

## MCH/CSHCN Director Webcast

February 14, 2008

CHRIS DEGRAW: Good afternoon and welcome to mchcom.com webcast coming to you from HRSA's Maternal and Child Health Bureau in Rockville, Maryland. This is the webcast for children with special healthcare needs. I'm Chris DeGraw welcoming you on behalf of Dr. Peter van Dyck who was unable to be here with us today. We have a very interesting program for you today but before I introduce today's speakers I would like to review technical information about the webcast.

Please note that in response to your suggestions, the speaker's Power Point presentation is available for download before the webcast. Slides will appear in the central window and should advance automatically. The slide changes are synchronized with the speaker's presentation. You don't need to do anything to advance the slides. You may need to adjust the time of the slide changes to match the audio by using a slide delay control at the top of the messaging window.

We encourage you to ask the speakers questions at any time during the presentation. Simply type your question in the white message window on the right of the interface, select question for speaker from the dropdown menu and hit send. Include your state or organization in your message so we know where you're participate being from. The questions will be relayed to the speakers. I think we'll hold the questions until the end of the webcast. Please identify which speaker you're asking the question of. If you don't have the opportunity to respond to your question during the webcast, we'll email you afterwards. We encourage you to submit questions at any time during the broadcast.

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At the end of the broadcast, the interface will close automatically and you'll have the opportunity to fill out an online evaluation. Please take a couple of minutes to do so. Your responses will help us to plan future broadcasts in the series and improve our technical support.

At this point I would like to turn the webcast over to Cassie Lauver, the director of MCHB Division of State and Community Health who will introduce the webcast and our speakers.

CASSIE LAUVER: Welcome. I know states have anxiously been waiting for the data we'll be presenting today, both to assess their progress in the outcome measures and translate these with the national performance measures as they relate to children with special needs as part of that your Block Grant application. We wanted to do the presentation today as a teaser to a broader discussion that we have scheduled for the skills building session at the AMCHP meeting coming up on March 2 in the afternoon of March 2. So I hope many of you can join us for that as well.

But today I would like to introduce our panel and I'll introduce everyone now at one point and then we'll just go through the presenters as we go through the session. First Dr. Michael Kogan, the director of the Office of Data and Program Development here in the MCHB, the Maternal and Child Health will present followed by Dr. Stephen Blumberg,

senior scientist at the Center for health statistics and Dr. Christina Bethell from CAHMI at the Oregon health and science university. She'll be joining us from Portland, Oregon. They'll be presenting on three different areas today. First we'll go over and overview of the 2005/2006 national survey for children with special needs. And then we'll have a discussion on the methodology and design of the survey including differences related to the comparability between this and the earlier survey, and then finally how the Data Resource Center can be used to assist you in your analysis and use of the new survey results. So at this point I would like to turn it over to Dr. Kogan.

MICHAEL KOGAN: Thank you, Cassie. I would like to -- that's Stephen's slides, not mine. Do you want to go with Stephen first? We need to change the slides, please. Our CADE folks to Dr. Kogan's slides. There you go. Thank you.

>> Welcome, everybody. Thank you for joining us, happy Valentine's Day. I would also like to thank Cassie for the introduction and thank her for bringing us her brownies. She's promised to bring them to you at AMCHP.

>> I need to start baking.

>> I'll give an overview of the survey and some of the main findings. How do we advance the slides, just tell them? Okay, go ahead. There were a number of purposes to the national survey of children with special healthcare needs. One is, as you probably know, this is one of the few national surveys where you can provide both national and state-level estimates. So this is the second survey we've done. The first in 2001 and this one covering 2005/2006. So for a number of instances we can now track the prevalence of children with special healthcare needs. We also describe the demographic characteristics

of this population and indeed in this survey we have certain enhancements that weren't on the first survey including information on specific chronic conditions and functional limitations. In addition to measures that were on the first survey, such as needs and issues of healthcare access and burden and impact on the family. Go ahead. Now, we had intended this survey to be used in a number of different ways. As you're probably interested in, this can be used to answer five Title V performance measures. In addition some of the measures are used for Healthy People 2010. A number of states have used the 2001 survey for planning and program development at their state level. For certain measures, you can compare to 2001 survey and for organizations such as family voices that work with children with special healthcare needs, it can inform their work. Finally a number of scientific publications came out of the 2001 survey including a special issue devoted just to state level analyses of this population and we're hoping to have a number of scientific publications come out of this survey, too.

