and urban indicators, but clearly the data sets available that was a whole other set of agenda. Indicators need to be reasonably accurate and also perceive to be useful for preconception health, not necessarily overall women's health but preconception health. The indicators should not be unnecessarily duplicative. I say not necessarily because some of the indicators we propose you might say are duplicative but that's because of the data sources that are available. We did not include what the outcomes of preconception health were mainly because we thought a lot of that was what's already defined and that is why we're trying to work on preconception health. They're already documenting indicators already out there that are well defined and so we did not want to duplicate that work. And then adolescence in men really needed some of their own set of preconception health indicators and given that this was a voluntary effort, we thought that one set of indicators was sufficient for us in terms of our task and we were going to recommend that future ones try to tackle some of the other population groups. The process was for us was to define the domains of preconception health at the time we got started no one was really proposing what was included under preconception health. And then from those domains we reviewed the literature and available state data sets for potential indicators that were proposed. We identified those indicators; we started to evaluate them, based off of five criteria. We actually then scored each of them off the five, we

roughly started out with about 98 indicators. We selected and recommended what those core indicators were and we even put them out for public review and comment. In the background of this Doc Sam Posner was very helpful, he convened a national expert panel to also give us input and comments about what we were doing at a decision point because we didn't want states going off all on their own without connecting in with the larger national effort and what should be considered. We ended up coming out with about 11 domains. General health status, chronic conditions, emotional/social support, genetics, epigenetics, health care, infections, mental health, nutrition and physical activity. We pulled out reproductive health and family planning out of health care since it was a predominant focus. Social determinance and tobacco, alcohol, and substance use. Almost all of these have indicators but epigenetics and genetics. We started there but we didn't find any that actually met sufficiently to be included. We also had some questions about environmental health but a lot of the indicators in environmental health weren't in our data set so that domain got dropped early. The data sets that we were considering went from abortion reporting to ART surveillance, to behavior risk factor surveillance survey. Census and current population survey, cancer registries, Prams, pregnancy nutrition surveillance systems, sexually transmitted infections reporting and vital records. The five criteria that we focused in on was public health importance, a policy program importance, data availability, data quality, and indicator complexity. The reason we did the last one is our experience has been that the more complex an indicator is the harder it is to implement, the harder it is to understand and so if something were simpler we tried to go with something that would make it simpler. From this we proposed 45 indicators. Hopefully everyone has a hand out. We did have them

out in the back. I am going to walk you through them because they did not make very good slides. So we'll do the old fashioned type of presentation before there were slides, but there is a table about four pages in the back.

This gives you just a brief overview of the actual indicators by domain, sub-domain and indicator and data source. We are actually...have gotten the indicators now accepted for publication in the MCH journal. They're working now on the galley so that it should be out in advanced publication soon. We've also got an agreement that CSTE will be posting the full descriptions of each of the indicators. There's like a three to five page description on each indicator selected for about 107 pages and that's going to be posted on their website so people can get detail references to the indicators that were selected. We're just walking through some of the indicators on the general health status we did go with self rated health. We thought it was important that we not only talk about health problems but the quality of health that people reported. We did not want to leave social determinants out. We think they're extremely important. We were not bold with the data sets we have but we think it's an area that may need further development. We focused predominantly on education and poverty. In health care we looked at health care access and utilization, access to dental care, reproductive health care, content and quality of care, under reproductive health and family planning we focused in on previous pre-term birth, previous fetal death, miscarriage and still birth inner pregnancy, (Inaudible)... birth spacing, pregnancy intention and wantedness, contraception, assisted use of reproductive technology. Under tobacco, alcohol and substance use we focused in on smoking, alcohol consumption, second hand smoke exposure. Under

nutrition and physical activity we included fruits and vegetable consumption, obesity and overweight, folic acid supplementation, exercise and physical activity. Mental health we also thought was a very important...so we included general mental distress, anxiety and depression and post partum depression. Emotional and social support we thought were important so we included domestic abuse, adequacy of support. Under chronic diseases and conditions we included diabetes, hypertension and asthma and under infections we included HIV, sexually transmitted infections and immunizations. As you can see our list is fairly comprehensive. Meaning to try and cover a lot of the waterfront of what was important to be included. However, as we did this there are some clear challenges and issues that we faced. One of the first challenges were that this is still an emerging field. We had some experts and others come back to us and say why are you proposing indicators now? We're still trying to develop what the field is what really is important and you should be waiting to determine what you need to be doing. And we sort of sat there and the question came back, waiting for what and when? And does that mean we're not supposed to do anything now while we're waiting so we shouldn't be assessing our priorities and we shouldn't be evaluating we just stay in a holding mode and for some reason with states that didn't resonate very well. So there wasn't a lot of debate in that. But the challenge of that is we're throwing out these indicators in the beginning of an emerging field. So these are what I like to refer to as mud on the wall. These are the first sort of rough things we're throwing up there and with time we'll get out there and we'll style it and we'll sculpture it and maybe we'll have to knock chunks of it off the wall but we felt like it would be better to have something that we were looking at and trying to work from then to not have anything at all. So we recognize that limitation and we

