

## **AMCHP 2007 ANNUAL CONFERENCE**

### **HEALTHY COMMUNITIES**

March 3rd to 7th, 2007

#### **MCHB/Division of State and Community Health Block Grant Training – Providing Data to Tell the MCH Story**

CHRISTINA BETHELL: Thank you. A couple things. There are a lot of seats up here for the people who are in the back, if you wanted to take a second to do that, not to put the spotlight on you, but I'm just, I wanted to have a chance to do that. And secondly, I did want to say that you can compress a PDF file, and that can be very convenient. So if you have a brochure, and you put it in Adobe, and you compress it, it will shrink it down even more. I just wanted to tell people that 'cause I didn't used to know that, and it's really been very, very useful to know that. Okay, great. So I'm going to just take a half hour here and introduce you to what's new, what's different, and what's the same in the new National Survey of Children with Special Healthcare Needs. And also make sure you know about the Data Resource Center as a resource. In the next few months, as you go through your process of doing the block grants, we may be able to be of assistance to you in both accessing the already available National Survey of Children's Special Healthcare Needs, as well as the National Survey of Children's Health data, where there is some connection with your performance measures. And certainly the needs assessments and so on and so forth.

So, those are my goals. And I do want to recap the survey. I also wanted to point out some of the handouts in your folder. The folders came up to the room a few minutes late and I had intended to integrate two additional handouts that I will make available at the back of the room. So before you leave you can pick them up, but for right now, let me just alert you to what's in here. So, on the right flap of your folder, the blue folder, is a quick guide to topics and questions that are asked in the 2005, 2006 National Survey of Children with Special Healthcare Needs. And the usefulness of this is that the long survey, as it was administered by the CDC, is over 250 pages. So you have to go through and it would take a long time to figure out what's actually in it.

This is maybe eight pages long, basically saying what's in there, and topically so that you can look at it in more detail. And there is of course on our Website also a version for the National Survey of Children's Health. So that's the first thing. The second is a one-pager on the Data Resource Center. So it just gives you a sense of the resources. This is sponsored by the Maternal and Child Health Vero, it's run by the CAHMI, and is a resource for you to go and access the data, compare yourself to other states, look at the data by subgroups of populations in your state, in an easy and friendly way and download it.

And then on the left-hand side, I will be going over a diagram with you that looks at the (inaudible) caters and core outcomes that are measured by the National Survey of Children with Special Healthcare Needs. And basically what it does is it

gives you a quick guide to what's--what's really changed enough so that it would be difficult to compare it to the last survey, the 2001 survey, and what sort of stayed the same, and then the major categories of what's the new information that was collected in this survey that was not available in the last survey. So it's a quick glance for you. And as you go through, thinking about your needs assessments as you move forward, and I don't know if you can, you can't probably put performance measures in that don't have existing data. But the data will be available for this in early fall, so, we'll be working it up over the summer and making sure that it's available for you in early fall. But this information should give you a good take on what will be in there, and you can also contact us.

The other couple things are in depth for those of you who want to really know what are the outcomes and indicators and how were they measured. This was a method's review that, may be more detailed than some people want. But for those of you who actually want to know what's inside the box, what is inside the family partnership's measure. What's inside the medical home measure, and how is it constructed, and how does it vary from 2001, this is something that will be a quick guide for you, because to do that in any other way, it's a laborious process. So, it's, sort of we're hoping this will be a gift for you to either delegate off to someone and your staff who you want to make sure really understands how medical home is measured, and be able to figure out what exactly is in these measures. Because they are mostly constructed of multiple items. It's not just one single concept. They're multiple concepts rolled up into one.

