

MCHB/CSHCN DIRECTOR MAY, 2004 WEBCAST

May 6, 2004

CHRIS DE GRAW: Good afternoon and welcome to the MCH. This is the latest in our series of monthly interactive Internet webcast with children with special healthcare needs. I'm Chris DeGraw we're going to have a presentation today about the next iteration of the children with special needs survey. Before I introduce my speakers I want to give you some technical information about the webcast. Slides will appear in the central window and should advance automatically. The slide changes are synchronized with the speaker's presentations. You don't need to do anything to advance the slides. You may need to adjust the timing of the slide changes to match the audio by using the 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 drop-down menu and hit send. Please include your state or organization in your message so that we know where you're participating from. The questions will be relayed to the speakers periodically throughout the broadcast. If we don't have the opportunity to respond to your questions during the broadcast we'll email you afterwards. Again we encourage you to submit questions at any time during the broadcast. On the left of the interface is the video window. You can adjust the volume of the audio using the volume control slider which you can access by clicking on the last speaker icon. Those of you who selected accessibility features when you registered will see the text captioning underneath the video window. The interface will close automatically and you'll have an opportunity to fill out an

evaluation. Please do so. Your responses will help us plan future services. I'm happy to turn the program over to Audrey Koertvelyessy. She'll give an overview of today's webcast and introduce our speakers.

AUDREY KOERTVELYESSY: Thank you, Chris, I'm Audrey Koertvelyessy and it's a pleasure to welcome all of you to our webcast today. This MCH.com broadcast today will focus on an update on the National Survey of Children with Special Health Care Needs. During the April region 8 conference, region 8 requested an update on what is happening with the next surveys. Thanks to them and in particular holly from Utah for stimulating the topic. It became readily apparent that this topic was one all states needed to know more about. Subsequent to that call the states on their monthly conference calls encouraged this program as a broadcast. The presenters here that are going to be presenting to you today -- The presenters assembled today for this broadcast represent the team of experts along with other representatives who have been working on the next survey and they'll provide you with more information on this important topic.

Today we'll hear from the following individuals. Ms. Marcie Cynamon, Steven Blumberg and Mike Kogan. I'll introduce all of them now so we can transition smoothly from one presenter to the next. They'll be interacting with each other. Marcie is with the National Center for Health Statistics with the city at disease and prevention. The director of the state and local integrated telephone survey and project officer for the national immunization survey. Steven blumberg is also with the CDC's national Center National Center for Health Statistics where he's the senior scientist and lead statistician. In

addition, he served as co-chair of the agency's research ethic review board. Both Marcie and Steven were experts on the first panel. Dr. Paul Newacheck is joining us from California and he'll be audible during the broadcast only. He is professor of health policy studies at the University of California in San Francisco. He serves on the expert panel for this project. You'll hear more about that panel during the presentation. He served in that same role during the first survey. He'll be providing comments throughout the presentation, particularly toward the end of Marcie and Steven's presentation. Dr. Mike Kogan is the director of the Office of Data Information Management, otherwise known as OTIM in the bureau. They're involved in guiding data collection and analysis within the bureau. He'll be providing comments on various products from the first survey. He'll be joining us in person from another meeting, the same meeting Peter is at, that was mentioned earlier. Also in the room with us and just joined us, we're fortunate to have Dr. McPHERSON. We're glad to have her with us today. Let's go to our program and we'll begin the presentation beginning with Marcie and Steven.

MS. MARCIE CYNAMON: Thanks, Audrey, thanks for the opportunity to allow us to talk to our colleagues about the status of the mental health survey. I'll start by giving a bit of historical perspective and Steven will talk about current activities. I'll come back in at the end to conclude with the options for the states and how they can be more involved in the planning process and then Paul Newacheck will answer questions or make comments that are relevant to the planning process. I wanted to put today's work, the planning for the next National Survey of Children with Special Health Care Needs by giving a little background about the first survey. This will be useful for those of you who weren't around

when we were planning the first survey or didn't have an opportunity to get involved at that time. We'll follow with a detailed description of the current plans and activities for the second survey and an explanation of what options you have regarding the survey's content and the format.