recognize that this is the first hopefully in a long series of recommended indicators. We struggle with the challenge of the difference between preconception health in women's health, because all of us accepted that women's health was extremely important but not all of women's health represents preconception health. And so we had a lot of debate about whether we kept some indicators because we thought they were really important indicators but the connection to preconception health was not clear and well defined and so we did not necessarily include them. Again, it's not that we didn't think they were important indicators for states, and not important indicators for women, it didn't necessarily fall under this rubric. Even though you could say in some ways we ignored adolescents and older women and men in these indicators, it wasn't because we didn't think they were important. It's just in a volunteer effort, once you start to think about the mammoth task and 107 pages of documentations of why you're selecting just the 40 something that you did select, it makes you realize that it's a large effort to go through these. So we really do think that future efforts need to include these groups and we think by having core indicators it may be easier to think about what the indicators might be in these other groups. When we walk through these indicators very, very briefly I didn't talk about the definitions but almost none of them have what we call modifiers. By that we didn't sit down and decide which age groups, which race/ethnicity groups, which economic areas, which women of different types and natures because we thought each indicator may have their own set of modifiers. We also felt we could spend a huge amount of time trying to define which ones should be included or not included and that may be not relate to what you can do with the power that's within your state nor may it necessarily fit the climate and culture in which your state may be. Hawaii is very

different from Maine, which is very, very different from Florida. So we think modifiers are important but we left that up to the users to decide. In our discussion we felt like these preconception health indicators really helped us bridge MCH and chronic diseases in ways that MCH doesn't always do and in fact we worked to have our chronic disease college join us in some of the development of the indicators and also included them in the review of the indicators trying to make sure what we were doing was appropriate. And given that we were using BRFSS and their data sets we also proceeded to use their definitions of the chronic diseases. They currently define them. So that what we were developing was not different from what they were doing given that we didn't have a basis to have something be different. We struggled with the true population at risk and that may seem funny but what do you mean by struggling? Well if you use BRFSS we don't always know exactly who's at risk for getting pregnant because BRFSS doesn't always talk about who's capable of getting pregnant. So we can generally define it by women of childbearing age going from 18 to 44, but we can't find out exactly how many always every year have hysterectomies or have had previous tubal ligations. We can't always tell how many have same sex partners and so preconception health may not be an issue in their current lifestyles. We can't tell any of those who are infertile so you're...BRFSS doesn't really capture all those women at risk of preconception health. The other major data set is Prams. And in Prams what we are doing is we're asking for those women who have live births about their preconception health prior to having live birth. But if you think about it that means all those women who had induced abortions, those women who had fetal deaths or spontaneous abortion are not included. Moreover that only talks about those women who got pregnant and not necessarily those women

at risk of pregnancy so the need for preconception health may not be well defined. So as we proposed these indicators what we started to realize that one of the real challenges is none of them are perfect and really capture the risk. And so sometimes you'll see we include both because we're not sure which one is better to have. And our hope is that things like BRFSS and other surveys may help us better capture who are the population at risk. In these risk factors, we speak more of the risk and less about did they receive the services needed for those risks. And as you think about preconception health it's not only important to know who is at risk but it's important to know what they need and what they should be getting related to those risks and are they getting them. And so future evolutions will need to focus in on that. Of course the challenge gets to be we already have 45 indicators and we haven't got a perfect set. So that the numbers can only increase in size and not get less and so that's going to be a challenge. And as we also move forward everybody had all these ideas of the other questions that should have been asked that were not asked and should obviously be added to the existing surveillance system. But welcome to competitive public health. To get onto Prams, to get onto BRFSS we have to compete against everybody else to get our issues included. And so we'll need to partner with others to figure out how to get the important indicators that we want included in the existing data sets because our likelihood of other surveillance systems are small. That begins to give you a flavor of where we are.

We want to now move from some of the theoretical pieces...the other news I did want to share is that not only has this been accepted for publication in the MMWR but we are already in discussions with CDC who is very interested in taking the lead to doing an

MMWR surveillance summary for the 50 states or for the certain number of states for the data may exist, that's in progress and being defined so our hope is that these are not only indicators in design and on paper but that we'll actually start seeing this...these indicators out and in use by public health sector, thank you.