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**LEADERSHIP, INNOVATION AND INVESTMENT IN
MATERNAL AND CHILD HEALTH**

Iowa's Maternal and Child Health Data Capacity Assessment Project

March 1st to 5th, 2008

DEBRA KANE: Thanks. Okay, okay, um, I'm doing an echo on Lucia's comment on interns and bringing the young people into the Iowa Department of Public Health. As we look at the average age of the people in our department and our bureau, we really need to be training the next generation of, um, work force and we just have the wonderful opportunity of working with Breana last summer but two summers ago, in 2005, the first time that we did this assessment we had a, um, a student from Des Moines University, Elizabeth Stoffer and I'm afraid, she was married I don't her, her new name, I forgot that. But she just did a wonderful job working on the assessment too and uh, if any of you know that looking for interns that are looking for a summer positions, we love interns in Iowa and really welcome them in our Bureau in Public Health.

But, let me, um, talk too about the Iowa results, Lucia is saying that I came to Iowa in 2005 and at our favorite coffee shop we are talking about how, how can we work on this together and one of my roles is that I'm a assignee to a state or one of the things we're asked to do within the first year of arriving at this state is

to conduct some sort of assessment, data capacity assessment to help us guide our work and look at what strengths does the health department have what're the areas of weakness that we need to work on and as I talked about the, my assignment and she talked about her goals for SSTI we realize that it was a perfect fit. And we could meet the goals of my programs as well as the SSTI program and moved forward with this assessment.

And we also have long discussions about, as we are preparing, where do we put the results section, do we save it in the end or do we put in the beginning. But we decided to put it early 'cause we thought, hopefully appetite to say "Oh, this is what I might be able to learn" by doing the assessment so we hope that she'll agree that this is a good place to put the results.

Okay, I'm going to have the results for both 2005 and 2007. As you can see we have, um, we have small sample sizes but really those are the primary MCH databases within, um, our Bureau of Family Health, as you can tell the response rate, people were really interested in participating in this study and I think that committee that Lucia referred to earlier help people to get interest and when Breana talks about the steps of carrying of this, um, process, you'll things within that discussion

Okay. So, what improved when we compared 2005 to 2007, and just so you know a little bit information when we, um, merged, um, in 2005 to 2007, there are

some databases that dropped out and some news that we add, so this represents actually 10, um, databases with a combined stats. But we found out, we were happy to see there are improvements on database access 'cause I'm sure some of you realize there are data manager that can access their data. So how could they use it for others things. So we saw that that improved the organization does have access to the data and we are thrilled to see that 100 percent of database managers have sort of defined, um, parameters for use , um, some way that people, who could access the data, do people need passwords, just something to define who, um, uses the data and we hope that that remains at 100 percent.

But we also found is improvements to data dissemination because as we should talk about the inventory, the keeper of the notebook, um, the state in her cubicle I mean, we're really have not used it, but what we're noticing now is that more people are getting out to do local presentations like with the Iowa Public Health Association as well as national presentation. In both situations this is increase. And one of the ways that we worked on that is we to look at when our, when our conferences, when do we get abstracts in you know, put that in our counters so that we could remind each other what projects are you working on, what do you think other people can learn from. And you know I will really waxed so we want to get out of word about all the good things going on here. 'Cause we're really pleased to see that more data and information is being disseminated.

UNKNOWN SPEAKER: Do you agree with that (inaudible)?

UNKNOWN SPEAKER: Yes. Absolutely.

UNKNOWN SPEAKER: What about the presentations?

DEBRA KANE: Um, actually a number of people, Iowa does the presentation, um, Lucia, Kim Piper from the genetic registry. Who're some other people? Do you know?

LUCIA KANE: Well, we asked them you know, each interviewee for each database, we asked them about their presentations so, you know, the genetics people especially uh, Kim Piper are genetics' core leader and she told us just the other day, she said you know, um, it's been because of uh, Debbie Kane's encouragement, um, to her in Iowa that she's presented, I think she's said three or three times in the last year and so it's kind of that ground swell or that bottom up approach to saying all of you folks get out there and present that you have stuff to tell about.

And, um, Kim Piper is doing presentation actually through the, um, the grand rounds sponsored by the MCH unit on Wednesday 'cause a lot of us is still in the conference. But that is our guys you could go back and look at that and she's

talking about steel birth ascertainment so you got a chance to see it again it gets recorded.

Okay, another, um, section of the survey was the question that we asked, um, "Do you use your database for than data collection?" 'Cause what good is the repository data I mean, I guess there's a lot of good reasons you repository data. As a data person, but we would expect people would use it for other things we saw improvements on the number of places. Lucia mentioned earlier the importance of program planning and program evaluation; you can see that in both instances. People are using their data to build programs and also for evaluation. Another piece that I did not include on the, um, um the results up here is that in 2005, 90% of the respondents said we use, um, our data for other things, but in 2007, 100% said we use or database for more than repository of data. Another really good uh, I think uh, piece of good news. And the, um, proportion of people that using the information for the needs assessments also increase for about 62% to 70%. I'm sure it will go up as we get closer to the, um, needs assessment but we're really please to see that people are using their data.