Next slide. The prevalence of children with special healthcare needs in this survey 2005/2006 was 13.9. It's a slight increase from 2001 when the overall prevalence was 12.8%, the percent of households of children who have children with special healthcare needs was 21.8%. Again a slight increase from 2001.

Next slide, please. Some of the new data from this survey shows the majority of kids had difficulty with at least some bodily function. Some kids reported no functional limitations taking that as an indicator that their condition was -- has been controlled.

Next slide. As with the 2001 survey, we used the children with special healthcare needs screener to screen kids in for the survey. It's a series of questions and conditions as you can see on this chart. Now, as for 2001, the most prevalent reason, the most prevalent

screening in factor for this survey was prescription medicines for 86% of the kids in this survey.

Next slide, please. Now, let me -- before I begin on this slide, this is something I'm sure you would be interested in. There are a couple of mistakes on this slide. Now, looking at performance measure two, partners in decision making, this is the estimate for your state is comparable to the estimate for your state in 2001. It's a mistake to say not comparable and Dr. Blumberg is going to go over these in more detail. I'm just giving the overview here. For medical home for a number of reasons it's not comparable between the two surveys for performance measure four for adequate health insurance it is comparable. For ease of service use it's not comparable. And performance measure six should be transition planning and that's not comparable between the two surveys, either.

Next slide, please. Now, as you see, the estimate is almost the same in 2005 and 2006 between -- overall for performance measure two for families partnering in decision maker from 57.5 to 57.4%.

Next slide, please. For performance measure three again I mention this is not comparable but the overall estimate is similar at 47.1%. In addition, we looked at what you do find is that there is a great variation among the states in the percent of states -- percent of children with special healthcare needs in a state who have a medical home. The range goes from about 39% for the lowest prevalence state to 57% in the highest prevalence state. Almost a difference of 50%.

Go ahead, next slide, please. Now, looking at some elements in medical home, what you see is a significant number of children of special healthcare needs lacked one or more

elements of care coordination. Over a third, 37 1/2% of all children with special healthcare needs lack care coordination of those who need it. With the predominant factor in that being the communication among healthcare providers at 31%.

Next slide, please. Looking at medical home by family income, as you would expect there is a rather steep family income gradient here. Of those at 0 to 99% of the federal poverty level, only 33% of those families were ascertained to have a medical home compared to 56% of children with special healthcare needs in families where the family income was 400% or more of the federal poverty level.

Next slide, please. Now, this I think is a particularly interesting slide. You may not think so but that's tough. I think it's interesting. If you look at 2001, you see that 21.7% of children with special healthcare needs received their insurance from public only. By 2005/2006 it had gone up to 28%. In addition to percent of kids were uninsured has decreased as well as kids who appeared without insurance which is not shown on this slide. Do we know the exact reasons for this? No. We can speculate that a lot of it has to do with kids being picked up by the state children -- at the SCHIP program.

Next slide, please. As I mentioned earlier, performance measure four is comparable between the two surveys and what you see here is that there is a slight increase over this time period from 59.6% of kids who -- families who said their kids' health insurance was adequate to 62%.

Next slide, please. Now, if we look at the percent of children with special healthcare needs whose insurance didn't usually or always meet the criteria for adequacy you see that for

charges that are not reasonable was the predominant reason why parents said their kids' health insurance wasn't adequate.