And the last handout is a diagram, it's a longer one, colored. And what it is is we went through the last round of block grants and looked at the state priorities and arrayed them by topical area, and what proportion of states indicated that those were priorities. It may give you some ideas of other states that you want to talk to about priorities that are maybe engaged in that. And I also have a nicer summary sheet that crosswalks this to data that's available in the Data Resource Center. And that's what I didn't get to put in there, because the folders came late. But I'll have it at the back of the room. So, it's a way for you to say, "Okay, well, I'm interested in breast-feeding, and so are these other states." Or "I'm interested in cultural competency." Here's the other states that are working on that, and it can maybe help you, you know, get some ideas, look at what they did the last time on the TVIS and so on and so forth. So with that, I will just take a couple minutes. I only had a half hour, which is why I wanted to make sure you knew about all the handouts and have a chance to go through them, and then I'll do the highlights for you now. So how many of those, how many of you already know about the National Survey of Children with Special Healthcare needs. Okay, so you're familiar that it exists. And how many of you have ever access to the Data Resource Center to get your hands physically on data. Okay, good. So there's some people who have and some opportunity for others to take advantage of that.

Well, the National Survey of Children with Special Healthcare Needs was conducted for the first time in 2001. And there is a screening method that's used that operationalizes the MCHB definition of children and youth with special healthcare needs, which is a broad-based consequences-oriented definition. And one thing that you should know, for those of you who were interested is that the way that the survey is administered and the way that the CSHCM screener is administered, will, is expected to lead to slightly lower rates than what you see in the National Survey of Children's Health. So any of you who are sensitive to the issue of prevalence, and want to understand why it looks different from one survey to the other, we have a nice summary of that that I can provide for you. But we do expect for methods, reasons that I can go into detail on for anyone here who is alert to that, that the National Survey of Children's Health already out, provides prevalence estimates, as does this survey. And they vary. They're different in your state. And they're different for reasons that are understandable, based on methodology. And so those of you who want to know more, we have a booth here at AMCHP, and I'd be happy to talk with you or even have a conference call for anyone who wants to struggle with that issue in particular. And we have a paper that will be coming out, an MCH Journal on that. And that's been something a lot of people have called about. So I'm putting it out there upfront.

Sampling and wading is a conducted (inaudible) for state level elements, which is fabulous. First time ever in 2001. And it was repeated in 2005/'06. And the way

this survey is supposed to be termed by according to the National Center for Health Statistics is the 2005/2006 survey. So, if you ever get corrected on that, we were calling at the 2005. But really, just as much of the data was collected in 2006 as 2005. It's harder to get this data in the door doing telephone surveys. People have to call back lots of times, so it takes them longer to collect it. It took them two years to collect this data, versus one.

And there's 850 in-depth interviews that were done with children and youth with special healthcare needs in each state. That's the target, and we'll find out in a couple weeks exactly how many are in each state. It might be a little bit above, it might be a little bit below. But that was the target. And it was 750 last time, so it's a little bit higher.

The way this survey is collected is there is phone call, households are called for the National Immunization Survey, they are asked if they have children in their age range. If they do and they qualify, they implement the screener process to find out if there's a child with special healthcare needs. And if they do, then they provide the in-depth interview for a randomly selected child and youth with special healthcare needs. This allows for three different denominators in the survey data set. You have a population-based denominator, where you can look at kids with and without special healthcare needs and their demographic characteristics. A lot of people don't know that you can do that. You can do that right now, on the Website, for the most recent survey. Which is the 2001. You

can find out how children and youth with special healthcare needs vary from children and youth without special healthcare needs, on household income, race, ethnicity, age, distributions, gender, other things like that. So it's often a unused aspect of the survey. But it is available for your query by state and demographic subgroup on the Website. The second is the screener file, which provides details of how children with and without special healthcare needs answer specific screener questions. A lot of children answer the questions positively, but don't, and then end up making the cut, because they didn't, the parents didn't answer the question in a way that let them screen in. But there's still a lot of information in there about use of services and so on.

And then finally is the in-depth interview. It's a random sample. Most of you are familiar with the concept where a random sample is collected and meant to represent the whole. So, I just went through the three screener files. And these are all three files that need to be integrated in order to analyze the data. One of the reasons we have the Data Resource Center is to save you the trouble of having to do that if what you're interested in is up to a three-way cross-tab. And if you do want the data with the indicators, it can be ordered and we can send it to you, already, already developed, variables constructed, and integrated. So, make sure you use that as a resource. If you are planning on getting the raw file, keep in mind that we can give you for free, the actual worked up file, when it's available, which hopefully will be, like we said, in the early fall.

