

AMCHP 2009 ANNUAL CONFERENCE

Public Health Data to Address Disparities:

Meeting the Challenges

February 20 - 27, 2009

SUZANNE BRONHEIM: Were any of you at the session last year that Sid Davies that I did on data. Nobody? Okay. Well, this is part two but it doesn't matter that you weren't here for part one. But if you were on that session where we all had a conversation about some of the challenges [inaudible] of data about race and ethnicity and the cultural issues, and that at the same time I think I'm going to address disparities. It becomes very, very important. And during the question on the intercession, we -- people were kind of saying, well, it's totally hard because each of the federal funders want something different in each state [inaudible] collects different kind of data. And they always [inaudible] someone from California and [inaudible] much of your colleagues that also said, we've been kind of working on this and we haven't worked on that in the universe, but around some of our adolescent health issues we've been trying to figure out how we could at least report data in one way. And so suddenly [inaudible] and as we brought people together, we learned a lot. She said they're [inaudible] Some of us were collecting three [inaudible] of us, and that this was -- this, really, was a collaborative process that really took a lot of a time and effort.

So we got really excited and said, well, I said, let's put [inaudible] for next year and we'll get the folks from California come to talk about what they did and how they did it. So you will notice this morning, I mean, most of the people, it was supposed to, originally, Sid Davies from last year Wichita State University but [inaudible] fell and we know the equipment, but you're going to hear his voice, so totally are techie. I wanted a hologram of him but, CNN was busy and [inaudible] hear his voice on the [inaudible] his few introductory slides. I will be talking a little bit about some of the contextual cultural companies issues that surround this whole issue of looking at data and health disparities. And then you'll see that Karen Ramstrom is going to be speaking to us but the budget X fell on her just like two weeks ago in California, and I started sweating and - because when she said, "Don't worry, you got the slides," but we are very fortunate that a colleague of hers has also evolved from this very same project [inaudible] who is here. He's going to talk about that California experience and then we're going to hear from you and we can't have a conversation about this issue because I think it's something we're all trying to get our hands on. Okay? So, any questions? All right. It seems like I'm on the airline. Everybody in the right room? All right.

So, we're going to start and you're going to hear Sid Davies. Sid is from Australia and he is Maui and he talked last year about the fact that he imagined himself to his lifetime and his, how he would be designated in terms of race and ethnicity could change many times. And he talked about being listed as Maui, then at his teen years identified with his European father and that side of the family, so when

he got a driver's license, okay, [inaudible] European, and then went to Europe to visit the family and decided he was German at some point but at that end, he said, and then maybe I would die alone some day and someone would look at me and try and figure out what my race and ethnicity was, which is unfortunately a hell a lot of our death statistics get reported and can be something completely different. So, we're going to start with Sid and he's going to be Australian with his traditional Maui greeting to you as well.

SID DAVIES: Greetings and welcome. Last year at Antwerp, [inaudible] and the discussion with the participants of the presentation centered on issues that were experienced in the field. The response was very positive and as a result were that. So I'll recap on what was presented and discussed by the participants I'm going to take a few months to overview that information and lead us into the material being presented today. Health disparities are complex and the collection of health data to address disparities is just as complex. The context of the survey purpose and the context of the target population environment is a good start to untangling this complexity as this provides the context of the methodology applied to data collection. The definition and use of ethnicity to assist in eliminating health disparities is an important aspect to remember. For the purpose of clarity of this presentation, I will use the term ethnicity as to represent both race and ethnicity as it is used here in the USA. Categories of the Office of Management and Budget, directive number 15 as revised in October 1997, can be problematic as CDC, U.S. Census Bureau help and other federal agencies do

not always have identical population categorizations, and state agencies respond differently to different federal requirements.