Next slide, please. Now, again as I mentioned earlier, the two surveys are not comparable because of different questions and different ordering. Here you see in 2005/2006 almost 90% of families said their service systems were organized for ease of use.

Next slide, please. Now, we asked a number of questions about unmet needs. Overall, 16% of children with special healthcare needs who reported that they needed health services but didn't receive them was 16%. Again, of those who reported that they needed service but didn't get it for preventive dental care, that was the most common reason. 6% of families reported they didn't get it when they needed it. For mental healthcare it was 3.7% on down the line, as you can see.

Next slide, please. I'm sorry. Let me just tell you before we go on to this slide, I just want to mention that again, when you look at healthcare needs and unmet needs, there is a very wide variation among the states with the lowest needs in states being on the range of around 10%. And in some states being as high as 23% of kids who -- families who said their child had a need for specific service but didn't receive it. Now, looking at this slide on financial impact on the family, what you can see is 20% of children with special healthcare needs, a families of children with special healthcare needs spent more than \$1,000 just on their child's care in the last year. This is an increase from 2001.

Next slide, please. If you look at impact on the parents' employment, again, having a child with special healthcare needs has a tremendous impact, often, on how the families organize their employment, which, of course, affects their income. Here you see that 24%

of families reported that they either had to cut back on their employment or stop work entirely to care for their child. This is a slight decrease from the 2001 survey when I believe 28% of families reported this. Now I also want to mention the performance measure six, which I don't have a slide for. About 41% of families reported on -- met the criteria for transition planning. Again, if you look at the overall variation among the states, that ranged from again a wide variation. That ranged from 31% all the way up to 54% meeting the performance measure on transition planning. So thank you very much. That's what I have on the overview.

>> Thank you, Michael. And I would like to turn it over to Dr. Stephen Blumberg to talk about methodology and some of the other points of the data.

STEPHEN BLUMBERG: Sure, thank you. My goal here today is to talk to you about the methodology of the national survey of children with special healthcare needs. I'm going to focus on 2005 and 2006 but comment on where we made changes from 2001. My hope is that by understanding where some of these changes occurred you'll be better able to evaluate whether changes that you see in the data from 2001 to 2005 and 2006 are real changes occurring in your state or may be changes that are simply due to the methodology changes that may have occurred.

Next slide. As in 2001, the 2005/2006 national survey of CSHCN was a random digit dial telephone survey using independent random samples in every state plus the District of Columbia. What it means is we randomly dial phone numbers and once we hopefully get an answer, we try to determine whether or not that phone number has reached a residence and whether or not that residence includes any children under the age of 18. All

children under the age of 18 are then screened for special healthcare needs using the CSHCN screener. This is exactly what we did in 2001.

Next slide, please. Similarly, as in 2001, once we identified that a household included children with special healthcare needs, we asked the detailed questionnaire about that child's and the special healthcare needs and the impact on the family. Now, if the household had more than one child with special needs living in it, then one was randomly selected from that household. Our goal was to achieve 750 detailed interviews per state and calling in the screening of households continued until we had met that target in all states. This took quite a while. Data were collected from April of 2005 until February of 2007. Those interviews that were completed in January and early February of 2007 were finishing up with appointments that had been made late in 2006. Therefore, we refer to these data as 2005/2006 data.

Next slide, please. The respondent was a parent or guardian knowledgeable about the health of the child. In most cases this was the mother. We did find, however, that in 2005/2006 we did have more fathers who responded to the interview than we did in 2001. The interview lasted about 28 minutes which was similar to 2001. And the interviews were conducted in English, Spanish and four Asian languages. In 2001, we had an additional five languages but had very few interviews that were conducted in those languages.