And as Lucia mentioned earlier, one of the things that we wanted to learn, um, and there's a section in the survey talking about this getting a handle on what are the skills that your data unit that needs. What are some things that you would like to do? We've got a number of questions in the survey asking do you need a skill like survey design, surveillance and number of different things and id you need

the skill, do you have staff to do this skill, because certainly people identify things that they have, um, but they need this but don't have staff and if you have staff, how adequate is this staff? And then finally, if you need it you don't have staff or the staff is not well-trained, what'll you do? What we found is in many instances, um, people mentioned that they have this need, they don't have a staff and what happens is that they simply don't do the project. They don't have the money to contract out so they're really not able to do some of the things they'd like to do with their data. In 2005 the, um, learning need that we identified was related to GIS and as we compare to 2005 to 2007 what we found is that the staff skill or the need remained the same and we're really pleased to see that people had increased staff. Now we're not taking direct responsibility for it but we're good to see that over the two years there's been some increase in staff to service particular need and the database manager we spoke to said that we feel that our staff is adequate and we're very pleased to see that. Now Lucia's gonna talk a little bit about, um, this training at SSTI that's how we worked out that piece.

LUCIA DHOOGHE: With SSTI funding, we were able to, um, not so much--we didn't so much pay for training but we were able to, um, you know, go through the department find out who was trained in GIS, um, sort of what the mechanism is were to, um, to obtain GIS resources within the department, um, and just make sure that people were--we didn't necessarily pay for the training but made sure that some people did get plugged into some increase training but I think the more important thing that happened because we have SSTI resources

to, um, focus on this, we were able to link programs staff to GIS trained staff. Um, we had the primary person within the department that works with, um, GIS we have him come and speak to our DISC group and data team and talked to program staff and day to day database managers and bureau chief level, um, administrators about what GIS could do for them, how they could access it within the department if they needed that resource. It was kind of like helping programs staff to understand you know GIS isn't just about, oh I could make a map. It's really much more than that and then if they're thinking, oh well, if its much more than that maybe I'd like to look at this and how would I do that, well this is how you plug into it. So linking program staff to GIS trained staff was really the key there.

Okay. With just a few more results, um, what we noticed as we compared 2005 to 2007 is that people identified a need for both survey design and surveillance. And we found that the need doubled when we looked at that need. At the same time that the need doubled, there was less staff, so as people recognize that need they said, oh and by the way I don't have people that I can't do it and they ranked their staff at, at least adequate now, you know, adequate means adequate or what does that mean so we need to look further at that. But look at surveillance, the need to increase by 60%, so there's a growing interest in doing surveillance and how to get that done. And what--we allowed people (inaudible) Breana has this great idea of saying it's not a yes or no and sometimes it's a yes but a yes but meaning we have limited staff. Yes, but we find that our staff is less

than adequate. So then what is our role with SSTI and how do you increased this skill level of people to meet the need to survey design and, um, surveillance.

UNKNOWN SPEAKER: I'm not sure when, can we ask questions?

DEBRA KANE: Absolutely. Go ahead.

UNKNOWN SPEAKER: Is--did you find that your need increase, um or doubled because you were getting more, maybe smaller branch or you have loss some large branch that's being replaced that multiple funding strip, what...

DEBRA KANE: I don't know that I haven't answered to that. It could be that people are realizing like with survey Mackey and some of the other surveys that there out there that might be something they can do. I know what the hearing, um, program they wanted to do a survey and realize that you know, we wanna learn whether or not parents are getting, um, information about new born screening at the time that the baby is born. And so we have a long conversation about well, how do we do that, what's the best way to do it, how we collect data though. I think there's a variety of reasons I don't know if it's specifically related to that but there's a real interest in, um, surveying and so actually, um, Lucia and I have been meeting the, um, the DISC group in the MCH, the other community is saying, we need to clarify what people meant by this and then look at how to address that so I don't have a complete answer to your question. But there's

seems real, um awareness about we need to go back out and gather more information so we, we're working on that. Other questions are right now? Alright, I will keep going then.

Another thing that we noticed when we compared 2005 to 2007 you know, that people are really interested and having an increase need for data linkages so over the next year or two we'll be looking at that to define, what, how is that need, how could we meet that need, what is the need but you see again that the limited availability of staff, staff might be present but is pulled in many different directions, so really can't commit themselves to that and that staff is at least adequate. Just gonna go a little bit into the results for, this is 2007 alone, this would not be the, um combined set and Breana will talk a little uh, a bit about how we changed the survey and built up the interested or, um, we had some interest in learning more about the data linkages so we really built up this section in the uh, um, survey. What you see is that 84 team, data sets out link and people are linking with anywhere between one and three data sets and you probably not surprise to see that the you know, the big heavy hitters and linkages are with medicare claims file, we're really fortunate in, um, at the Iowa Department of Public Health have a great relationship with the medicare people and we can requests claims information and can do a lot of good work looking at, um, the services that people whose services are paid for by medicare, um, how good that service is and of course vital records. I'm sure that doesn't surprise you that they're an important, um, part of the linkage process.