The first survey was fielded during a year and a half period October 2000 through April 2002. The next survey is slated to begin January 2005 and run for two years rather than one and a half. The primary goal for the first survey as it is with the second, is to produce prevalent estimates of children with special healthcare needs at the state level and to describe the impact of these needs on the children and their families. Planning for this, the first survey, began in 1999 with the national expert panel consisting of representatives from five states, AMCHP, federal programs and academia. The group convened to identify the broad subjects that should be included in the survey starting with the national core performance measures. A subset of this group that we call the technical expert panel met very frequently to flesh out the concepts identified by the national panel and identify existing questions that would achieve these goals. We also developed new questions and tested them in a series of cognitive field tests and -- cognitive tests in the laboratory setting and field tests. Two screeners were also tested and compared. They were based on the field work and medical records as one and the other -- included that in the first survey and plan to include it in the second for purposes of continuity.

The special healthcare needs survey was conducted using a survey engine called slate. You heard Audrey say it's called the state and local area integrated telephone survey

which is managed by the national Center National Center for Health Statistics. It's not a survey per se as we understand it, an ongoing survey that you can add questions to. It is actually a mechanism that allows us to create new surveys, to customize them to meet the very specific needs of our sponsors as we did with the first special healthcare needs survey, the one in the field now is the national survey of children's health which is also being done for the federal Maternal and Child Health Bureau to assist the states with their program planning and development. We use new questions or off the cuff questions which are tested thoroughly and evaluated as best as we can. Sometimes validated with records, sometimes against other data sources such as national data sources where they have appeared in recent surveys. It's unusual for federal surveys to address the needs of states at a very detailed level. And this is why slates is important as a mechanism. It fills that void, or attempts to do so as much as possible. It's also possible for slates to produce data for smaller geographic areas but it hasn't been used to do that often. It's a very economical mechanism for states to use and the federal government to collect state data because it benefits from the existence of another ongoing survey which is the national immunization survey.

The NIS has been in existence for ten years and it is used by us because it pays for the selection of the sample we use for slate and it identifies telephone numbers and households that we use for our survey, slate survey. This actually is one of the most expensive aspects of the telephone survey. So we're very fortunate to be able to use their sampling frame. The NIS produces quarterly estimates of the up to date immunization status of children 19 to 35 months of age. These estimates cover the entire United States

but are divided into the 50 states and 29 urban areas including D.C. In order to achieve the target number of interviews for each of these 78 geographic areas, over one million households are contacted every year. About 35% of these households have children, but fewer than 4% will have a child within the age range for the national immunization survey. The rest of the households that don't have a child 19 to 35 months of age are not asked any other questions unless there is a slate survey. The economies realized by the special healthcare needs survey, for example, because we can continue with an interview once we've identified an appropriate household. So the primary features include expanding the national immunization survey, which uses a random digit dial technique. The interviews are computerized and administered by very specially trained interviewers who are carefully monitored to minimize errors of all kinds. I think you need to be on the next slide.

This survey is really popular with interviewers, those conducting the children with special healthcare needs survey because it was so much more interesting to them than collecting information on immunizations. They personally identified with this. The first round of -- OK. The first round, again, was in 2000 to 2002. I talked a little bit about the broad perspective of slates and now I want to go and focus specifically on the first children with special healthcare needs survey. Each state has an independent sample. These samples can be combined to produce regional and national estimates. Following the age screen for the national immunization survey, households are asked if there are any children under 18 living there. A parent or guardian is summoned if they aren't already on the phone and informed consent script is read to them and the children with special healthcare needs survey is administered.