Next slide, please. We screened 364,841 children for special healthcare needs. Obviously that is going to vary in every state because our goal was to achieve a similar number of detailed interviews in each state. So those states that had greater proportions of children with special healthcare needs may have required us to screen fewer children in order to achieve our targets. However, you will see that there was some greater variation in

2005/2006 than there was in 2001. The reason for some of this variation was because of an effort to increase response rates in some states that had lower response rates. So even though we may have hit the target, say, in California, response rates were sufficiently low there that we wanted to continue to interview and exceed our targets in order to achieve those higher response rates. Ultimately we completed more than 40,000 detailed interviews for CSHCN and achieved at least 750 in every state except for Alaska, which was just shy of that mark. Now, we did achieve more than 800 in almost half of the states. And what you'll realize is that that is slightly more than the approximately 750 that we achieved in 2001. It may be that with these extra interviews in 2005 and 2006 that states may have the ability to examine the estimates for particular subgroups that may not have been possible in 2001.

Next slide, please. I've been talking about response rates and our overall response rate was 56% in 2005 and 2006. This is slightly lower than we achieved in 2001 where the response rate was closer to 61%, if I remember correctly. Some people may be concerned that that indicates some increased potential for non-response bias with the new data. However, we have seen no evidence yet that the non-response bias is any more problematic in the 2005/2006 survey than it was in 2001. The overall response rate is a very conservative estimate of the -- of the response rate. The reason for this is that we look at a number of different rates when it comes to the response rate. And include in here adjustments that look at whether or not we've even been able to reach somebody at a telephone whether or not we were able to reach somebody who had children. You'll see our screener completion rate, that is the proportion of households in which -- that had children in which we were able to complete the screener was nearly 80%. That's quite good for a telephone survey.

Next slide, please. The structure of the CSHCN questionnaire, the detailed questionnaire, was very similar to what we did in 2001. It included questions on access to care, medical home and so forth.

Next slide, please. But there were a number of sections where we attempted to improve the content in 2005 and 2006. These are some of the ones that had some more major changes. These include additional data about functional status of children with special needs, as well as indications of some common health conditions that they may experience, asthma, attention deficit disorder and so forth. We completely revised the section on care coordination, on community-based services, and on transition services. Now, as a result of these revisions, the comparability of data from 2005 and 2006 to 2001 for content such as this obviously can be called into question. Starting at the bottom, the changes to the transition section were certainly so dramatic that it's probably best to think of these data from 2005 and 2006 as a baseline measure. You may remember that for most states the transition estimates from 2001 weren't even at the level of reliability that we were willing to have faith in those estimates anyway.

So moving up the slide, next slide, please, you can see that for performance measure five as the service systems organized for easy use, in 2001 we had asked parents whether the services were organized in a way that made them easy to use. Very straight forward question but found that many parents really couldn't comment on the organization of the services. So in 2005/2006 we changed that question to whether or not the parents had had difficulties trying to use any services during the past 12 months. You can see that there was a dramatic change in the estimate from 74% to 89%. Again, the question has changed so much that this probably is not comparable from year to year.

Next slide, please. Another example of a fairly major change comes in the care coordination section. In 2001 we had asked how well the parent thinks that the child's doctors and other healthcare providers communicate with each other about the child's care on an excellent, very good, good, fair, poor type of scale. We recognized, however, after fielding this that there were many parents who really weren't sure how well the doctors were communicating with each other but they knew whether or not they were satisfied with that communication. And so in 2005 and 2006 we changed the question to a satisfaction question about whether they were satisfied with the communication among child's doctors and other healthcare providers and you can see again that the estimate increased. In 2001, 54% said that the communication was excellent, 2005 we found that 64% reported being very satisfied with the communication. Again, the questions are so different that it is probably not appropriate to compare 2001 to 2005 data. But let me show you one where it's not so clear-cut.