What we found is that, we in a linkage section, we're asking, do you need to request for the, um data to be linked, is it routine? Tell us what's it like and we were really I think, happy to see that the majority of the data linkages are routine, meaning, someone who did not have to get a request together it happens on a routine basis, they're not having to wait for data. It's something that's worked right into the process. As far as the frequency, it varied in anywhere from daily, there are some daily data linkages and some of them data sets to one of the projects that I worked on which is the, um, the match between medicare claim files and vital statistics, that's once a year but it gives us years of analysis and plenty of things to learn from it. But it is an annual thing, again it's, um, I'm really thankful for the good relationship we have with the medicare folks. And what we found almost exclusively in our health department is that people are using a deterministic method to match their databases versus the probabilistic.

UNKNOWN SPEAKER: What is deterministic?

Deterministic, primary, read the definition from there.

UNKNOWN SPEAKER: It's on page two of the tool.

Yeah. We worked, we worked really hard at the definitions and, um, we, we had many meetings to be sure that we were following, um, it says deterministic

linkage refers to the linking of the pairs of records on the basis whether or not they agree on certain variables. For example with the birth certificate we might be looking at the mother's first name, last name, birth date, baby's first name, last name and that you relax the criteria and examined whether or not a matches occurred, so in some ways quite uh, manual process means some of it automated but there is some eye bowing things, looking at mother's maiden name for example, you're using, we don't have a unique identifier that we can use with the medicate claims file, we don't collect social security number on the birth certificate, so we're using it that way so, um, some of the common variables that you would expect to be the same between records, but as you know uh, birth dates can differ, spellings of names can differ, um, there's a lot, um, things can run into. Thanks.

UNKNOWN SPEAKER: Can I ask one more question?

DEBRA KANE: Sure.

UNKNOWN SPEAKER: When you say that, um, majority of the linkages were routine, what exactly is meets the standard in order what?

DEBRA KANE: It means, no that's the only report but its standard that everyday medicates sends information to the CARE's database. No ones has to call and say, um, would you please send us the, medicate claims information where if the

medicate matched once a year I have uh, request that I save every year, we update that and then I send it to the medicate folks. They gather information, send us the information (inaudible), um, most of the time either just on going process is that people that don't have make a specific request for.

Okay, with the linkage process, um, as we look at it what we found and I guess we have to talk about this bit is it, is it strength or is it weakness? But we don't really have a standard for our linkages that are occurring. There's a just really wide variation if you talk to one database manager, and they have a different process than another database manager. So I think over the next couple years we've been looking at that and see you know, do we need a standard, shall we develop a standard so this are some things that we'll be looking at in the future but then one of the questions we included in the survey was asking the databases managers, what will you gain by this linkage, how does this strengthen the information that you have? And what you see is people get good information about demographics, um, I really interested looking at the medicate claims file and birth certificates to learn about maternal behaviors during pregnancy and what difference does that make when I compare medicate women to non-medical women. We get information about infant outcomes but the real big one was demographics and so some, maybe holes or pieces of missing information in one database by joining the two or three together, we have much more information to, um, do program planning, to do needs assessments and carry on with your program.

Alright. Now, here's how you can do it. As we were getting ready for this, um, presentation, we thought you know, I think, I think, Breana, Brenie, you came up with this idea, she said you know, there are steps to this and why don't we put it in steps because I think that's a really good guide. That's a good method for people who say I have step one, then I go to step two and we have eight steps that we came up with, um that will show you how you can do this. I'm gonna start talking about step one and then I'm gonna turn you over to Breana.

Okay. I mentioned a little bit about the sort of the, marriage of the SSTI and the MCH, um, EP assessment and the MCH EP team which is a part of the vision of reproductive health that's CDC actually develop one of the early drafts of that tools for us to take out to this states when we we're in our assignments. And I have used an earlier version of that tool when I was, um, a fellow in Mississippi, I got to tell you it changed a lot after it. I'm sure you've all worked on tools and then once you go out and use it you think, what was I thinking and now as our experience with having use a tool in the field so, um, we made many changes to it. We want to personalized it for Iowa and some of you might remember that the cause was territorial epidemiologist did the nationwide survey MCH EP team took some information from that and said how we personalize this for ourselves and I guess the bottom line is the public use document played with it, make it work for your agency and in 2005 after we did that survey, then we realize some other things when we we're said what were we thinking again? So then Breana came

and said here, let me help you clarify your thoughts and, um, in 2007 we made some more revisions to the tools and now let me turn you over to Breana who will walk you through some more of the steps of this process.