There are five key elements to the screener if you're not familiar with it. The use of prescription medication, service use that is greater than that for children of the same age. Limitations in functioning, need for special therapeutic services, and need for counseling. An affirmative answer to any one of these questions can qualify the child for the complete interview that is as a child of special healthcare needs as long as the affirmative is due to a condition that has lasted or is expected to last for 12 months, and is due to a condition. The prescription medicine element brings in most children. Older children screened in at a much higher rate than did younger children using this mechanism. All children under 18 in the household are screened. If there is more than one child with special healthcare needs, one was randomly selected. Children who were the subject of the national immunization interview are not excluded so there are some households where there were two interviews. The detailed interview broadly included questions on health and functional status, access to care, utilization of care and unmet needs, healthcare coverage and perceived adequacy of the healthcare coverage, care coordination, satisfaction with care, and the impact of the child's condition on the family.

We established a target of 750 completed interviews in each state. The size of the sample available in each state depended on a number of factors, some very specific to the NIS and some specific to the national healthcare needs survey. The number of households contacted in each state varied widely based on these factors. The state specific response rate, the percent of households with children under age 18 and under and between 19 to 35 months of age. The state specific special healthcare needs rate,

and the number of sampling units in the NIS. By this I mean whether the NIS produced estimates for the whole state only or for the whole state and one or more urban areas in that state. The larger number of units in the national immunization survey sample, the more households are available for slate. I know this is awfully detailed but I'll come back to why this is important later. It has to do with your options for involvement in the survey.

For states with just one unit, obviously the sample size is going to be less. And for states with several units, then you can have a larger sample. In order to achieve a target of 750 interviews, a certain number of households have to be screened and that varies. This impacts the cost of the survey and how many households appropriate to the screener are available. In actual numbers, we screen between 3100 and 5,000 households in every state. So almost 200,000 households in the country. These households contain 5600 to 9700 children who receive the screener and we fluctuated 650 interviews. The low was 739 and a high of 766 in each state. It's not an easy -- as easy as it would seem to hit the nail on the head. This variation was due to factors that I mentioned about how the sample is selected and screened. It really involves a keen set of skills, foresight, hindsight and some dumb luck. We completed hundreds of screening interviews and detailed interviews that would otherwise not have occurred by interviewing in quite a few languages. This is unprecedented for the national Center National Center for Health Statistics and was very successful. Special paper and pencil procedures were developed and professional translators were hired to complete these interviews.

Overall, for the survey, the response rate was 61%. Using the most severe definition of what a response rate is. In households where no children had a special healthcare need, there was yet another survey conducted. Healthcare coverage characteristics were asked in these households with children regardless of special healthcare need status. Questions on type of coverage, current coverage status and gaps in coverage were included. Many of these questions appeared on the special healthcare needs survey. So we had information from all children. For children living in low income households, questions on Medicaid and S-chip knowledge and experience were asked. Also a few of the basic health status and access questions from the special healthcare needs interview were included. This component was commissioned by the department to inform Congress in a mandatory report on the progress of S-chip. At present there are no plans to include this component in the next special healthcare needs survey. I mention this only because the content may have -- may be of interest to you in evaluating some of your programs. The data that we produce are weighted to account for many potential biases, including non-coverage bias, that is, how the sample was drawn. Non-sponsor refusal to participate in the interview and households without telephones. Each state has its own weight which must be used when data are analyzed on their own and when they're combined to analyze national estimates.

What we found in the first survey was that 12.8% of children in the United States have special healthcare needs. The good news is that according to their parents and guardians the majority of them receive care in a medical home. They receive all the care they believe they need. They are satisfied with the care they've received and feel that they're

adequately insured. We also found that a third of the children are not adequately insured. A third had a condition that affected parental employment. A fifth had a condition that impacted the family's financial situation. And one in six had an unmet need for some sort of medical care. These rates were highest for children in lower income families. I want to turn this over to Steven now to talk about our goals for the second round, the content of the survey and the process that we have been using to identify new areas for exploration.

STEVEN BLUMBERG: Thank you, Marcie. My job here is to give you a little bit of a flavor of what this second round of the children of special healthcare needs survey is going to look like. Unfortunately at this point no concrete decisions have been made to finalize content or the design or the sample or just about anything else related to the survey. So what I'm going to tell you is preliminary. It's based on our best guesses at this point in time. But anything that you hear may change over the next six or seven months. And so we're in the field come January.