To design effective state public health interventions, broad ethnic categories are often insufficient and much narrower or specific categories are necessary to obtain meaningful information. Data collection needs to have categories that provide us some information that can still be rolled back to meet federal requirements. Another area is multi-ethnic groups which are also problematic and many are asking what do we do with this problem. As ethnic identity is fluid and more and more people in U.S. come from a multiplicity of ethnicities, people may identify with different areas of their ethnic makeup over time. Last year, I presented a story of the Hawaiian Japanese in Samoan German heritage prison and how the ethnic identity changed over their lifetime. There is no easy solution and it is important to remember that data gathering is based on a snapshot of a given point in time. Multi-racial responses and data sets are reported as being small but they are significant and we need to apply a process of categorization and not relegating to other and forget about it.

Standardization of data collection is required at multiple levels and requires attention to a number of issues. I will cover only a few at this time. First, it is important to remember that national surveys are designed to provide an estimate for the nation and it is left to the state to find and conduct surveys on the main part. Data is not collected for a number of reasons, and this is the same for not

standardizing data collection methods. Standardization does not need to be a globalized implementation. It can be done in small steps. There are a number of factors that need to be considered. For example, there is the cost of changing IT systems, privacy and confidentiality requirements, legality of data collection, and various to data linking between systems and agencies. One of the important issues that can be standardized is when and how population ethnicity is collected.

People that self-disclose versus observation are a key issue, with self-disclosure being the gold standard, which means that people that collected ethnic data need continual and meaningful training to collect this valuable information. It is also important to remember that private health key providers and insurance companies may or may not collect ethnicity. Another area to consider is the small population data sets need to be done and oversampling or other methods should be used so that a single large other sample is not obtained or relegated to the white categorization. Another area that may need attention is the inspectors and their need to be disaggregated. There are also differences within ethnic groups and not just between ethnic groups. As an example, the study on cancer with the Asian population in California, where cancer rates for different types of cancer differ by different agent ethnicity. Along with SES is issues of time and country, foreign-born compared to U.S.-born, language spoken as well as the corporation, health literacy. Culture is also important with cultural behaviors and the associative health-seeking practices. Of course, there are frontier rural urban

metro comparisons but how about neighborhood characteristics. There are a lot of issues about SES that needs to be considered, and these along with other factors discussed today and how these have relevance to the purpose of data collection to eliminate health disparities.

The context of data purpose and context of population environment has a direct relationship to the context of the methodology of data collection. I hope today's presentation and discussion will assist you in your data planning so that data collection can assist you in discovering factors that will address health disparities. AMCHP has provided a download service for handouts via the conference Web link. I have provided a link to this presentation with notes and an extensive annotated bibliography of references to ask, articles, and other literature that I've used for this presentation. Thank you.

SUZANNE BRONHEIM: Thank you, Sid. All right. Now, let's see. Okay. Oops. Let's see if I can make this work. It's too high tech for me. Okay. I'm sorry. It's just I don't know why this is being so strange. Okay. We don't -- do we have a tech person in here, by any chance? It doesn't -- when you tell it to start from the current slide, it goes back to the beginning. So, all right. I'm going to start talking while you can -- at least you can see it even if it's not in -- it stops itself after his slides. It didn't use to do that, and I need to start from this slide and move forward as a show...

UNKNOWN SPEAKER: Is it this one here, six?

SUZANNE BRONHEIM: Uh-huh. When I tell it to start the slide show from that slide, it goes to the beginning. Yeah.

UNKNOWN SPEAKER: Just can't forward.

SUZANNE BRONHEIM: Yeah, you can't. There's something stopping.

UNKNOWN SPEAKER: I'll call someone into the room.

SUZANNE BRONHEIM: Okay, thank you. Sorry. This worked on my computer at work. Can you see this well enough? Okay, because I don't want us -- but I hate when you have the presentations where you spend half an hour trying to fix it. And hopefully, [inaudible] by the time you get there, we'll have it. I just wanted to talk a little bit, again, he talked a lot about the context of data collection and from -- coming from the National Center for Cultural Competence, I really want to think about the fact that, and data collection is not something we should do to people but something we should do with people. And for the communities where collecting the data on that there are engagement, the individuals becomes very, very important on many levels, first of all, because we want to get by in and people to participate, and secondly because we want to make sure that the kinds

of data we're collecting, the ways we're collecting it are not seen as harmful to the community or stigmatizing, and especially when we talk about health disparities, and we'll talk about in how we report it, all that becomes very important.