So the kinds of information are health and functional status, health insurance status, access to healthcare, care coordination, family centeredness, impact on a family. You have the longer list of the topics in there. And this data specifically gives you information for measures two through six of the national performance measures, as well as a wealth of much more information. In terms of 2001 versus 2005 comparison, how many here are interested and think that they might be interested in comparing how things went in 2001 versus the new survey? Most people are interested in that.

Okay, so here's some guidelines for that. Outcomes one and three are not a problem. Some things, little things change, but they're not a problem. Outcomes two, five, and six are sufficiently different that you need to be alerted to that and maybe look at the tables I handed out to you to understand how you want to frame that comparison. Mostly, the community-based services, organized, the families can use them easily and transition to adulthood. Well, that dramatically improved, but in a way that gives you a different population of children for whom the questions were asked and the specific questions. So that's something important to know. Medical home, use the same definition of medical home. But also, was changed sufficiently to make comparison something that you need to be aware of.

And we've tried to give you, in your handout today, what you need to be able to ascertain that. And we are actually, we are happy to talk with you on the phone,

through e-mail, have a conference call or what have you if you're getting into a medical home and want to know how to characterize it. It's a much-improved measurement set, and we're excited to start working with all of you on it. The indicators are a set of indicators that the bureau defines that are separate from the performance measures, that get it additional information. And so these are some of the indicators that are in 2005/'06, that are also in 2001 that did not change sufficiently to alert us to any concern about comparison.

Present with health conditions who are consistently and often greatly affected in their daily activities, percent of school-age children and youth with special needs with 11 or more days of school absences, gaps in insurance, current insurance status, adequate adequacy of insurance. Unmet needs for a range of specialized services that children and youth with special healthcare needs require. Family centered care, families experiencing financial problems, and cutting, family spending 11 or more hours a week providing or coordinating care for their child. So those ones are all more or less intact from the last survey. The ones that changed sufficiently, and again, improvements were made, is percent of families with unmet family support services, problems getting needed referrals as a new concept. So they find out if they needed a referral and did they have much of a problem they had getting it.

Percent without a usual source of care, who will only rely on the ER was changed in a way that's outlined in the table. There is debate about whether people think

that's changed enough to make comparison a problem. It looks like maybe that happened when we look at the data. But we will be happy to talk to anyone who wants that, to look at that further. Percent without a personal doctor or nurse, percent with families paying more than a thousand, that's a typo there, sorry for that. And medical expenses for their child and with, percent of children with families who had to cut back or stop working due to their child's health. So there are some issues that happened there. What's new is really exciting. Many people say, "We want to know more about who are children and youth with special healthcare needs, what are the issues that they face in their day-to-day life? What are the conditions that the parents report that they have?" There is a long list of reasons why we don't use condition checklists, or as a way to define children and youth with special healthcare needs, both misdiagnoses, missed diagnosis, parents not knowing the name of the diagnosis. There is not having access to healthcare, they're not getting a diagnosis, any number of reasons why. However, there was a condition checklist used in the 2005/'06 survey, said that for children and youth with special healthcare needs meeting the criteria, we can characterize them along those dimensions. And 18 different functioning issues that are very aligned with the ICFCY, for those of you who are familiar with it. So, we worked with the CDC Dunlawler and MCHB to define a list of functioning issues that range from participation in life to physical functional issues, mental, social behavior, emotional functioning issues, and so on.

There's a lot more rich data that is in the survey, and again, the tables that were handed out give you that detail of what those are. We also have a booth, so you can come and learn more. There's also information on number of ER visits. That, believe it or not, was not in the 2001 survey. Problems getting referrals, I already mentioned, is a new concept that I think also will be a really nice one to have.

And other topics that were not in the last survey is primary language at the household. And that is extremely valuable for the 82% of states who said that they were interested in disparities, assessment, and reduction as part of their state priorities. We know that when we look at race ethnicity, that's one thing, but language being brought in really adds a whole another layer of specificity to who you're targeting, and who has issues. So without the language variable it could be hard to look at acculturation and some other things too. Whether people who needed an interpreter got that, got an interpreter, and also family composition.