The primary goal of the second round is the same as the primary goal of the first round. That is, to obtain national and state-based estimates on the prevalence and impact of children with special healthcare needs. But because this is the second round of this survey, we're able to also add a couple other goals to it. Namely, to be able to assess the changing needs of children with special healthcare needs over the past four to five years, and to continue to monitor MCHB's key performance measures and outcomes for children with special healthcare needs. In addition, given a second chance at this survey, we hope to be able to address some of the limitations that have been identified in the first survey.

What are those limitations, you may ask? The first limitation that we often hear about is that the responses are subjective and they're based only on families' experiences and perceptions, rather than on some objective criteria, some measurement of health using something other than parents' responses. The fact is, is that we don't tend to consider this a limitation of the survey. In fact, this is the first survey that looks at the experiences of children with special healthcare needs from the perspective of their parents. And we think that that perspective is as important as any other perspective that may exist. So -- that limitation will not be addressed in the second round of the survey. Some of the other limitations we hope to be able to address. One limitation is that the survey does not contain conditions specific information. It is based on the Maternal and Child Health Bureau's definition of children with special healthcare needs, which, as Marcie talked about, is based on the consequences of those needs rather than any specific identified condition. Nevertheless, we've heard from a number of data users that condition information would be useful and therefore we may pursue that in the second round. Some of the other limitations that I wanted to mention are the limited ability to compare children with special healthcare needs to children without special healthcare needs.

As Marcie said we did have the health insurance control sample which allows a comparison of health insurance coverage rates for children with and without special healthcare needs. But we didn't ask any of the other health-related questions of children without special needs. That poses some limitation because in doing comparisons, it requires that data users compare the data from the children with special healthcare needs survey to data from other surveys such as the national health interview survey where

those sorts of comparisons may be inappropriate because of differences in the way the surveys were conducted. Another limitation that has been identified is that analyses of subpopulations especially at the state level may be limited due to sample size. We do have a sample size in the first round of 750 children with special healthcare needs in every state, but where that is sufficient in some states to look at differences, say, by race or by ethnicity, in other states where minority groups are quite in the minority, there may not be sufficient numbers among those 750 to get stable estimates. And a final limitation that has been identified is that in the first round states were not permitted to customize the surveys to meet their specific needs for data. They were given the opportunity to expand the sample size. Only Missouri did so. But in this round we hope to be able to offer states the opportunity to customize the survey even further. So we gathered input for the second round first through a survey of data users that was distributed on the slate list serve in February.

Comments that we got back from that survey of data users were given to the technical expert panel that was convened for the second round of the survey and this panel met in March of this year just about six or seven weeks ago to begin discussing the data users comments and to recommend survey modifications. Just a quick note on who is a member of that technical expert panel. The technical expert panel is chaired by Paul, who is on this presentation and will be talking later. The panel includes state representatives from Washington, from lawyer, as well as two experts from the child and adolescent health measurement initiative which was formerly the foundation for accountability. And also Ruth Steen from Albert Einstein College of Medicine. We also have the panel made up of

several MCHB staff. So, the panel met initially in March of 2004. But will continue to meet through the spring and summer of this year in order to discuss comments that continue to be received. And towards the end of this presentation we'll give you some email addresses if anyone listening to this presentation has comments, we eagerly request further comments so that we can address everybody's concerns or to the extent possible incorporate people's preferences into this survey. Ultimately, however, the Maternal and Child Health Bureau makes the final determinations and decisions about the content of the survey as well as anything about the sample design and the way we'll conduct the survey.

I want to take a few minutes now to talk about some of the comments that we have received so you can get a flavor for what other -- if you haven't sent comments in yet, what other individuals have submitted and what discussions have been had by the technical expert panel already. Obviously there is no time here to present every comment that we've received. So I'll just be giving you some examples and as I said, no decisions have been made yet. So where I can mention people's concerns about the survey, any final decisions about how to address those concerns still rest with the Maternal and Child Health Bureau and we have not received their final decision.