Next slide, please. Here we can look at the -- one of the components of the medical home performance measure, that is whether or not the child has a personal doctor or nurse. In 2001, we asked whether they -- the child has one person who the parent thinks of as the child's personal doctor or nurse. And 89% said yes. 2005 and 2006 we changed it to whether or not the child has one or more persons that the parent thinks of as the child's personal doctor or nurse. This change occurred because we were made aware that there were several parents who have two doctors, three doctors, for instance, all of whom they think of as their child's personal doctor and in 2001, because we focused on one person, they had said no, my child doesn't have one person. You can see there was an increase from 89% to 93 1/2%. You may say that was a sufficient change to the question that perhaps these estimates are not comparable. Well, let me ask you to think carefully when you're making these sorts of judgments. That it is important for analysts to carefully

evaluate whether the changes that you may notice in the estimates are of the order that you would expect from the change in the question. What I mean by that is, if, for example, with this personal doctor or nurse question you find that your state went down from 2005 to 2006, that is that fewer children with special healthcare needs had a personal doctor, that's significant and important despite the fact that the question changed because the change in the question would have -- we would expect that that would have increased the rate. So it's very important to educate yourself and to evaluate whether changes that you observe in estimates really are reflective of changes within your state or are reflective of changes in the methodology.

The next slide, please. I can show you here that there are several performance measures in which there was little or no change. Dr. Kogan had talked a little bit about this already but there is really no change in the questions that get at the performance measures for partnering the decision making or for adequate health insurance and there is little change to the performance measures that look at some of the components of medical home such as whether there is a usual place for sick care and whether there is family-centered care.

Next slide, please. Let me close by just encouraging you, if you're going to be at AMCHP, to come to the skills building sessions on Sunday afternoon where we're going to be talking in more depth about the various changes in the questionnaire and in the methodology, and we'll be available to answer some of your questions about whether or not these changes may have impacted estimates. Also, you can go online to the national survey of children with special healthcare needs website where you'll find a document titled summary tables from the survey. In this document are a series of tables, but in addition, there is also discussion about the changes that occurred in the questionnaire for every performance measure and component to those performance measures. Finally I've

also included my email here in case you have any questions that the skills building session or the summary tables document doesn't answer. Thank you.

>> Thank you very much. And I think that's helpful information and certainly helpful contact information. You are brave to -- you may be hearing from some of our partners. And now we're going to switch to Dr. Christina Bethell who is our bicoastal partner today in Portland, Oregon. As we wait for the magic of cyberspace to link her in I want to remind people, if you have questions think about them and enter them in here and that way we can have them online when we finish the next presentation. So think about questions that you might have for any of the presentations today and go ahead and enter those in. At this point I would like to--

>> To get it to do its magic I was told I had to speak really loudly.

>> Dr. Christina Bethell.

CHRISTINA BETHELL: Let me know when everything looks good on your end. Look okay? Great, good. Happy Valentine's Day to you all as well. Cassie and I both have our little red jackets on. It's great to be here with you all. I wish I could see you in person. My goal today is do a walk-through through a resource supported by the Maternal and Child Health Bureau and that we here at the child and adolescent health measurement initiative have the honor of putting together in partnership with MCHB and Stephen be and his team as well. I'll go through slides and give you background on why it exists, how you can access different kinds of profiles and the help you can get as you proceed in doing your needs assessment and so on. So I guess we're at the first slide, I can't really see myself. But I'm assuming we're at the first slide. If you can go to the second slide it shows a home

page for the Data Resource Center. And let me tell you a little bit about the background. The DRC was first envisioned around 2001 as the first national survey of children with special healthcare needs was being conducted and by 2003 we had gotten to a point of piloting it and kicking it off in 2004, a year after the first dataset came about. The goal was to dramatically expand and expedite people's access to the data at both the state level comparing with other states and the nation and looking at subgroups and things like that so we could really expand policymaker, provider, family access to data online. The two surveys that are in the Data Resource Center are those sponsored by and signed by the Maternal and Child Health Bureau, the National Survey of Children's Health and Healthcare Needs and today we're talking about the survey with children with special healthcare needs.