So, we may want to engage the community population that's part of a specific program, community support and advocacy groups that may be specific to a population. It may be ethnic or racial specific that may relate to sexual orientation. It may relate to particular diseases. The folks who were doing all of the work on genetics in the human genome project ended up having to have what they call a community advisory group because people were getting very nervous. Studies would come out and say, "We found the gene for bipolar disorder in the Amish community or in the Jewish community, or this or that community." And so, there was beginning to get some very strong feelings of people worrying about being stigmatized and of course the impact for that not just socially but health insurance, all kinds of other things. So having in a community advisory group about how you gather data, how you report data becomes really important. You want to have natural community leaders, not just sort of the designated people that are elected. Come on. Oh, come on. All right. Part of it is it gives you a lot of insight and to figure out how people in that community do self identify. We have this OMB labels but is that really about people in a group that you want to get data about actually call themselves? I mean, there's the raging debate. Latino, Hispanic, Chicano, I mean, depending

on the [inaudible] country. Which population? Which word you use, you can get people to buy in or you get people who check out and are really angry about the process and say, "I don't see myself here anyway." If you want to look at some populations you may not be able to, from your macro level, figure that out.

By engaging community, engaging other folks, you may. And then obviously to get the buy in. And when do you want to get that engagement? Too often we put all together what we want to do. We put our study together. We put our protocol together. We go to folks in the community and say, "So, is this okay?" But at that point, it's -- we're too far down the road and people feel very marginalized in and don't feel like we're particularly sincere about wanting their input. So it really needs to be -- before you get started talking about why are you going to gather the data? Does that make sense to them? How it's going to be used? Any sensitivities during the effort? And then afterwards, the analysis, folks who are on the ground in the community and members can be invaluable in helping you -- you get some anomaly in your data and you're going like, "Wow, what is that?" can get tremendous help from those folks. And then afterwards, how do you report it out? How do you tell the story? We're always in that balance between we want to demonstrate need because you don't get money to do stuff if there's not need without looking only at the weaknesses of communities and individuals. So that becomes very tricky.

We have a lot of challenges in getting accurate data. Sid talked a little bit, particularly when we get data not collected directly from an individual or family. I think about the infant link birth death data. Lots of kids change race and ethnicity in a very short amount of time, and that's because that death data is often reported by funeral homes, other people. Someone takes a look at a kid and goes, "That kid looks like they're -- and they write something down. They sort of feel like they might not want to burden the family. Different agencies have different ways they collect data. And the other thing we find is that there's a lot of personnel who are not willing or skilled in asking for that data. I work with a family organization in Maryland and, of course, because they get federal funds, they're supposed to be reporting raised in ethnicity and all this on all the folks they're seeing. And when we finally sat down and really got to it and we said, "So how are you doing that?" And they said, "Well, I can usually tell by their voice on the phone." Or, "I actually met her." "But did you ask?" "Well, no." "I didn't feel comfortable." They wouldn't feel comfortable. What people usually say is they wouldn't feel comfortable. They wouldn't want to answer. And, of course, we all know what that means. So you really have to do a lot of training. And actually, I think I've listed on at the very end of Sid's resources, there's a really nice training module put out for use by hospitals and healthcare folks. But I think it really -- there's a set of modules for training people and asking for this information that can be very helpful because we often just say to people, "Go do it," and they're not comfortable.

And for those of you who weren't here last year, it always amazes me when public health people feel so queasy about asking about race and ethnicity because they ask people about how many sexual partners they've had and what kind, and whether they were upside down or sideways. But, I mean, I think it just speaks great deal to -- for all we've -- newspapers have been talking about when the post-racial age, I think we all know the realities of that and race and ethnicity are hot button issues. And so, when people go to ask about it, there's an issue. And yet we're not going to be able to address what we need to address if we can't get that data. So this is the tool kit. It's the health that research and education trust. The link is on there. If you go online to get these slides, you'll be able to get right to it. And it's got training materials and examples about how to handle different responses and questions from the person you're gathering the data from. It's really very concrete.