Let's start with section 2. Section 1 is just the intro to the survey that does the informed consent process and insures we're talking to a household and that the household has children. Section 2 is the screening section of the interview. Which contains the screener, the questions that Marcie talked about earlier, as well as demographic questions about all of the children who we've screened. Those of you who have looked at the data may have

noticed that nationally the prevalence estimates for Hispanic children are lower than the prevalence estimates for other racial groups or ethnic groups. There has been some concern expressed about whether that reveals true differences or whether the screener is less valid in certain sub populations, for instance, among Spanish-speaking parents. Or whether there are other cultural differences in the screener. During this summer and fall we hope to be able to address some of those questions, which may necessitate some changes to the screener if, indeed, we do find that there are some differences in how various cultures respond to those questions.

Moving on, we certainly have gotten a lot of questions or comments about the demographics. Some of the suggestions that we've received about additions to those demographics include race of the parents, race and gender of the child's personal doctor or nurse, language spoken at home, the information about family composition. Does the child live with two parents or with only one parent or are grandparents in the household, or are they living with step parents or foster parents, for instance? Some have requested the employment status of all of the adults in the household. So they may be able to consider, for instance, working parents or the working poor to combine it with the income data. But perhaps the demographic information that is requested most often concerns additional geographic variables. Those of you who have used the public use data file recognize that the only geographic information that has been publicly released are the states that the child lives in as well as for most states whether the child lives in a metropolitan area or not. Many researchers have asked for finer detail when it comes to geography. We'll never be able to release anything that is specific to zip code or even counties because of

confidentiality rules and concerns about the ability to identify a particular individual or a particular household in the survey. However, some have suggested that it would be useful to have classifications that might be related to healthcare access. So classification such as rural, urban, commuting area codes or simply the time or distance to a major medical center or to the doctor's office. So we're continuing to pursue the possible geographic identifiers that we may be able to obtain and to ultimately put on the files for the second half of the survey.

Moving on to health and functional status section three. This section in the first round includes questions about the frequency and magnitude of activity limitations due to the child's condition, a rating of the severity of the conditions on a ten-point scale. The stability of the child's healthcare needs. Do those needs change on a regular basis or do they remain fairly stable? Questions about use of early intervention or special education services depending on the age of the child and the number of days of school the child missed due to illness. One suggestion that we have received from several people is that they would like a better description of the population of children with special healthcare needs. What do I mean by a description of that population? Well, who are they? OK? Can we obtain some information that allows us to identify who these children are based on conditions or based on some classifications of special healthcare needs by body systems or other domains? In addition, some data users have asked us for additional information about why some children who have been identified as having special healthcare needs are then identified by their parents as being never affected by that condition. Some have suggested if they're not affected perhaps they don't have special healthcare needs. We

clearly don't feel that that's the case. That if a child is receiving proper treatment, perhaps the condition is controlled by medication, that that could be a reason the child was never affected now. But some have asked for additional questions that we may be able to parse that out. In addition, as I just mentioned, many of the severity questions on the first round of the survey dealt specifically with activity limitations. And some have asked for additional questions that look at the severity of all of the difficulties that are experienced by children with special healthcare needs rather than focusing only on their activity limitations. Moving on to section 4, access to care utilization of unmet needs.

This section asks for sources of care and the existence of a personal doctor or nurse. Asks if the child -- or if the parent ever had to delay care for the child and questions about unmet needs. Those unmet need questions were assessed by asking for need and receipt of 14 different healthcare services, as well as three family services. We also had problems obtaining needed referrals. Most of the comments that we've received are not specific to this section where we have gotten some comments or suggestion to add OB/GYN services so we're essentially at a 15 specific healthcare service for adolescent female, children with special healthcare needs. And some have also asked for questions on difficulties obtaining care. Delayed care and the need may have been met but the parent might have had quite a bit of difficulty beyond simply obtaining a referral to a specialist.