If you go to the next slide I'll talk about our goals. We provide a centralized and we hope user-friendly interactive access to standardized data. The reason that's important is a lot of people can get a dataset and work with the variables and think they're doing it the same way and it might not be the same way. It's a challenge to do that. Standardization is the key goal that we can create a place where people can look at data and have confidence it was constructed in the same way and also the same way the Maternal and Child Health Bureau and MCHS has approved of. That's goal number one is to provide that data. The second is also to build some common knowledge and build capacity around using data. Some of the audiences most important to use data might be the most strapped for either time, resources, background and that sort of thing. So this is meant to cut through that and make it much more easy for people to quickly get data as well as use the Data Resource Center to figure out what kind of more in depth analysis they might have want to do. We have both an educational goal and support goal and a data dissemination goal.

Go to the next slide. It is an umbrella page to reiterate again the website is child health data.org and there are two portals that you can get to by going there or go to them directly. At their own URL. It can be accessed directly to them. It's just a point for some of you who might like to go there directly. So what features are available? What can you do if you go to this website? First of all you can learn about the surveys. As Stephen was talking about, it's really important to understand what is in the surveys, for one. And what is of interest to you and how were the questions asked. We try to make it as easy as possible are you to learn about how the questions were asked. A lot of the technical documentation can be lengthy and difficult to access and help navigate people to quickly see how was the care coordination asked or how was the transition to adulthood question asked. It's one of the things. Learn about the survey and this document you can print out and hand out to other people but at the summary level help them understand, too, what's in the survey. How the data was collected and of course the next is the central feature of the DRC which is the search and compare feature where -- I'll talk about that mostly in the next few minutes. There are three different ways that primary ways you can access data. And then, of course, there are resources. We try our best to collect examples of how the data is being used in the field by families, by Title V leaders as well as publications and the great chart books that are put out based on the data and getting expert help is a great feature. We get requests every day and respond to them as quickly as we can and I'll say more about that later. We can help with technical assistance questions either about some of the comparability issues that Stephen was talking about, if there is something you need on the data that you can't quite see online and so on.

The next slide shows that we do provide datasets that people can download from our site after requesting the datasets. We just sent out a couple dozen of them yesterday or the last few days so if you're interested in doing more work with the datasets and would like

the data with the indicators and performance measures already constructed, and the documentation as well that goes with that. That's available. Then, of course, you can sign up for E-updates. We don't send out too many of them but we send them out when new features are available and so on and so forth. So let me go directly to how to search the data. There are three primary search options that I'll highlight today. First is getting a state profile where you see your state compared to another state or nation on a number of indicators. The second is interactive all states comparison tables where you can pick an indicator, compare it across all states at one time and go further to subset by a population subgroup and continue your comparison interactively and finally is picking a single indicator and diving down into comparisons across states interactively or the nation or various subgroups. When you get single graphs and tables showing the data in more depth for that single indicator. I'll quickly go through those.

So first getting a state profile, there are two steps. First it's easy. You go to the home page of the data.org and click on the icon of the US map and pick your state. In this case we're picking California. Here you can see is the 2005/2006 national survey of children with special healthcare needs state profile with California compared to the nation. Once you're in there you can interactively choose another state versus the nation and what you can see here is California is lower, a little bit on some of the outcomes as well as prevalence and you can get a quick snapshot and you can actually go in here and click on any single one of the prevalence or indicator outcomes that are here and that will put you right into the data search tool to do more in-depth searching. You can see that easily when you go online. This is one of the state profiles. We have others, though.

You'll see there is an arrow at the top pointing you to compare survey years and so if you go to the next slide, what you see is a quick profile comparing your state to 2001. And also

building on what Stephen and Michael have talked about, there is a quick glance symbol put in there to give you a sense of whether this is an indicator or outcome that can be compared with confidence. And for more information, we also have summary tables and more detailed tables on each indicator outcome on what exactly has changed from 2001 and what the items were and what they are now. So there is some quick glance reviews if you want to go even further. Soon we'll have a state profile in the next week or so looking at the 2005/2006 for your state comparing to the nation's none CSHCN reference sample. Stephen probably should tell more about exactly what that survey is.