There is a number of variables that were included, that are similar to those that were included in the National Survey of Children's Health, that allow you to look at the data by family composition. And it would be a whole day for us to talk about how to construct that data, how to present that data. But the data is there, and we'll be getting some input and advice over the next few months from advisers on how to, how to upload that into the Data Resource Center and what construction of variables do we want to use that will allow you to query the data by family structure.

There are many, many other new items. We have a detailed crosswalk, an Excel spreadsheet for anyone who wants to get into the detail of it, but we've given you the highlights here. So in terms of getting the data, the public releases in fall of 2007. The Maternal and Child Health Bureau is working on a timeline to get the chartbook out at the same time that the data is publicly released. And in turn, the Data Resource Center is also working on a timeline to have the data available on the Website for active query, also at the same time that the data is publicly released. That's possible because the final data file actually will be made available in May to the Maternal and Child Health Bureau. And then it goes through a six-month clearance process or so, five or six-month clearance process. But in that time frame, it's possible to work with it internally and they will be doing that. We will have that data, I said, at the same time, but we contractually need to have it within two to three months. But we hope to have it on the day that it's publicly released. So that's our challenge.

Technical assistance for you on how to consider using this data, or promise that you will use the data in your block grants is something we can work with you on now, answer questions about what's possible. We can also work with you on how to make better use of the 2001 data when I looked at the block grants. Most of what was in there was just reports from the National Chart Book, the hard copy chart book, and not necessarily looking at the 2001 CSHCN data by population subgroups, and a lot more rich application of the data. And if there's something that's not on the Data Resource Center that you do want, we often do special

runs for states, we've worked with almost every state at some agency in some state, with doing special data runs for special questions that they have.

So definitely feel free to contact us by e-mail or phone, and give us your input on how you think this new data for 2005/'06 can be made most valuable for you. We look at the outcomes and the indicators that I outlined, obviously making sure they can be displayed across all states, ranked across all states, compared by subgroups. But there is many other things that you may look at the data in this quick guide to questions asked that I handed out, and say, wow, I can really imagine a way of organizing this data to get me information about x or what have you. If that's true, and you have an idea about that, so now is a great time to let us know that you want to look at something, and you can't find it on the Data Resource Center, either for this survey or the National Survey of Children's Health, and perhaps we can, can help you with that.

So, I encourage the use of it for every stage of the Needs Assessment Process. I guess right now, since the '05/'06 data is not out, mostly you'll have to look at it conceptually. But don't forget, the 2001 data is still in the Data Resource Center and will be, and is available for you to access. And this is what the data Website looks like, and you pick a survey you want to look at, and then you either click on "Learn about the Survey," where you can learn about fast facts about the survey, guides to topics and questions asked, search the data, and then get ideas about how to report results. You can also click on your state profile. There's three

things that you can get multiple indicator state profiles, so for your state arrayed on multiple indicators and compared to the nation. You can look at one indicator and rank yourself against all states by any subgroup, population subgroup that you want, age, insurance status, type of insurance, other things like that, and then data graphs and tables. Let me just show you a few examples. This is the state profile page, California, and this is an example of a multiple indicator profile. And within the next three months, you'll be able to do customizable profiles. So you'll be able to pick the indicators you want to display rather than the ones that we've selected for you based on the MCHB chart book.

Here's an example of a single indicator looking at all states on, this is BMI, you can stratify it by any group, but this is BMI by all state, and you can rank for any category. And then this is an example of a single indicator table comparing two geographic areas. But you can also go the next step and compare the two geographic areas by a population subgroup, let's say, insurance type. And this an example of a graph that you can get and easily download just by right-clicking, copying, pasting it into your documents, and your needs assessment or your attachment. So all of that's doable right now.

Okay, and encourage you to come to the Data Resource Center Booth, if you want to ask any questions. We don't charge for anything, so I hope you'll make good use of us. The Title V programs are our primary target, and we're here for you. So, thank you for your attention. Are there any questions? (Applause) He's

worried about time. And so I think Chris was too. (laugh) Are there any questions about either this survey or prior surveys and how they might be useful to you, or about my presentation? No? Okay, great. Good.