Section 5, the care coordination section looked at the need for receipt of and frequency of professional care coordination, as well as satisfaction with the help received and then

some questions about the quality of doctor's communications with other doctors and service providers and the use of services from Title V programs. There was a general sense among the comments that we've received so far that this section was not quite working as intended. And I wanted to give you just a couple of examples of what we mean -- or what the commenters meant by that. For one the section was focused on professional care coordination. And some have commented that care coordination is not necessarily have to come from professionals and that we should explore care coordination that is received from any person providing assistance as opposed to simply a professional. Others have said the section should include all with services received from different providers. Rather than excluding parents who perceived no need for care coordination. This section was preceded by a question of whether the child needed care coordination. Most parents said no, the child does not need professional care coordination. Nevertheless, there is a general sense, I think, that some parents may not recognize a need for care coordination, may not even understand what care coordination is all about. May know it as case management which is a term we did not use in the survey. There are other things that a parent may not know so we asked about it in this section. As for the quality of communication among the doctors, parents may not know because they may not be present at the time the communication is occurring. And in addition, while parents may know about is services that they've received, they may not know whether the program is actually supported by Title V dollars. So asking whether they've received services from the Title V program may be asking them something that they cannot answer.

Section 6 looked at satisfaction with care and transition to adult care providers. So we asked number of doctor visits, satisfaction of services received and a rating of whether those services are organized for easy use. We also asked a series of five questions about whether the care is family centered. Comments we've received include concern that one question about whether services are organized for easy use may not be sufficient to really assess that concept. Perhaps we need to have some scale or at least several questions to look at that. This section also looks at transition to care.

Next slide, please. The section on transition to care looks at whether doctors have talked about transition issues and changing healthcare needs and have developed a plan for this transition. There is also a question about vocational and career training for an adult job. A lot of comments were received about this section. In particular, the vocational training question behaves very differently from the medical transition question and the medical transition questions may be a bit too focused on medical services. There were suggestions that the technical expert panel has discussed about some of the other components of transition that weren't addressed in the first round but perhaps can be addressed in the second round. Some of those sorts of comments are that none of the questions address whether children have the skills or knowledge to operate independently within the adult healthcare system. That none of the questions address whether insurance or another healthcare payment source will be available once the child turns 18. And that there were no questions to address the availability of adult service providers or service providers who treat adults within the community. Again, this may be something

the parents may not actually know, but technical expert panel is exploring all three of these possible additional components to the transition concept.

Sections 7 and 8 looked at health insurance. Current coverage type and the continuity of coverage over the past 12 months. Adequacy of the coverage and satisfaction with health plans using a couple of different questions. Those -- some of the comments that we've received, a number of people have asked for comments or additional questions on managed care and have asked us to verify that the state program names we'll be using in 2005 and 2006 are accurate. Moving quickly along because we really haven't gotten many comments on the later sections of the survey.

Section 9 looked at impact on the family. Here there was a desire for continuous measures of expenses. We had reported expenses categorically to allow for a calculation of expenses as a percent of income. As for the income section, we asked about income as well as receipt and cash assistance and S.S.I. and one data user asked for additional questions about the use of faith-based or community resources for families. So now that I've talked about some of the content that we're exploring for the second round of the survey, let me just briefly mention the tentative plans that we've got for the design of the survey. As I mentioned before, the goals for the second round were to obtain, again, national and state-based estimates for the prevalence and impact of children with special healthcare needs, as well as to be able to assess changing needs and to be able to continue to monitor MCHB's performance measures. To do that we're going to be using very much this same design, I believe, that was used in the first round of the survey. That

is, it will be a random telephone survey with equal size samples from every state and the district of Columbia. We'll use the same screener and selection criteria as in the first round with the possible exception in some of the cultural examinations we suggest the screeners should be modified slightly. The questionnaire will be modified slightly based on the comments received and the suggestions of the technical expert panel that we hope to be able to maintain the questions as consistent as we can so that we can look at changes over time. The health insurance control sample and the low income supplement that we had mentioned will not be repeated at this point in time and the survey will be fielded from January 2005 through December of 2006. So I said before we would try to address some of the limitations of the first round. So is the limited ability to compare special healthcare needs to children without those needs. We're exploring the possibility of adding a sample of healthy children to the survey and to administer an abbreviated survey to them. To address a limitation we want to increase the sample size to 1,000 children with special healthcare needs per state.