There was an attempt to look at non-CSHCN as well and there is a profile coming on that one. That's a little bit about state profiles. There is more to say but I'll go on to state ranking tables. For this there are a couple of steps. Steps, go to search the data feature. There are three options, learn about the survey, search the data or get information about reporting your results.

We go to 2005/2006. You get a choice to select what are the major search areas you want to look at. We'll go to the national chart book indicators and outcomes or indicators and outcomes that are expected to be put into that document and then you click all states. Here you have a choice to pick the geographic area that you want and instead of picking your state or the nation, you just pick all states. And then you select the topic area in here we're picking MCHB core outcomes. I don't know if I sent you forward enough we should be on the slide that says select an indicator for the all-states comparison tabled and circled in red is the medical home. Hopefully we're there.

What I want to point out before going too much further, you'll see at the end in blue the word derived. And what that means is you click on that and then a box will come up and it

will tell you what the numerator and denominator were for creating that measure and the items that were used in creating it. And some of the high points of differences from 2001 as well as some references for more information. So that's an important little bit to know about for those who really want to know what's in there. Okay.

So then you click on medical home and the next is actually a table bigger than this but for purposes of displaying it on a slide I broke it up and am showing you the top states and bottom states on medical home and stratified it by age. We received coordinated on going air from 18 -- it ranges in age up to 59.4. That's an example of the kind of state ranking table you can actually click on any of the stratifier options and it will resort it according to that stratifier. If you clicked on 0 to 5 it would stratify it by 0 to 5. So that's a quick review of that. The next is the detailed indicator tables. Again, you go into the 2005/2006 search the data feature. Click on it and in this case I'm going to pick a state, Colorado. And look at how the levels of demographics. I'm called geographic area and search topic.

Next slide, I'll say it now. Titled example data findings. This again is a picture of the table that is in the Data Resource Center web tool. There is a little more detail provided there than is shown here. For purposes of illustration you'll see we're comparing Colorado and the nation on households who have children with special healthcare needs or households who do not. What's important to see here is that we give you the estimate, the weighted estimate, as well as the confidence interval which can be very important for purposes of communicating the results and the precision of the results. The actual number of children who answered that question, the raw N as some people call it and the estimated number of children that that raw N translates into when it's weighted and the magical weights that Stephen and his team weight this data. That's what you get here.

In addition on the next slide you will get a graph. So you can choose whether you want graphical or tabular ways of displaying the data. Once you're in this interactive tool you can go back and forth looking at another state, a subgroup, that kind of thing and you'll see it when you get into it. Here we see Colorado and the nation. If you right click on a graph or table, then you click copy, then you can paste it into a word document or Power Point document. That's one of the goals here is to allow you quickly to get a table or graph and put it into your own materials.

So the next slide is just a note to encourage you to go to the Data Resource Center and really begin exploring variations. What it's looking like a story at a national level compared to your state is not the whole story. You see my state is better than the nation but then looking down further by subgroups can be very important to do. Here is an example. So in variations across state for the outcome families partner and decision making and are satisfied we have a range from about 46.6 in California to 65.7 in Nebraska. But when you look at Nebraska and then you go down to subgroup household income, you see that people in -- children in Nebraska were in the survey who are under 100% of the federal poverty level actually had a lower rate of meeting the criteria than California which was the lowest ranking state. 46.2 going up to 72.6. It's that system illustration to encourage you to go further in looking at variations in the data. And then also variations across years for those things that can be compared do exist for some more than others. And -- but it is there and we've seen examples of big jumps for some states and some indicators so definitely look there as well. And then in terms of the Data Resource Center my closing comments would be to encourage you to use it for a number of purposes but what we see people using it for the most is first of all to identify and document needs and performance. To build partnerships and create dialogue and build partnerships around key issues with children with special healthcare needs. Educating policymakers, advocacy and grant

writing and we're available to answer questions every day even on the weekends we actually have a check on our RTA. I hope we'll be hearing from you. That's it.