Next slide, please. And also we will permit states to pay for further sample expansion as we did in the first round. Finally, previously states were not permitted to add questions to meet their state-specific data needs. In this round of the survey, we hope to be able to permit states to pay for up to six additional minutes of state-specific questions. I'm now going to turn it back to Marcie who will talk a little bit about what the costs are involved in that state customization.

MARCIE CYNAMON: The reason we're telling you all this is because we want from you first to give us comments on the existing questionnaire and you can find that on the slates website at www.cdc.gov/slats.html. Steven told you some of the changes we're considering. Secondly, in addition to asking for your comments on the existing questionnaire and improvements that you think we could make, we want to know if there are questions that are specific to your state that you are passionate enough about that you would like to pay to have added to the survey. We have some tentative costs. Everybody ask, what does it cost? That's very important to you as it is to us. We do not have yet a signed contract with the new company to conduct the survey. So I am giving you estimates. And you can see on your screen that for two minutes there is a range of 13 to 15,000. Four minutes. I won't read it for you since we're short on time. Consider in one minute you can ask one or two -- probably two fairly short questions. Nothing long winded with 35 answer categories, but something read at a reasonable clip about two questions.

We're considering having little optional modules that states can choose to select if enough states want similar types of information. The reason Steven went into detail about what we're considering is that we didn't want to duplicate -- have you duplicate your effort by thinking about what you wanted to add if it's something we're already considering doing. The other option open to you is adding sample, as Steven mentioned. This is a lot more expensive and a lot more complex. As I tried to explain a little bit earlier on the samples available in each state vary depending on the number of national immunization survey sampling units so the expense varies greatly. This is also harder to cost out without an existing contract that defines in great detail how the sample will be selected. So I'm giving

you a very broad cost estimate for adding sample and please -- there you go -- I know this is a broad range but consider that in some states, for example, Utah, where there are a large proportion of households with children in range for the NIS and good response rates, there is very little extra sample for slate so it's a very expensive state to add samples to. In other states like California where we have five sampling units it's a very inexpensive state to add samples to, relatively speaking. And here I've given two options for sample augmentation. Finally, as Steven mentioned, we want you to have our website -- our email addresses so you can provide us with comments or questions. And we hope to hear from you soon. I want to turn it over to Paul. If you have any wrap-up comments, things that you think we missed that were critical for the states to know?

PAUL NEWACHECK: Thank you, Marcie. Well, I just would like to say this has been a terrific and fruitful collaboration between the Maternal and Child Health Bureau and the National Center for Health Statistics in the Maternal and Child Health Bureau field. We've assembled an excellent technical expert panel. To give credit to those who deserve it from MCHB that included Bonnie Strickland, Michael, Cassie and Peter van Dyck. I want to give Peter special credit for being willing to pony up the money to do this survey a second time around and then from NCHS sides besides Marcie and Steven there is Kathy O'Connor, Matt and Julian. And together we have a great team at the federal level plus all the other folks that Steven mentioned, or Marcie mentioned in the slides earlier. I think the big challenge for the technical expert panel, this is where you all can help us, is deciding what to keep and what to change. There is a tension here because we do want

to change the things that are not working well but we only want to change those things that aren't working well to preserve the ability to assess trends and the other indicators. So that is our big challenge and in addition we also would like to be able to add questions where we can. But adding questions is expensive so it probably means we'll have to cut back in areas if we add significant number of questions. So we very much would welcome your comments on what is useful, what has been useful and what has not been useful as well when we think about that.

Just a couple other points. One is that there are a number of articles and reports now starting to come out from the survey, the first version of the survey. I want to draw your attention to the supplement of pediatrics. There is an article describing the six core outcomes and where we stand on each of those based on the survey and another article on medical home that also uses the survey data. Those are both excellent articles and I hope you all have a chance to see them. Finally just to say I want to encourage all of you to think about the offers on the table that Marcie and Steven described by adding sample size, especially if you're interested in looking at subgroups of the population, say for example minority groups or low income populations because you really can't go too far with that at the state level without additional sample. Then the second thing is the adding questions to help you with your needs assessment, program planning and evaluations. The costs might seem a little high there but actually it's quite a good deal. So give that all serious consideration and give us your comments. Thanks a lot.

AUDREY KOERTVELYESSY: Thank you very much. We're going to go quickly now to Mike Kogan to make his final comments for us.

MIKE KOGAN: Thanks, Audrey. I would like to talk about a couple of things. First, as a follow-up to Marcie and Steven's comments, if you have any comments, could you please send them soon in order to make changes, they have to get clearances and they'll have to conduct pre-tests. Is there a certain date you would like it by?

AUDREY KOERTVELYESSY: Soon.

MIKE KOGAN: Soon. We'll leave it at that. And the next thing I want to talk about are some of the products that are coming out from the last survey. And Paul started -- touched on that briefly. And first, you'll get a more formal announcement from Peter, but I want to mention that the data resource Center for this -- for the last survey is now up and operational and you can access it at www.cshcn.org and it is almost completely filled in. For those of you who used it it is quite useful and quite good. Second thing I want to mention is as you probably heard, we've put together a chart book and we keep updating you on when it is going to occur. We've been checking every couple of weeks as its progress through the clearance process. Now, last we heard, which was a couple days ago, one more agency has to give final signoff on it and they don't expect there to be any rewrites. So if everything goes OK, then hopefully we'll be moving on to the next stage very soon. And getting it out as soon as possible.

Next thing I want to mention is we're putting together a special issue of Maternal and child Health Bureau run by the state and community health. We've gotten responses from 21 states who are interested in doing state level analyses and submitting to a special issue. We think it will be really good. A couple of examples of what states are submitting. New York is proposing to look at risk factors for delaying routine healthcare for children with special healthcare needs. Illinois is proposing to look at patterns of insurance coverage for children with special healthcare needs. And its implications for the Title V program. New Mexico is proposing to look at program and policy in New Mexico for children with special healthcare needs regarding oral health. Mississippi is proposing to look at what factors affect health and dental care access among Mississippi children with special healthcare needs. And Paul mentioned some of the papers that are coming out. There are others that we know that are in press coming out. There is some being worked out that will come out in pediatrics. I see it's 3:00 now so let me wrap up there. Thank you very much.

CHRIS DE GRAW: Thank you, Mike. We have three questions so far. This is your last opportunity if you have any other questions, just type the question in the white message window and we'll try to get to it. If we don't we'll ask our speakers to respond by email to the question. The first question, all three questions seem to be addressed to the speakers in general is a comment and question. The first survey had no questions about nutrition in children with special healthcare needs yet nutrition is legislated in part H, can you please add questions for the need for, access to and use of nutrition services. Anyone want to take that?

>> We'll add it to the list, bring it up with the technical expert panel.

>> For whoever submitted that, if you have very specific issues in mind, could you let us know what they are?

CHRIS DE GRAW: Next question is, how many questions total are on the survey and how much time per interview will it take?

>> The interviews were 25 minutes on average. And I can't begin to count the number of—

>> I don't think anybody has ever tried to count the number of questions.

>> Because of the skip patterns. Nobody gets everything unless they're really unlucky.

CHRIS DE GRAW: OK and finally-

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>> Toward the end of the survey when we wanted to boost response rates a bit we did go back to households that refused where we knew there were children -- wait, wrong survey, no, no, no. The answer is no. But, but we have done it more recently on another MCHB survey and it is very successful.

So I have no doubt that we will again look at incentives as a possible way of increasing response rates in the second round with children of special healthcare need survey.

>> Don't tell any of the respondents.

CHRIS DE GRAW: OK. If we don't have any other questions at this time I would like to thank all of you for participating in the webcast. Thank our speakers and I would like to thank our contractor the Center for Advancement of Distance Education for the University of Chicago School of Public Health for making the technology work. Today's webcast will be archived and available in a couple of days on the website, www.mch.com.com. Tell your colleagues know about the website. We would like to make these webcasts as responsive to your information needs as possible. If you have suggestions or comments, please email them to us. Thank you and we look forward to your participation again next month.