>> Thank you, Christina. That was very helpful and I think it will be a useful tool particularly where they can go in and take the data that you have and actually click on it and be able to move into their own document. So at this point I would like to turn it back to Dr. DeGraw with any questions that may have come in.

>> We have a few questions here but before I get started with those, I want to remind you now is the time to ask your questions. Type them in and send them on to any of our speakers. Okay. Our first question and the speaker isn't identified. Whoever feels like they have the answer, jump right in. First question is, when is the chart book coming out on the survey?

>> Okay. I'm glad that question was asked because the chart book is scheduled to come out probably next week. It will come out on the web and there will be a hard copy for people who want that. So hopefully we'll have them available at AMCHP and also when the chart book is officially released, we'll probably put out the information on listservs that go through Cassie's listservs to MCH and children's special healthcare needs directors.

>> About how many families reported having difficulty getting a referral when they needed it?

>> That's a good question. Because one of the things we found in the survey is that at the primary point of contact, whether having a usual source of care or having a personal provider or nurse, children with special healthcare needs, their families did quite well. It

was over 90% for both. When we found difficulties, it was with this secondary sources of care in terms of care coordination or difficulties receiving referrals. For example, for difficulties receiving referrals for this question it was around 21% of families who said they needed a referral, had difficulty getting it, and in addition again there was a fair amount of state variation from families in different states ranging anywhere from almost a three-fold difference from 10% in low states to about 30%.

>> Okay. We have a couple more questions related to different types of disorders. About how many children were reported to have autism spectrum disorder?

>> Well, as I mentioned previously, this survey, unlike the 2001 survey, asked parents to the best of their knowledge did their child have this condition. Again, let me emphasize the question wasn't asked has a doctor or health provider ever told you that your child has this condition so it's parental self-report. Now, having said that in this population, 5.6% of kids - - 5.8% of kids reported to have autism spectrum disorder.

>> Okay. And finally, what were the most commonly reported specific health conditions?

>> Do you want to take that one or do it together?

>> Certainly the most commonly reported conditions were allergies and attention deficit disorder and asthma. So the three big As, essentially. Following those there were significant numbers of children with other mental health-related issues. Such as anxiety and depression.

>> That's all the questions we have submitted at this moment. I'm sure people will have more questions and catch up with you on AMCHP or by web. Cassie?

>> Thank you. I want to thank all of our presenters today. We've been looking forward to the opportunity to present. I know we've had a data speak and the data have been out there a month or so for states to look at but have wanted to have this kind of opportunity as well as the opportunity in a couple of weeks at AMCHP where we can go into more depth and have the opportunity for face-to-face discussion and be able to ask questions and hopefully answer the questions. So I want to thank the panelists today and Chris, I'll turn it back over to you.

>> We want to thank all of you in the view audience for participating in this monthly webcast. I would like to thank the contractor the Center for Advancement of Distance Education at the University of Illinois at Chicago School of Public Health for making the technology work and our friends in Oregon for successfully linking in. Today's webcast, as with all of our mchcom.com will be archived and available in a couple of days on the website [www.mchcom.com](http://www.mchcom.com). We encourage you to let your colleagues know about the website and hope they find it useful. We like to make these webcasts as responsive to your information needs as possible. If you have suggestions for topics you would like to see addressed in future webcasts or have comments in general, either talk to Cassie and the staff about them or email them directly to us at [info@mchcom.com](mailto:info@mchcom.com). Again, thank you and we look forward to your participation in future webcasts.